PATIENT PATIENTS?
Achieving Patient Empowerment through active participation, increased knowledge and organisation
Sophie Söderholm Werkö
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Patient Patients?

Achieving Patient Empowerment through active participation, increased knowledge and organisation

Sophie Söderholm Werkö
To my grandfather for inspiration.

To my mother and father who taught me how to question and never give up.

To my beautiful sister for her support and the perfect illustration.

To Robert, Maximilian and Olivia for being the way you are.

And to those individuals who believe in the power and far-reaching effects of grassroots empowerment and strive to see it transpire.
Contents

List of Figures .................................................................................................................. xi
List of Graphs .................................................................................................................... xi
List of Tables ................................................................................................................... xii
Abbreviations .................................................................................................................. xiii

Acknowledgements ........................................................................................................ xv

1. Introduction .................................................................................................................. 17
   The Third Sector and Civil Society .............................................................................. 21
   Background .................................................................................................................. 22
   Labels ............................................................................................................................ 23
   About patient organisations ......................................................................................... 24
   Collective Action ......................................................................................................... 25
   Diabetic patient organisations .................................................................................... 26

The Purpose of this Study ............................................................................................... 27

Introduction of the empirical data employed in this research ........................................ 27
   The local diabetes branch organisation in a mid-sized town in the North ............... 28
   The local diabetes organisation in a City .................................................................. 28

Outline of the book ......................................................................................................... 29

2. Research approach ..................................................................................................... 31
   The Case studies ......................................................................................................... 31
   Organisations ............................................................................................................. 32

The Research Process & Design ................................................................................... 32
   Sampling ...................................................................................................................... 35
   Data Accumulation .................................................................................................... 37
   Interviews .................................................................................................................... 37
   Observations .............................................................................................................. 40
   The surveys and the questionnaire .......................................................................... 40
   Data Processing ........................................................................................................ 42

3. Swedish health care planning – lay participation ...................................................... 45
   A health service in constant financial changes ........................................................ 46
   Complacent patients .................................................................................................. 46
   The Swedes are socializing individuals .................................................................. 47
   The people change their general views in the new millennium ............................... 47
   Contemporary examples of a few county councils’ participatory efforts ............... 48
   Conclusions and Contemplations .......................................................................... 49

4. Membership and Empowerment ............................................................................ 51
      Selective incentives ................................................................................................ 51
      By-product theory .................................................................................................. 52
      Dissatisfaction ...................................................................................................... 52
      Turning to the public – abandoning private concerns ......................................... 54

   Active Membership – Why do people participate actively in voluntary organisations? .. 55
      Socio-economic status ......................................................................................... 55
      The rebound effect .............................................................................................. 55
      Abilities and prerequisites .................................................................................. 56

   Empowerment ......................................................................................................... 59
   Defining Empowerment ............................................................................................ 63

   Co-Production ......................................................................................................... 64

   Patient Empowerment ............................................................................................. 65
   The Patient .............................................................................................................. 65
   Patient Empowerment ............................................................................................ 65
   Patient education ................................................................................................. 68
Reasons for joining the organisation ................................................................. 113
Two clearly different profiles are found in the North and in the City .......... 113
Collective action – together we are strong? .................................................... 116
The influence of the SDA and the branch organisations on the diabetics’ situation in society ................................................. 116
The local branch’s influence on the Swedish Diabetic Association .......... 118
The members’ influence in local branches .................................................... 119
Examples of members trying to influence the local branch ................. 120
Most important and influential actors ....................................................... 120
Membership Participation ........................................................................... 122
Reading the membership magazine ........................................................ 122
Opinions about the membership magazine ................................................. 123
Membership Participation ........................................................................... 124
Increasing members’ activity .................................................................. 125
Holding an office ....................................................................................... 125
Satisfaction with their branch organisation .............................................. 125
Member satisfaction with the performance of the branch organisation ... 125
Satisfaction with their membership ........................................................ 126
Suggestions for improving the situation for diabetics ......................... 127
If not, what then? Alternatives to the SDA? .............................................. 128
What if there were no diabetes association? Would there be a change of status? ................................................................. 128
Suggestions for improving the local branch .............................................. 129
Alternatives to the SDA? ........................................................................... 129
Passive member and don’t know? ............................................................ 130
Comments on the survey ....................................................................... 131
Summary ................................................................................................. 131

8. Summarising and analysing the life of two branches of a patient organisation ................................................................. 133

Membership Engagement ......................................................................... 133
Selective incentives: membership magazine, activities and support ......... 133
Joining ...................................................................................................... 134
Long-term recruitment perspectives .......................................................... 135
Active membership ................................................................................. 136
Board Members – intensely dedicated or status-seekers ..................... 137
Membership Influence ................................................................................ 138
Member satisfaction .............................................................................. 139
Member influence .................................................................................. 139
Travelling distances ............................................................................... 139
Strong Organisations .............................................................................. 140
Lobbying .................................................................................................. 140
Conflicts .................................................................................................. 140
Co-operation with the medical services – the question of co-production 142
Co-operation with other patient organisations ..................................... 143
Strong organisations? ............................................................................ 144
Resources ................................................................................................ 145
Patient Empowerment ............................................................................. 146
The way to…-project - empowering the participants .............................. 147
Empowerment and identity ..................................................................... 149
Understanding the growth of empowerment through membership .... 149
Empowerment as a room ....................................................................... 150

9. Conclusions and contemplations ........................................................... 153
Implications for further research .............................................................. 156
So what is new? ...................................................................................... 158
Possible implications of working with empowerment .......................... 159
REFERENCES

APPENDICES

Appendix 1: Questionnaire to members in two local diabetes organisations
Appendix 2: My accompanying letter with the questionnaire
Appendix 3: Copy of the original letter from the two branch organisations to their members
Appendix 4: Reminding letter sent out two weeks after the first letter, also this time with a questionnaire
Appendix 5: Description of the survey study and the response rates
Appendix 6: Descriptives of respondents and non-respondents of the surveys and the Dropout analysis
Appendix 7: Results from the questionnaire
Appendix 8: List of interviews and observations
Appendix 9: Example of a typical circle meeting
Appendix 10: Examples of Empowerment Programs
Appendix 11: The Diabetic Registry
List of Figures

Figure 1.1 Focus of the study .....................................................................................................................20
Figure 1.2 The Third Sector in the Welfare Triangle...................................................................................21
Figure 4.1 A simplified version of Verba, Schlozman and Brady’s Resource Model...............................57
Figure 4.2 Prerequisites and effects of an active membership / participation .........................................59
Figure 5.1 SDA revenue and cost distribution in 2005 ..........................................................................77
Figure 8.1 Prerequisites and effects of an active membership / participation .........................................147

List of Graphs

Graph 7.1 Age types per city of the respondents .....................................................................................110
Graph 7.2 Age and type of membership ..................................................................................................112
Graph 7.3 Proportion of members who were previously in other organisations and who are now current members of other organisations .................................................................112
Graph 7.4 Frequency of reading the membership magazine as assessed by the respondents .................123
Graph 7.5 Level of participation in the branch’s activities as assessed by the respondents ....................124
Graph 7.6 Wishing to be more active in the organisation as assessed by the respondents .....................125
Graph 7.7 Whether there exist other sources of support for people with diabetes as assessed by the respondents ..........................................................................................................................130
List of Tables

Table 2.1 Interview sample from the local organisational level .................................................................38
Table 2.2 Outline of the studies ....................................................................................................................43
Table 4.1 Patient participation and decision making: potential conflicts....................................................68
Table 7.1 Age and gender distribution of the respondents ........................................................................110
Table 7.2 Types of membership and gender distribution of respondents .......................................................111
Table 7.3 Reasons for respondent membership ..........................................................................................111
Table 7.4 The respondents’ reasons for joining the organisation .................................................................114
Table 7.5 Level of ability of the SDA and the local branch organisations in affecting the diabetics’ situation in society as assessed by the respondents themselves ........................................117
Table 7.6 Level of the local branch’s ability to influence the Diabetic Association as assessed by the respondents .................................................................................................................................118
Table 7.7 Level of the individual’s ability to influence the local organisation as assessed by the respondents ..................................................................................................................................................119
Table 7.8 Actors of influence on the local organisation’s work as assessed by the respondents ..........121
Table 7.9 Level of interest regarding the content of the magazine as assessed by the respondents ......123
Table 7.10 Level of member satisfaction with the branches’ performance as assessed by the respondents ................................................................................................................................................126
Table 7.11 Level of satisfaction with membership as assessed by the respondents ........................................126
Table 7.12 Suggestions given by respondents on how the organisation could improve the situation for people with diabetes ..................................................................................................................128
Table 7.13 Level of change of the status of diabetics if the local branch / the SDA did not exist as assessed by the respondents ..........................................................................................................................128
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABF</td>
<td>Arbetarnas Bildningsförbund (Workers’ Educational Association in Sweden)</td>
</tr>
<tr>
<td>BHW</td>
<td>Socialstyrelsen (The National Board of Health and Welfare)</td>
</tr>
<tr>
<td>DHR</td>
<td>De Handikappades Riksförbund (The Swedish Federation of Disabled Persons)</td>
</tr>
<tr>
<td>DYR</td>
<td>Direkt Yrkesinriktad Rehabilitering (The Direct Professional Rehabilitation Delegation in Sweden)</td>
</tr>
<tr>
<td>HSN</td>
<td>Hälso- och sjukvårdsnämnderna (The Local Health and Medical Care Committees in Sweden)</td>
</tr>
<tr>
<td>HSO</td>
<td>Handikappförbundens samarbetsorgan (The Swedish Disability Federation)</td>
</tr>
<tr>
<td>HSV</td>
<td>Handikappsamverkan (The regional co-operative body for regional disability organisations in Sweden)</td>
</tr>
<tr>
<td>KFO</td>
<td>Kooperationens förhandlingsorganisation (The Independent Employers organisation for Cooperative Business)</td>
</tr>
<tr>
<td>KHR</td>
<td>Kommunala Handikapprådet (The Community Council for the Disabled)</td>
</tr>
<tr>
<td>LO</td>
<td>Landsorganisationen (The Swedish Trade Union Confederation)</td>
</tr>
<tr>
<td>OTA</td>
<td>Ortopediska avdelningen på sjukhuset (The Orthopaedist division at the University Hospital)</td>
</tr>
<tr>
<td>SDA</td>
<td>Svenska Diabetesförbundet (The Swedish Diabetes Association)</td>
</tr>
<tr>
<td>SEK</td>
<td>Swedish Crown (in December 2007, equivalent to 0.15 US-dollars)</td>
</tr>
<tr>
<td>SFAM</td>
<td>Svensk förening för allmänmedicin (The Swedish Association of General Practice)</td>
</tr>
<tr>
<td>SOU</td>
<td>Statens offentliga utredningar (Official Reports from the Government)</td>
</tr>
<tr>
<td>SRF</td>
<td>Synskadades Riksförbund (The Swedish Association of Visually Handicapped)</td>
</tr>
<tr>
<td>WHO</td>
<td>Världshälsoorganisationen (The World Health Organisation)</td>
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Sophie Söderholm Werkö
1 Introduction

This chapter introduces the research topic, discusses the problem and presents the purpose of the study, as well as the procedure used in finding answers to this study’s problem.

The many privatisations that took place during the 1990s in Sweden in different fields such as the deregulation of the electricity market and of the telephone monopoly, created a situation for the consumers such that they were free to sign contracts with the provider of their choice. The increased levels of freedom in turn empowered consumers who now had the opportunity of making informed choices of what provider to use. Regardless of how great (or poor) this new empowerment was, it was strictly individual. Influence can be exerted on different levels: on an individual level (e.g., through the right of voting or through the market) and on a collective level. It is principally this form (i.e. the collective level) which is referred to when user-influence is discussed in Sweden (Möller, 1996). The user should be able to exert influence over the activities in the capacity as member in a collective, the user-collective, and not as a separate individual. Yet, little has been said about collective empowerment and collective acting.

The conventional academic view emerged of patients as largely unimportant and passive consumers of whatever the medical profession provided (Wood, 2000, p. 174). The discussion of the role and influence of patients in texts on pressure groups and health studies has focused on patients as individuals rather than collectively. Health care topics have not been focused on much within the field of business administration, or within the social sciences for that matter, especially not from the patients’ perspective. Here lies the major contribution of this study: the combination of two themes, collective action and the field of health care. This combination can broaden the topic of business administration. Overall there is little research done on patient organisations and their members. This study will contribute to the field in focusing on voluntary activity and membership in a patient organisation.

Let’s say you have just been diagnosed with a chronic disease. Your life and lifestyle is inevitably affected to such an extent that it may never be the same. Now, assuming you are over the age of 18 years and thus entitled to vote, you can influence your life in five ways:

1. As a citizen: vote in the election every fourth year. Take an active interest in politics by joining a political party that promotes greater resources for health care in general or for your disease in particular.
2. As a consumer: buy services, think of your rights and demand information and participation in the decision-making concerning the treatment of your disease.
3. As a patient: either by yourself with the health services where you try to influence your own situation, or
4. As a member: by becoming involved in an interest organisation, such as joining a patient organisation to gain more information and influence.
5. As an active member in a patient organisation: by becoming involved in the organisation, where you take an active interest in the issues the organisation deals with or initiate your own issues to put on the organisation’s agenda.

What do you choose to do and why?

Patients’ influence can be difficult, particularly because of the asymmetric relation that exists between the patient and the doctor. Patients are usually weak actors in the sense that they are normally powerless and in a position of dependence in relation to health professionals.

During the 1970s and 1980s, the Swedish health care came under heavy criticism. The primary reason for the criticism was that it was not considered flexible or personal, giving too little room for patients’
wishes. The public commission of inquiry on power from the end of the 1980s claims that health care is the area that has the greatest element of “quiet powerlessness”. The citizens felt that they had no possibility to influence their situation as a patient (Peterson et al., 1989). Politicians have therefore increasingly focused on the situation of the patient. There has been a slowly growing recognition of the rights of patients, including respect for autonomy and for the dignity of the individual. Rapid advances in technology and medical and health sciences have raised patients’ expectations and better-informed patients have started to assert their rights in their dealings with health professionals. Patients’ rights are becoming increasingly incorporated in statutory regulations throughout the world. Regulation may give patients direct legal rights in their relationships with health care providers (classic patients’ rights include access to medical records, the confidentiality of data and informed consent) or may help to strengthen their position through, for example, hospital certification and administrative health laws (WHO, 2000, p. 130f). In 1983, a new health care law was passed that more distinctly than earlier legislation takes the consent of the patient into account. Although Sweden is the only Nordic country that has not yet introduced a special law on patient rights, reforms have been carried out during the 1990s that aim at strengthening the patient’s position. The Swedish health care law was changed in the beginning of 1999 to further strengthen the patient’s position (the National Board of Health and Welfare, 2001, pp. 306-317). From the national political level, there have been several attempts to increase patients’ influence and the possibility to choose. During the 1990s, several political decisions have strengthened patients’ influence in health care and patients’ position has gradually become stronger. For example, patients are now faced with expanded options for choosing health care providers (e.g., local health centres, hospitals and general practitioners). Another example is the introduction of maximum waiting times for visits and treatment. The problem, however, remains in that the regulations that are important for patients’ position in the health services are spread across several laws. The legislation is thus not easily accessible and hard to overview for involved persons, i.e. patients, the public and the health service personnel.

The Swedish health care system, however has mostly been planned without any input from the patients. Lay participation in local health care planning has not really existed in Sweden until lately, with several examples of the county councils’ initiatives of involving citizens in prioritising decisions for the future. It was not until the late 1990s that patient influence was even mentioned (the Ministry of Health and Social Affairs, SOU 1998:16 and SOU 1999:21). For example, there are still demonstrations against decisions to close down hospitals. The emergence of ‘the health care party’ (sjukvårdspartiet) is an indication of the lack of patient empowerment (Svensson, 2005; Olsson, 2005; Demker, 2005 and Holmström, 2006). However, the controversial issue of stronger patient influence in health care is high on the political agenda in Sweden, and a debate about the view of the people using health services is currently taking place. Whether they should be seen as health care consumers or patients is a controversial issue. A quote by Åsa Moberg (2006) is illustrative:

“I dream about a health service in which I am a customer. Because those who have customers have to listen to what their customers want, but nobody has to listen to a patient (or the patient’s family). As a patient I cannot let the health care politicians know what I would need instead of what is being offered. And the politicians cannot even in theory grasp all the needs of the patients and their families.” (Free translation).

Further, lay participation in local health care planning seems to have been recently strengthened in Sweden. County councils are now asking their citizens for input in the local political debate. These topics have also been focused on in research (e.g. Anbäcken, 1985; Hogg, 1999; Laverack 2004; Laverack 2005).

Several Swedish doctoral studies have researched different views of patient participation. For example, in a study by Sätterlund Larsson (1989) it was found that patients satisfied with the care and the surgical outcome were more likely to state that they had been involved in the decision to undergo surgery. Andersson (1994) studied the patient’s integrity and found that it has to be respected in order for patients to participate in their own care; this presupposes that caregivers learn what the patient experiences as problems, provide relevant information and ensure that the patient understands the information. Another field that has been studied is client participation in the rehabilitation process (Wressle, 2002). The results

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1 Regardless of whether it is imagined or real, the absence of power (i.e. the powerlessness) assumes that the behaviour of an individual cannot determine the outcome sought. Powerlessness consists of an experience of economic vulnerability and disenfranchisement, generalized distrust, self-blame, a sense of hopelessness in gaining social and political influence and a feeling of alienation from resources for social influence (Kieffer, 1984; Laverack, 2005).
showed that rehabilitation improved when clients were engaged in their health care and that a structured method improved clients’ participation in goal formulation. Runeson (2002) focused on children’s participation in the decision-making processes in health care. She found that children had different needs in non-threatening and threatening situations and that they were not always allowed to participate to the extent that was judged optimal. Strandberg (2002) focused on patients’ dependency on care. She concluded that struggling against feeling worthless, threatening powerlessness, threatening loneliness, threatening being left without help and trying to move forward in a life that hurts, together form the meaning of dependency of care. In 2006, an overall study on the concept of patient participation was published (Eldh, 2006). This study defines both participation and non-participation, stressing the importance of avoiding non-participation in promoting that the information given to the patient should be based on the individual’s need and with recognition of the patient’s knowledge and context.

Nowadays, there are numerous patient organisations for different types of disease such as anorexia and bulimia, asthma, cancer, diabetes, allergy, multiple sclerosis, motor neurone disease and HIV/AIDS. Such organisations have contributed to greater knowledge about the respective diseases and what kinds of help are available (Sverne, 1997, p. 70). While there is significant scholarly work on those diseases, the patient organisations have received little academic attention both by business researchers and political scientists. Other social disciplines have shown more interest in their financial contribution to medical research (economists), their support and self-help role (medical sociologists) and their activities regarding service provision (social policy). Most studies either focus on the unique medical conditions of the specific patient organisations, a specific country or geographical setting, a specific cultural or social context or the role of specific health care professionals, social workers or other professional groups. Very few focus on patient associations in general or on their political work and activities. After numerous searches, only two studies appear relevant for this research: one focuses on the politics of patients’ associations in Britain and in America (Wood, 2000) and the other focuses on the importance of Swedish patient associations for individuals with cancer and their collaboration with health care (Carlsson, 2005). Wood found that the political role of patient associations in Britain and in America usually was a covert one. Only a few stated that lobbying and campaigning was their main priority (2000, p. 17f) and only in a few areas in health care, AIDS and mental illness, could he find indications of patient influence. In America he also found that patient organisations had been successful in influencing increases of state funding for basic research. An overall conclusion was, however, that despite possessing real political resources, many patient organisations chose not to positively acquire or deploy them. They preferred to primarily remain support rather than as campaigning groups (ibid, p. 183).

When studying reasons for membership (both joining and remaining) in patient associations for cancer patients, Carlsson (2005, table 4, pp. 6-7 in study II) found that the most important motives concerned ‘needs created by having cancer.’ Examples were feelings of powerlessness in the situation, anger, sorrow, depression and a need for having living proof of the possibility to survive cancer. The members sought both fellowship and experience. These motives were more important for joining than remaining a member, which could mean that some of these needs were satisfied during the time of membership. Other important reasons were the individuals’ needs for information and activities from the patient associations. Reasons for remaining a member also concerned feelings of security if the cancer re-appeared (Carlsson, 2005, p. 32f).

Within many voluntary organisations that are formed around a common situation in life or a common problem, there are often self-help groups that can be used by the organisations’ members (Karlsson, 2006). The form of patient influence that is dealt with in this study is patient empowerment that arises from patient organisations.

One problem is that there are major differences between individual and collective action. Very little academic research in business administration is found on patients’ collective action. The aim of this dissertation is to fill the gap of knowledge between individual and collective action and to contribute to a better understanding of collective patients’ organisations. But where do you start? It is natural to start by asking why people join patient organisations. Then you need to ask how they can gain influence. Becoming active is one obvious alternative. Most members will limit their activities and influence to the

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3 The motives for membership varied however with the various cancer types: associations for cancer patients with breast cancer, gynaecological cancer and prostate cancer were included in this study (Carlsson, 2005).
local level, at least initially. What do membership and local influence mean for patient empowerment? The primary focus in this study will be on members and their interaction with local branch organisations.

In Figure 1.1 the focus of this study is highlighted, which is on the two lower sections of the figure (the local branch organisation and the members). This does not mean that we can ignore the other levels completely as they in turn affect both the local organisation and the members. The two upper sections in this figure are the regional organisation and the association (at the national level). It is mainly the work carried out by the association that produces a value for the members and thus an incentive to join a local branch. Nonetheless, there are naturally reasons at the regional and the local level as well for members to join the organisation.

**Figure 1.1 Focus of the study**

This focus implies many questions. What influence do patient organisations have, if any, and how is it used? How are patients’ opinions valued and do they have any kind of influence in the decision-making processes? How can they affect the decisions of their treatment? How are they organised? What does membership in a patient organisation entail? What is patient empowerment? Why do some patients choose to engage in a patient organisation? What types of people participate actively? Why do they become active? Why do some people choose to spend some of their free time performing mostly unpaid work for an interest organisation? Obviously, many people find compelling reasons for joining and engaging in the voluntary work of various organisations despite numerous obstacles such as interacting with strangers and carrying out time-consuming and, for the most part, unpaid work. In addition, these people have usually sought out the opportunity to serve in the organisation as opposed to being faced with the opportunity suddenly, where escape is more difficult. Yet, people apparently do engage in voluntary organisations and activities and do so in considerable numbers. In 2000, 90 per cent (6.2 million) of the Swedish population were members of at least one voluntary organisation. Seventy per cent were members of several organisations and 44 per cent claimed that they were active members (Statistics Sweden, 2003).

Can patients influence their situation and care by becoming a member in a patient organisation? Do patients want to influence their situation? What actors have most influence within a local patient organisation? What effects of a membership do patients see?
The study was planned with these specific questions in mind. Finding answers to any of these questions will further the understanding of these issues, raise more specific questions within the field, open up for discussion and debate and, in the long-run, help to improve the patients’ position. This can be done through changes in the health care policies, in attitudes or in the mind of the patient.

The study should also contribute to filling parts of the hole because of the lack of scientific studies focusing on the patients’ views (Ottoson, 1999) and on the politics of patient organisations (Wood, 2000). Further, the study should contribute to the academic field of organisational studies, participation theory and empowerment theory. This study is of multi-disciplinary character, applying theories from economics as well as political science to explain reasons for membership.

**The Third Sector and Civil Society**

The non-profit sector, also called the third sector in an economy, is characterised by multiple roles, structures and services. The figure below puts the third sector in its proper context (Pestoff, 1998). It is difficult to formulate a basic definition for all organisations in the non-profit sector. Anthony and Hirzlinger have suggested a general approach (1980, p. 31): “A non-profit organisation is one whose goal is something other than earning a profit for its owners. Usually its goal is to provide services”.

**Figure 1.2 The Third Sector in the Welfare Triangle**

Non-profit organisations are non-commercial. They operate on a basis of cost recovery and focus on their mission, which is generally to serve the needs of their members. They will not return any of a surplus above the costs generated to owners, directors, trustees, members or employees, either directly or indirectly, and this feature that distinguishes non-profit-making from profit-making businesses (Pestoff, 1998, p. 43). These organisations should be structured democratically, implying at least the eligibility of the executive board and the reality of membership. The membership is voluntary (Rosskopf & Witt, 2002). As a further characteristic, there should be some degree of voluntary participation with respect to activities or in the management of its affairs.

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4 The state is usually referred to as the first sector and the business sector as the second.
Civil society, which is understood in contrast to the state, is another term describing the non-profit sector. People are supposed to act voluntarily and with a moral conviction in civil society, one that is not due to coercion, manipulation or monetary rewards. There is disagreement on what constitutes civil society, except for the fundamental distinction between the state and civil society. The definition of civil society is negative, i.e. more about what it is not than what it is. It is seen as an alternative sphere to the economy, the market, the state and the household. Relationships that go beyond the family, but are not within the realm of the state, are included in civil society, the most associated organisational form being voluntary associations but also movements and networks (Ahrne, 1996). According to Ahrne (1996), it is only through the interaction between many organisational forms that we understand the concept of civil society.

There are three principles of voluntariness (Ahrne, Boström and Forssell, 2004). First, a member can voluntarily join or leave an organisation. Second, a member can voluntarily participate in all of the organisation’s activities and has a right to do so. Third, the individual’s motives for membership and the organisation’s goals must comply (ibid, p. 27). The individual is foremost a member in the organisation because he or she agrees with the organisation’s cause. The main characteristic for voluntary organisations is that they are established by people with common interests who see this as a way to increase their possibilities to pursue a certain type of work, building collective resources for this purpose. The members typically contribute with all or parts of the resources the organisations need, both by paying member fees and by working for the voluntary organisations (Ahrne, Roman & Franzén, 2003).

In recent years research on voluntary organisations has met increased interest in Sweden, both within the fields of sociology (for example Ahrne, 1994 and Olsson, 1998) and business (Wijkström and Lundström, 2002). While several researchers note the specific characteristics of voluntary organisations in comparison to other types of organisation (e.g., Lundström and Wijkström, 1995 and 1997, Wijkström and Einarsson, 2006), Ahrne (1994) emphasises the similarity between different types of organisation. Olsson’s (1998) definition of voluntary organisations is an attempt to combine these perspectives. He argues that despite specific organisational traits, all voluntary organisations have a set of common features. In his definition (ibid, p. 154f) a voluntary organisation has access to collective resources, members who voluntarily have joined the organisation, replaceable members at various positions (c.f. Ahrne, 1994, p. 18), control over the organisation’s resources and activities, specialised work tasks and depends on the surrounding world for its existence. Furthermore, a voluntary organisation is dependent on leaders or on a core of persons and it is the organisation’s ideology that gives members (and future members) their motive for why the organisation exists and why its actions are of a certain nature.

Background

The history of the Swedish non-profit sector is largely one of its relations to the state. Not only during the past 50 years, which has been the era of the Swedish welfare state, but even during the sixteenth century non-profit-state relations have been of vital importance. The popular mass movements have been an important element of the sector’s history, with their focus on activism, democratic decision making and membership (Olson, 1993).

In response to the social tensions and poverty in the nineteenth century new organisations for charitable activities emerged. These associations drew no clear distinction between poor relief organised by municipalities and private charity (Lundström and Wijkström, 1997, p. 218). Major popular mass movements, often inspired by similar movements in other countries, were established during the latter part of the nineteenth century. New forms of association were created, including the labour movement, the adult education institutes, the free churches, consumer co-operatives, the sports movement and the modern temperance movement (ibid, p. 219). These types of popular mass movement or social movement are significant elements within the Swedish non-profit sector.

In terms of membership and influence the labour movement had its peak between the 1930s-1960s, during which time both the free churches and the temperance movement lost considerable influence and their members. After the Second World War, new social movements emerged, including several immi-

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5 The idea of voluntary membership, however, can be problematic as you cannot decide on your own to become a member of a voluntary association. You have to apply and the other members make decisions about affiliation. Unless you embrace certain ideas, ideologies and values, you will not be granted membership. In this sense, all voluntary associations are to some extent exclusive (cf. Ahrne, 1994).
grant organisations and later the movement for the handicapped. The women and the environmental movements were particularly strong during the 1970s-1980s and the referendum on nuclear power in 1980 was an enormous manifestation of the influence of the environmental movement (ibid, p. 220). The growth of the welfare state during the twentieth century led to diminishing importance of many social welfare activities that were carried out by philanthropic organisations. Often at the organisations’ own initiative, many activities were taken over by the state. Rather than in opposition to, or instead of, the welfare state, the Scandinavian non-profit sector evolved consistently with the welfare state and had a considerable impact on society during the twentieth century (Kuhnle and Selle, 1992). The Swedish voluntary sector, in contrast to other countries, was more developed in the fields of leisure time, sports, adult education, advocacy and culture, and less in the areas of education, health care and social services (Lundström and Wijkström, 1997, p. 216 and Rothstein, 2001).

Contrary to the international belief that Sweden, often being described as a country more or less completely dominated by the state, has weak voluntary organisations, a large comparative research project found that Sweden had one of the largest voluntary sectors in the Western world (Wijkström and Lundström, 2002, p. 278). Today, the Swedish voluntary sector is similar to that found in the other Western industrialised countries in terms of activity, economy and membership (Pestoff, 2004). It is, however, less dependent on public support and more self-sufficient than in most other countries (ibid).

**Labels**

The non-profit sector includes many types of organisation and a broad set of activities (e.g., activities of church institutions and the participation of voluntary movements). In Sweden, there are two main types of non-profit organisation, the foundation (stiftelse) and the non-profit association (ideell förening). An association is created when a number of individuals (or legal entities) join to co-operate toward a common objective. There are also economic associations (ekonomisk förening) that are non-profit. The Swedish term förening puts its emphasis on the collective aspect, rather than on the individuals who join to form it. The term förening usually indicates that this group is accessible and open to any interested individuals. Common expectations of the non-profit sector are the orientation toward the public good and the notion of membership.

The Swedish non-profit sector is heterogeneous and therefore difficult to fit under a single rubric that describes the whole of the sector with one single concept or term. According to Lundström & Wijkström (1997, p. 221), none of the major concepts used in Sweden covers more than 50 per cent of the organisations in the sector. Terms that are frequently used are voluntary sector, popular movement, interest organisation and ideell sector. Further, other notions are used, although not to the same extent. These notions include leisure sector, social economy, informal network, civil society or informal sector. Nevertheless, these various concepts often refer only to subgroups and sometimes include activities or organisations that usually do not belong in the non-profit sector.

Sweden is often described as a highly organised nation and a significant feature of the Swedish non-profit sector is its high degree of association membership among the population (the National Committee for the Preparation and Implementation of the 7th European Conference on Social Economy, Ministry of Industry, 2001). Characteristics of the non-profit sector in Sweden are thus associations dedicated to promoting ideas and furthering their members’ interests as well as the public good. Almost 50 per cent of the Swedish people are active volunteers in different associations (Lundström & Wijkström, 1997, p. 222). Although decreasing somewhat now, membership in associations among Swedes has increased throughout the twentieth century. Another important characteristic of the non-profit sector is the number of multiple umbrella organisations, which, because of the heavily structured and organised Swedish non-profit sector, makes these federations important actors on the national scene.

There is a distinction between the labels popular mass movements and popular mass movement organisations (usually taking the form of associations). The organisation has the same ideology, but the structure is more hierarchical and formalised, which is necessary in order to gain political influence and maximise its public impact (ibid, p. 225).

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6 Although the distinction between foundation (stiftelse) and association (förening) is crucial, there is no specific legislation on these ideell associations. Further, the new legislation on foundations is very recent.

7 The Swedish term ideell is usually translated to idealistic, or ideell förening to non-profit organisation.
Organisations, which are usually referred to as interest organisations, are first and foremost farmer federations and labour unions, which traditionally have had a fair impact on Swedish society. Other associations include those for the temperance movement and the disabled. The interests of the non-profit sector are of major importance considering that this sector is primarily involved in representation and advocacy rather than service delivery. It is not uncommon that interest organisations exert pressure on the government. Some associations present ideological standpoints or serve a social mission, such as groups that were created to support the national defence, fight for the protection and preservation of the environment and represent the interests of the handicapped and disabled.

The segments of the non-profit sector devoted to social service delivery are generally referred to as the voluntary sector (frivilligsektor) (Kuhnle and Selle, 1992). This term emphasises the activity, or the voluntary aspect of participation, rather than the purpose. In a survey carried out in the mid-1990s by Lundström and Wijkström (1997, p. 225) fewer than 10 per cent of organisations in the non-profit sector identified themselves as part of the voluntary sector.

Yet another label, and perhaps the most politically neutral term for the non-profit sector, which is commonly used in Sweden, is ideell sektor. The concept of an ideell sector provides an important distinction between the efforts made by volunteers in various forms of public or semi-public organisations and public good efforts.

Non-profit organisations are largely entitled to several benefits (e.g., the exemption from value added tax for activities traditionally used by non-profit organisations to raise funds, the right to organise gambling and lotteries and eligibility for subsidies from different levels of government). Other benefits are provided by the postal service, the national telephone company or the Foundation for Control of fundraising. Furthermore, only membership organisations are eligible for public subsidies under Swedish law (ibid, p. 234).

In Sweden, the non-profit sector and the popular mass movements are viewed as an integral part of the democratic civil society. State support for organisations within the non-profit sector has grown substantially after the 1960s, whereas the state policy has varied in different areas of the non-profit sector (ibid, p. 239). Non-profit organisations play a minor role in the health area. This is because most of the health services have been produced within the public sector. Important contributions are made informally at the local level by professionals and members of non-profit organisations. For example, there is volunteer work that supplements the health services. Such work includes support to hospital patients, persons with alcohol or drug-related problems and persons under correctional care. In most of these areas the non-profit organisations are co-operating with the municipalities and depend on them for their support (ibid, p. 240). In the future, it is likely that the government will allow non-profit organisations provide new services within the health field, especially on the local level. As is shown in Chapter 3, there have already been contemporary attempts from both non-profit organisations and local government to create voluntary participation in the health area.

About patient organisations

The non-profit, nongovernmental societies or associations interested in health and health services in Sweden were started by people having an idealistic attitude and who wanted to contribute to the developments in society with their knowledge and free time outside of their daily commitments. Some were started already in the middle of the 19th century and the numbers of such non-profit societies have proliferated since. There are really two kinds of associations although both have the mutual goal of trying to improve the situation for the person with a disease.

One kind of association is dominated by the medical profession (sometimes with governmental support), with the dominant aim to stimulate research in order to improve the conditions of the patient but also to educate the patients or soon to be patients about the background, diagnosis and treatment of a specific disease entity. The general philosophy is rather paternalistic in the sense that they want to influence knowledge and treatment through research and education.

The other kind of association grows out of a patient movement, where persons with a chronic disease, or their families, co-operate to strengthen the interplay between people with similar medical problems in order to increase patient knowledge and influence. They comprise a pressure group asking government or professions to increase the resources for the medical condition in question.
The difference between these two associations can be illustrated with the situation regarding lung and heart diseases. To combat the spread of tuberculosis in the beginning of the 20th century, the National Association against Tuberculosis was created in 1904. At that time, more than tens of thousands men, women and children died from pulmonary tuberculosis every year in Sweden, many of them in their twenties or earlier. The creation of a national association was supported by doctors (also their organisation), civil servants and the Royal Family. At the inauguration, the Swedish Crown Prince was elected chairman. At that time, nobody thought of having a representation of patients on the board. The current paternalistic view of medicine made members of the professions believe that they should educate the public on how to live in order to avoid infection with the tuberculosis agent, and, when infected, how to decrease the risk for people in the environment.

Because tuberculosis is nearly extinct in Sweden, the aim of the organisation has shifted and is now working against lung and heart disease (it is now called the Heart-Lung Foundation). The association is still most interested in stimulating and funding research but is also conducting a certain amount of health information. Further, it still maintains a paternalistic philosophy, wanting to educate the public about the risks of falling ill to heart or lung diseases.

Somewhat later (in 1939) the Heart and Lung Association was established, with the ambition of giving the patients or persons with signs of heart or lung diseases a forum for influencing their situation. This organisation is thus purely patient-led and has a democratically elected board without any professional membership. The main goal is to give the patients and their families influence over the treatment process. This organisation is, in contrast to the Heart and Lung Foundation, a member of the Disability Federation and thus receives some support from the government. There is a certain competition between the two organisations concerning money from the public, but they also co-operate towards a similar goal.

Many patient organisations are small-scale bodies, but a few are professionally led medium-sized organisations, managed by salaried officials. There are currently more than 100 organisations, where all are interested in only one fairly well defined disease entity. Most of these incorporate in one organisation the two aims that were demonstrated in the two associations interested in lung and heart disease. This is most certainly the case of the Diabetes Association that has both professional and patients interests on its agenda.

**Collective Action**

Up until the mid 1960s when Olson changed the view on collective action, the traditional view on the existence of organisations and groups had two explanations. One view held that their ubiquity was due to a fundamental human tendency to form and join associations. The other view was that their existence was an aspect of the evolution of modern, industrial societies (Olson, 1965 & 1971, p. 17). The analytical pluralists had focused on group attitudes, group interests, group action and group pressures while neglecting individual interests (ibid, pp. 111-131).

Olson’s theories concerned the notion that the existence of a large group with a common interest does not automatically give rise to collective action. Instead, he suggested there must be an individual incentive to join or a compulsion to join. By offering members benefits (or selective incentives) that can be withheld from non-members, there are incentives to join the organisation. Membership and the power of the organisation are a by-product of the organisation’s activities and other benefits offered to its membership.

Often interest groups are divided into three levels, namely the local, the regional and the national level. The association at the national level is a meta-organisation (Ahrne and Brunsson, 2001) and usually provides various organisational and informational services to the local organisations. Nonetheless, the individual member and even the individual local branch organisation are essentially only individual units in a latent group. Olson argued that they can make no decisive contribution to the success of the national organisation, but will get the benefit of any achievements of the national organisation whether they have participated or not (Olson, 1971, p. 146). Although this is true, one can nevertheless argue that it is all these individual components that together make up the national organisation. From this view, they are indeed important: there would be no national organisation if there were no local organisations or individual members.

One explanation of why people turn to action in the public was offered by Hirschman (1985) who claimed that people did so because of their disappointment. Under favourable conditions disappointed consumers in the private arena to whom the choice of action in the public is available may be inclined to
take this course of action. Resource mobilisation theory, however, posits that disappointment is not an important explanatory factor, whereas control and access to resources are (e.g., Kendall, 2002).

Other important factors on the individual level when discussing active participation and membership are a person’s socio-economic status (e.g., Verba and Nie, 1972; Verba and Schlozman, 1995b) and a person’s skills, abilities and resources (Verba, Schlozman and Brady, 1995a and b). Participation in itself is another explanatory factor in that it develops and fosters the very qualities necessary for it. Participation is a form of education in that we learn to participate by participating (Pateman, 1970).

Empowerment is a relatively new and popular concept with many different meanings ascribed to it. A definition is presented in Chapter 4 along with the concept of co-production (Ostrom, 2002). Co-production is important in showing the interplay between patients and health care personnel. Patient empowerment describes the right of the patients to decide on their medical care, ultimately questioning who is in charge of an individual patient’s care. One important contributing factor in the emergence of patient empowerment is the increase in knowledge in the public and easy access to medical information through the media and the Internet. The earlier exclusive medical knowledge that characterised the medical profession has become accessible to the public, dramatically changing the balance between doctors and patients. Patients have the power to reject being passive recipients of care. The increased discussion of patients’ rights makes it important to investigate the significance of patient organisations and support groups (Ottoson, 1999, p. 375).

**Diabetic patient organisations**

Patient organisations differ in many ways from each other. There are two main categories of patient organisations. First, there are those that deal exclusively with the patients, and second, there are those that finance medical research. This study focuses on the first kind though the Swedish Diabetic Association (SDA) is a major financer of medical research at the national level.

Obviously, the specific disease and its characteristics have a profound impact on the organisation’s form and memberships, as does the size. There are organisations with several thousands members and there are organisations with less than a hundred members. As will be discussed later, it can be hard to organise patients and/or their family members. A consequence is that those who are weakest and need it the most usually don’t join organisations and thus have little or no power. Although patients share some of the most vital common interests and they are among the largest groups in the nation, many patients are unorganised. They belong to groups that exert no pressure and have no lobbying power. Because patients are organised fragmentally with their respective disease entity, they do not have any general representation.

Often one of the most important services patient organisations offer their members is information on the respective disease and what help is available. However, other services are also provided. These services can range from individual help in arranging a meeting with health care personnel or personnel from the social services to arranging social activities or investing in research.

I took the decision of studying the Diabetes movement after learning from the many health care professionals how ‘strong’ the organisation was in Sweden. A strong organisation provides a success story or best practice that others can learn from. Here we should expect to find patient empowerment at its best. For example, people with diabetes are unique in that they are the only patients in Sweden that have free access to medication, insulin and their aids. As stated in the New Pharmaceutical Benefits, insulin for treatment of diabetes is today completely free of charge for the patients and thereby holds an exceptional position within the present pharmaceutical benefits (SOU 2000:86, p. 213). This is a result of the intense lobbying efforts by the SDA. They have succeeded in influencing government policies on the care of diabetes and have been recognised by government as the voice of people with diabetes. However, their membership numbers only represent approximately 10 per cent of the diabetes population. Although other groups of patients could argue to the same extent as the diabetes population that they need their medication for survival, the fact remains that it is only people with diabetes who can get their medication without paying.

Diabetes is a serious chronic disease. Contrary to popular opinion, diabetes is both progressive and life threatening with potentially devastating consequences on the health of the individual. These include a higher risk of heart disease, stroke, kidney failure, eye disease (diabetic retinopathy) that can lead to blindness, and foot ulceration, which can lead to amputation. Diabetes doubles or triples the risk of dying prematurely. However, living with diabetes does not mean one has to miss out on things one enjoys do-
ing. By making adjustments, a person can live a full life without compromising his or her diabetes control. The conditions of this disease were thus assessed to be good for the purpose of the present study.

In this study the term ‘diabetic’ or ‘diabetic patient’ is sometimes used when it might be preferable to use other terms, such as ‘individual with diabetes’ or ‘health care consumer’. The use of the term ‘diabetic patient’ reflects the fact that research has focused on the interaction between the diabetic population and the health care system. I would like to emphasise the importance of not labelling people with chronic conditions as patients.

The Purpose of this Study

The purpose of this research is to explore and analyse collective action among Swedish patients with a chronic illness. Diabetes was chosen as the illness of study and members of the Swedish Diabetes Association therefore provide the focus of this study.

In order to achieve this purpose, four questions have been formulated which in turn are divided into a number of related sub-questions. These sub-questions are explored through interviews, observations and a questionnaire to members of two local branch organisations of the Swedish Diabetes Association. The four main questions are the following: Q1) Membership Engagement: What are the reasons for joining a patient organisation? What type of persons become members in a patient organisation? Why do some of them choose to become active members? How do active members differ from ordinary members? What common characteristics do they share, if any? Are there any geographic differences between the two local branches? Q2) Membership Influence: Do members in patient organisations want influence and what other function(s) does membership fill for them? What do the individual members think about their own influence in their local organisation, if any, and what does active membership entail? Q3) Strong Organisations: How do ‘strong’ local branch organisations work, what are the issues that the local branches commit to, and what characterises these organisations? Q4) Patient Empowerment: How does membership, activity and influence relate to patient empowerment? What influence can patient organisations and their members have and how do they use it?

These questions will be answered by exploring patient empowerment in two supposedly strong local diabetes branch organisations in Sweden. This thesis contributes to research in business administration and organisational theory by focusing on collective action among patients from their own perspective. This perspective normally receives less attention by students of business administration and organisational theory than from scholars in other disciplines, the health care sector, politicians and health care personnel.

Introduction of the empirical data employed in this research

This study uses two case studies to illustrate the influence and work of strong patient organisations and the potential empowerment of their members. The case studies have been chosen with regard to the study’s area of interest. Another selection criterion was the access to the case studies. By studying management and the wishes and input from the members in two organisations, a fair study of member influence, patient empowerment and organisational influence in ‘strong’ patient organisations is possible. Both organisations represent the same disease: diabetes mellitus. This disease was chosen because it is chronic but not directly life threatening and if properly handled severe complications can be avoided. However, the most important criterion was that many health professionals felt that the association and the organisations were the ‘strongest’ of patient organisations in Sweden in terms of getting their demands

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8 The perception of the diabetes organisation being ‘strong’ may be partly due to the necessity for the person with diabetes to take an active part in the daily treatment of the disorder. The diabetic state causes a disruption of the body’s governance of the important function of delivering the right amount of energy to each organ in the body from very active situations to the complete resting state (see chapter 5). Diabetes is a chronic disorder where the person can influence the development through active observation of symptoms and signs and modulate them through their lifestyle. This may be done with or without the help of medication that interferes with the handling of energy in the body (the National Board of Health and Welfare, 2005). Patient empowerment is thus of great importance for the person with diabetes, probably greater as compared with most other disease entities.
through to politicians by their lobbying efforts. Strong, local organisations were selected because the intention was to study collective action at its best. Strong here refers to organisations that are most active regarding membership activities at the local level and the local organisation’s activities and influence at the regional and central level.

The local diabetes branch organisation in a mid-sized town in the North

The first organisation studied became a local diabetes branch in a town up North, which had been assessed by the SDA as being one of the ‘strongest’ of the local branches. The regional organisation there was known to have a very active and committed chairwoman and the local branch was therefore seen as active. Up until recently, there had not been any regional organisation there, so when it was decided that there should be one, the local branch was made into a regional organisation and a new organisation was formed for the local branch. However, because the separation between the two organisations was very recently done, the division of work was still unclear at the time of my visit. They also seemed to have tight co-operation and were sharing the same premises and office staff. All this made it hard, if not impossible at times, to separate the two organisations. By studying this ‘strong’ patient organisation, I felt this case had the prerequisites to make an interesting contribution because of its activity and commitment. Because the office staff and the board members were positive and happy to have me there, I was allowed to stay with them for 10 days in January and February in 2000.

After a few days I had already begun to question my own research question. It seemed that not all, not even the majority of patients with diabetes, were very interested in having any influence. Instead of asking what type of influence they had, I began thinking that I should ask whether they wanted any influence at all? But focus in the study was not shifted completely; rather, this new question was added.

In the second part of this first study I turned to the members directly. During my stay at the two branches, I only met a few members and almost only those that were active. Where were the others? I realised that the interviews that I carried out with active members could not represent the members’ views as a group. I wanted to contact the members directly. This was done by sending out a questionnaire to all the members in the local branch. The purpose, among other things, was to ask the individual members about their interest in the organisation, their activity, what they felt the membership entailed and how they looked upon their local organisation’s impact in society.

The local diabetes organisation in a City

The local diabetes organisation in one of Sweden’s larger cities became the second organisation to study. This organisation had also been judged by the SDA to be one of the strongest of the local branches in Sweden. In addition, this branch was very active and even had their own health care consumer group, one of their many working groups.

As the organisation in the city had different prerequisites than the one in the north (situated in a big city with a higher population, having around three times as many members, etc.), I thought it could be interesting to compare this organisation with the first one in order to determine whether there were some common characteristics that could explain why these two were deemed to be ‘strong’. Perhaps the issues the organisations worked with also would differ in these two organisations?

In the City organisation office staff and board members were also positive and happy to have me study them and their work. I was granted access and went to this city for 10 days in April 2000. The annual meeting for the members of this organisation took place during the time I was there, where I then had the possibility to approach individual members and ask questions. Perhaps more important, however, was that I was free to observe the meeting.

I sent out the same questionnaire as was sent to members in the North branch. About one third of the City members were sent the questionnaire, which was about as many as the total number of members in the North. The purpose of the questionnaire was to gain the members’ opinions on their membership and their organisation.
Outline of the book

This book is divided into three parts. The first part is theoretically oriented and begins in Chapter 2 where I account for how my studies of membership and patient empowerment through patient organisations have been planned and carried out in this study. Details about how I have conducted my studies at the local branches of the Diabetes organisation are presented in this first section. Chapter 3 functions as a background chapter presenting the larger trend on a macro level of which the focus of this thesis is a part of. In this chapter, a brief description is presented of the organisation of health care in Sweden and of recent examples of lay participation in health care planning at the local level in Sweden. Reviews of theories on reasons for membership and active participation follow in Chapter 4. The concepts of empowerment, patient empowerment, and to a lesser extent, co-production are defined and discussed.

The second part of the thesis is empirical (based on questionnaires, interviews, participant observation and official documents). The chapters in this part mainly contain empirical data and do not discuss theoretical issues or implications. First, diabetes is described in Chapter 5 in order to create understanding for people living with diabetes and give insight to what it is like to live with diabetes. Thereafter, the Swedish Diabetes Association is described. This chapter serves as an introduction to the empirical part. In chapter 6, the qualitative data is presented, where how local patient organisations work and what issues they are committed to are in focus. This chapter is an overall presentation of two local branches within the diabetes organisation, their work, activities and the issues they deal with on a daily basis. Such information is important in understanding their function within society and, more precisely, for their members’ understanding. Chapter 7 presents the results from the questionnaire that was completed by members of the two branch organisations. The results focus on the members’ opinions about their membership in the patient organisation and their reasons for having joined it. The data are mainly described in terms of what the members think about their membership, their influence, the local organisation, its work and influence.

The final part of the thesis is the analysis and conclusions of the study. A summarising analysis is made in Chapter 8 and discussed with regard to the theoretical framework. Questions concerning membership and active membership will be examined. Other questions concern whether members want to have influence in the organisation and what function a membership in a patient organisation fills. The discussion in this chapter will evolve around membership and its functions, participation, co-production and patient empowerment. Finally, in Chapter 9 the conclusions of this study are presented, with a concluding discussion on membership and empowerment.
2 Research approach

This project’s methodological approaches will be presented and discussed in this chapter, as well as reporting on how the research has been undertaken. My mode of procedure as to answering the questions put forward in this study, together with the textual representation and the choices I have made, is described in this chapter.

“Methodology, like sex, is better demonstrated than discussed”, writes Eduard Leamer (Leamer 1983, p. 40). When put this way, it is difficult not to agree. Nevertheless, in this book I believe it is necessary to discuss and show both overall methodological considerations and some methodological problems concerning the data collection and study. A relevant metaphor for research was used by Asplund (1970). He compared a research process with solving a mystery in a crime novel. Two central elements are of importance here: to formulate the mystery and to solve it (Alvesson & Sköldberg, 1994, p. 363). It is, however, also important to show the account of the solution. The aim is to make it possible for the readers to position the author’s perspective and thereby be able to understand and follow the study’s realisation. My concrete methodological descriptions will be discussed later in this chapter.

The Case studies

This research project revolves around two case studies, which were purposefully chosen based on the study’s purpose and problem. The potential richness of information of the cases was also taken into consideration. The reason for choosing two ‘strong’, local diabetes organisations was that I wanted to study collective action at its best. This seemed the best way to do it.

A case study is, according to Yin (1994), an empirical study that looks into a contemporary phenomenon within some real-life context, where the boundaries between the phenomenon and the surrounding are not clear and sharp and in which multiple sources of evidence are used. Case studies are extensively used in social science research, not only in the traditional disciplines but also in practice-oriented fields as well as a mode of thesis and dissertation research in these disciplines and fields. Traditionally, the case study method has been looked upon as a method only fitting the exploratory phase of an investigation. However, because case studies are far from only being an explorative strategy, Yin does not believe that this hierarchic view is correct. There are different applications for the case study strategy (Yin, 1994). Using case studies to develop causal explanations, interventions that are too complex for mapping or experimental strategies, is one. Description of the surroundings in which an intervention has occurred is another area of use. An evaluation can also benefit from an illustrative case study showing the intervention. Finally, the case study strategy can be used to explore situations where the studied interventions do not have clear or unambiguous results. What separates the strategies is not the hierarchy, but the following three conditions: type of research question, the extent of control an investigator has over actual behavioural events and degree of focus on contemporary events (Yin, 1994). These conditions are matched with different methodological strategies. According to Yin (ibid), case studies are particularly appropriate when studying a contemporary set of events over which the researcher has little or no control and a ‘how’ or ‘why’ question is being asked. The distinction between three types of case study research made by Yin (1994, p. 4) refers to exploratory, descriptive and explanatory uses. According to Merriam (1994, p. 25), the case study is characterised by insight, discovery and interpretation. The case study is to its nature inductive rather than deductive. Case studies can illuminate how situations change over time and increase the understanding of them. The purpose is not to present the truth but a trustworthy interpretation (Merriam, 1994, p. 43ff). In this study, this means that the cases can widen and confirm known relations and conditions, just as unknown relations and conditions can give a new view of the studied situations.
Organisations

Because focus in this study is on organisations and their members, it is important to describe my view on organisations as social, open systems. New and modern types of organisations are often described as open systems, seeking to find forms for collaboration and dialogue with the world around them (Von Friedrichs Grängsjö, 2001, p. 62). Societies and social institutions do not exist isolated from individuals’ thoughts and actions, but are constantly being maintained and changed in daily social interaction. Organisations thus consist both of their social structure and their participants. These two components are interrelated and constantly help shape and reshape each other. Human action is meaningful to those who act and organisations are, in this respect, seen as a multitude of human interactions and relations. Salzer-Mörling (1998) argues that the organisation does not exist as a fixed entity: instead, it constantly becomes. An organisation’s meanings are both within and outside. The organisation cannot be seen as detached from the rest of the world, which, in my opinion, seems to be a common approach within organisational literature; instead, the organisation and its environment mix.

According to Ehn and Klein (1994), all researchers both influence and are influenced by their studies: the researcher is a part of what he or she is studying and not a spectator from the outside. The research process is seen as an interplay between these two actors: the researcher and those who he/she studies. Consequently, I have not tried to hide my presence in this text or to treat it as if it is ‘untouched by the human hand’ (Salzer-Mörling, 1998). Both Ehn and Klein (1994) and Van Maanen (1988) mean that impressions are textualised in the moment of experience when the researcher makes ‘mental notes’ on invisible paper. The recreating process consequently began already when I, as the researcher, acquired my first impressions from the organisation. My work with this study has hovered between induction and deduction, aiming at increasing the understanding of patient organisations and their work.

A more traditional definition of an organisation is the one of Barnard (1938) who wrote that:

An organisation comes into being when (1) there are persons able to communicate with each other (2) who are willing to contribute action (3) to accomplish a common purpose. The elements of an organisation are therefore (1) communication; (2) willingness to serve; and (3) common purpose. (Barnard, 1938, p. 82).

According to this definition, the individuals in an organisation have a common purpose. As most organisations consist of a number of subsystems, these units have some kind of common qualities and characteristics. It is from this basic viewpoint that I set out to study two patient organisations. In this study I have chosen a case study oriented method in which I have used both quantitative and qualitative approaches, which I now will discuss.

The Research Process & Design

The reason for using qualitative methods in this study was the ambition to gain a deep and detailed understanding of the study’s problem and to be made aware of underlying issues. Quantitative methods have also been used for a somewhat different purpose. I wanted to get a general picture of the members’ views as a whole, as well as to reach all the different member categories. By using quantitative methods, I gathered information I would not have been able to gather had I only relied on qualitative methods (e.g., this way I got an image of the members’ social background and their organisational and general experiences). Because these two approaches focus on different objects of analysis, one or the other perspective would have been lost if only one of the studies was conducted. Yet, I regarded both qualitative and quantitative studies as necessary in this study. Given my vague preunderstanding of both organisation studies in general and empowerment/influence issues, qualitative studies were needed. Certainly, you cannot begin a research process tabula rasa. To a greater or lesser extent, we all bring our preunderstandings with us. Preunderstanding is based on two things: firsthand personal experience and the experiences of others that are conveyed to the researcher second hand. The fact that my preunderstanding was rather limited, granted me the permission of not having to know all questions beforehand; instead, I was free to wait for

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9 Preunderstanding refers to such things as the researcher’s insights, experience and knowledge before engaging in a research program or a consulting assignment (Gummesson, 1991).
their gradual unfolding. Thus, the alternative of using only quantitative methods was never an option. Nevertheless, given the nature of the research problem, a combination of both a qualitative and a quantitative approach seemed appropriate. The quantitative approach was suitable for the survey I wanted to carry out, as I was seeking information from many people at the same time (e.g., Eggeby and Söderberg, 1999; Silverman, 1989; Patton, 1990). The combination of both a qualitative and a quantitative approach can initiate new lines of thinking by providing fresh insight, calling attention to paradoxes and surprises, ‘turning ideas around’ (Miles and Huberman, 1994, p. 41). Perhaps this is one-step closer to what De Bono (1967) calls ‘lateral thinking’, as opposed to ‘vertical thinking’, which means logical thinking. He argues that both types of thinking are needed, lateral thinking for generating the ideas and vertical thinking for developing them. The combination of qualitative and quantitative methods offers benefits in the form of providing richer detail and triangulation. Triangulation is a way of action, where different methodologies, theoretical perspectives and information sources are combined.

The concept of triangulation has generally been interpreted as the use of more than one method and thus more than one type of information. In this respect quantitative and qualitative research can be viewed as different ways of studying the same phenomenon. By combining them, researchers can make stronger claims of their conclusions being valid since they have been confirmed in two ways. The quantitative and the qualitative approach can confirm and strengthen each other in a triangulation of methods.

It is, however, not unusual to find differences regarding results from studies which have combined quantitative and qualitative approaches (Bryman, 1997). Getting contradicting results also corresponds very well with the idea behind triangulation; on the other hand, it does not mean rejecting one result and accepting the other. Differences and contradictions can force the researcher to go deeper into the problem area, which can give rise to new, fruitful questions. More effort can also be put into the analysis as an effect. Silverman (1989), for example, decided at first to use quantitative measures aiming at demonstrating that his qualitative analysis was reasonably representative of the data as a whole. However, the figures revealed that his overall impressions were in fact not in line with reality. Consequently, his analysis was tightened and the findings were specified more carefully. Eggeby and Söderberg (1999, p. 26) claim that this is one of the reasons for using quantitative methods, namely, the possibility of achieving surprising results, forcing the researcher to reconsider his or her findings and hypotheses.

When combining quantitative and qualitative approaches, one method of data accumulation often tends to get greater importance than the other(s). In most cases it seems that one of the approaches dominates as the most important source of information. Quantitative and qualitative research can have varying degrees of relevance for different stages in the research process, however. When choosing methodological approaches, of decisive importance is the problem and purpose of the project. The choice of different methods should not impose any problems per se. A prerequisite for this is the concept of methodological openness.

…the practical mandate in evaluation […] to gather the most relevant possible information for evaluation users outweighs concerns about methodological purity based on epistemological and philosophical arguments. The intellectual mandate to be open to what the world has to offer surely includes methodological openness. In practice, it is altogether possible, as we have seen, to combine approaches, and to do so creatively. (Patton, 1990, pp. 193-194).

A number of criticisms have been levelled against qualitative methods. Quantitative research is portrayed as being representative and reliable, where its systematic statistical analysis ensures that research findings and interpretations are robust. In contrast, qualitative research is portrayed as being unrepresentative and atypical with piecemeal, impressionistic and idiosyncratic findings (Devine, 1997, p. 141). The qualitative method is criticised for being unreliable and not easily generalisable. The evaluation of the interpretation or interpretations of the findings is also difficult. Generally, it is argued that quantitative research

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10 Quantitative methods require the use of standardised measures in order to fit the varying experiences of people and their perspectives into a finite number of response categories that are predetermined and to which numbers are assigned. All methods for data collection give rise to both advantages and disadvantages, the advantage in the case of quantitative approaches, being the possibility of measuring "the reactions of a great many people to a limited set of questions, thus facilitating comparison and statistical aggregation of the data" (Patton, 1990, p. 14). This gives the benefit of achieving a broad, generalisable set of findings. Silverman (1989), who argues for combining qualitative and quantitative research, means that the advantage of quantifying data is the ability to survey the whole corpus of data, which usually is lost in intensive, qualitative research. Here the reader is given a chance to gain ‘a sense of flavour’ of the data as a whole, instead of having to take the researcher’s word for it. Furthermore, in this way researchers are able to remove any doubts about the accuracy of their impressions about the data by revising and testing their generalisations.
is replicable and comparable, and generalisations can be made with a high degree of certainty, whereas qualitative research is neither replicable nor comparable and therefore not a basis on which generalisations can be made. One of the issues which sometimes causes problems when using only qualitative methods is that the researcher cannot show or prove the general or typical in the described courses of events. The tendency to rely on anecdotic methods in presenting information contributes to this uncertainty and concern.

The critical reader is forced to ponder whether the researcher has selected only those fragments of data which support his arguments. Where deviant cases are cited and explained [...], the reader feels more confident about the analysis. But doubts should still remain about the persuasiveness of claims made on the basis of a few selected examples. (Silverman, 1989, p. 140).

Although qualitative research cannot be representative, its data is usually relying only on a relatively small number of informants; it can aim to embrace heterogeneity of experiences and accounts, therefore, seeking diversity.

One researcher who argues against this view is Flyvbjerg (2001, pp. 73-81). One of the four misunderstandings about the case study as a research method that he debates is the view that one cannot generalise based on a single case. This depends upon the case and how it is chosen. Flyvbjerg argues that a strategic choice of case may add to the generalisability of a case study. Furthermore, he states that formal generalisation, based on single cases or large samples, is considerably overrated as the main source of scientific progress. Formal generalisation is only one of many ways by which people create and accumulate knowledge. Finally, he corrects the misunderstanding that one cannot generalise based on a single case and that the case study cannot contribute to scientific development. Instead, it should be:

One can often generalise on the basis of a single case, and the case study may be central to scientific development via generalisation as supplement or alternative to other methods. But formal generalisation is over-valued as a source of scientific development, whereas ‘the power of the good example’ is underestimated. (Flyvbjerg, 2001, p. 77).

It can be hard in a case study to rise above the empirical level (Alvesson and Björkman, 1992, p. 16). However, this study is not meant to be used for strict generalisations. Rather, the results are interpreted to give angles of approaches and ideas to a more general reflection on the existence of local patient organisations, its work and influence, as well as the members’ reasons for their membership, participation and possible empowerment and influence in the organisations.

To Alvesson and Sköldberg (1994, p. 10) there is no clear delimitation between the methods (to some extent they overlap with each other). Qualitative methods take their starting point in the respondent’s perspective, whereas the quantitative methods start from the perspective of the researcher. It is rather limiting only to discuss quantitative and qualitative research in terms of what methods of information gathering are being used. There is a tendency of interpreting the two traditions and the methods associated with them in ‘either-or-terms’. Too rigid distinctions between qualitative and quantitative research imply that the methods cannot be employed in conjunction with each other, i.e. they are mutually exclusive. In this study, my assessment was that only collecting data by qualitative methods would limit the study. I wanted the information from the survey to function side by side with the qualitatively collected material as indications of the members’ thoughts and experiences concerning their membership, their empowerment, their influence and the organisation’s influence. This study has therefore followed the idea of combining qualitative and quantitative methods. The triangulation in this study mainly concerns the different approaches of collecting data, but it also has covered two cases in two parts of Sweden. Although both cases were chosen out of the same criteria, they have two completely different demographic bases, i.e. one rural and one urban city with different population size and resources, etc.

Qualitative methods are often particularly oriented toward inductive analysis (e.g., Patton, 1990 and Strauss and Corbin, 1990). This means that the researcher is approaching the research setting without imposing pre-existing expectations on the phenomenon or setting under study. Where pre-decided theory may blind the researcher and only let him or her see what is included in the theory, the inductive approach implies no pre-conceived theoretical assertions. Instead, important patterns are assumed to emerge naturally. The deductive approach, on the other hand, is built on experiments that require specific hypotheses and specified main variables before the data collection begins. As the framework for understanding specific cases or observations is provided by general constructs, the variables of importance and the expected
relationships among those variables must be decided in advance. Because this study used both a qualitative and a quantitative approach, they have thus been approached both inductively (qualitative) and deductively (quantitative). However, my work has altered between theory and empirical findings and vice versa. The qualitative studies were carried out before constructing the questionnaires. These were then based on my research questions, which had been adjusted after the qualitative studies.

Conducting the qualitative study first was beneficial as it gave access to and contributed to the construction of the quantitative study. I have also deemed it important to read relevant literature, both before and after the empirical studies. Some authors (e.g., Yin, 1994 and Miles and Huberman, 1994) have emphasised that literature studies and the construction of conceptual frameworks play a focusing and bounding role within a study. By clarifying and providing questions and clues of what may be important at the research setting, it directs the researcher to topics that need further investigation. Furthermore, according to Yin (1994, p. 31), a theoretical framework is fundamental for generalising the results of the study. It also makes cross-case comparisons with a joint theory possible, thus claiming replication. Closely related to this is the issue of validity, where it is important to relate the data to previous experiences described in the literature. This is necessary in order to validate the study. There are, however, pitfalls; for instance, Glaser (1992) and Strauss and Corbin (1990) raise the possible ‘blinding-effect’ of the literature.

The implementation of the case studies in this study is presented in the sections that follow.

Sampling

I knew I wanted to study patient empowerment, specifically through patient organisations. I also wanted to carry out a comparative study, following two local patient organisations. With the aim of studying the patients’ influence and empowerment, I soon came to the insight that it had to be an organisation of people with a chronic disease, as this would allow the patients to have at least a certain degree of self-care. This would be useful in studying the phenomena of patient empowerment.

During the fall of 1999, I was in touch with a number of people within the medical field in Sweden. In various conversations I asked about patient organisations in general. It seemed that most, if not all, of the health care personnel I spoke to was of the opinion that the Diabetes Association was by far, in terms of influence, ‘the strongest one’. So was the opinion of the persons in charge of democracy-related issues at the Federation of County Councils who I spoke to during that time. Perhaps a contributing reason for this was the actual disease itself and its symptoms. Diabetes is a chronic disease, which assuming that it is kept under control, still can let people live normal lives. (The disease is explained further in Chapter 5.) Therefore, I decided to study organisations for people with diabetes.

The decisions I took and the choices I made regarding the design of this study have consequences for the application of the results and the conclusions that can be drawn. One delimiting decision was to only study persons who were members of diabetes organisations, knowing that approximately 90 per cent of the diabetes population are not members of the diabetes organisation. However, an unknown number of diabetics are likely members of other patient organisations, as people with diabetes commonly have other complications, though no one has mapped them out. It is unclear whether I would have come up with another result if I had instead studied, for example, the organisation for the visually handicapped, the organisation for kidney patients or the Heart and Lung organisation. The issue of what organisations and members to include in the study is important since it raises questions of validity. Due to methodological reasons and practical constraints in, for example, identifying individuals with diabetes who are not members of a diabetes organisation, I chose to include only those who are members in this study. This means that diabetics who have not joined a diabetes organisation or who do not know that a diabetes organisation exists are not represented in this study. Insights that could have been achieved from the unorganised diabetics are thus not available in this study (such as thoughts on why so few diabetics have joined the organisation).

The choice of what local organisations to study was made at a meeting at the Swedish Diabetic Association (SDA) in December 1999 and was chosen based on their level of influence and strength. I had presented my research question and asked the Association for help in picking out the two or three ‘strongest’ local diabetes organisations. ‘Strongest’ in terms of high levels of local activity and having influence both on local authorities and on the regional and national level within the SDA. I had already decided to choose at least two different cases, as multiple-case sampling adds confidence to findings through replication (Yin, 1994). We can understand a single-case finding by comparing similar and contrasting cases as...
to where, how and, if possible, why it carries on as it does (Miles and Huberman, 1994). The precision, the validity and the stability of the findings are thus strengthened with multiple cases. Because I did not know much about the various local organisations, I had decided to rely on the Association’s proposals. First, we discussed the research topic and then the criteria for the ‘strongest’ organisations. They were defined as being the most active in terms of membership activities at the local level, but also the local organisation’s activities and influence at the regional and central level. I wanted the organisations that most actively promote their ideas. This resulted in the Association recommending me to get in touch with the two local organisations that fit the definition of ‘strongest’: one local organisation in the North and one in a major city. I contacted both of these organisations by letter during the same month. The local diabetes organisation in the North instantly granted me access and agreed to have me come in the beginning of 2000. The first case is thus the one of the local diabetes organisation in the North, a town in northern Sweden. It is not one of the largest cities in Sweden, though it is a big town in a rural region, but still very small relative to a major city. It was studied during 10 days in January-February 2000, which is before the questionnaires to the members were sent out in May 2000. My focus was on the members’ personal experiences of and opinions on their empowerment and influence, as well as on their local organisation and their membership. The local diabetes organisation in the major city politely declined my request, explaining that the local organisation was currently faced with an ongoing reorganisation and had a shortage of knowledgeable people. This was due to many of their employees going on maternity or paternity leave. They felt they would not have the time to devote to this research project. Consequently, I then turned back to the Association and the local organisation that, according to them, came in third place. This was the local diabetes organisation in the City. They had a positive attitude and granted my request of access. The issue of access (cf. Gummesson, 1991) was indeed facilitated by the very positive attitudes of the local diabetes organisations in both the city and in the north. In both cases my impression of their reaction towards the research project was one of fascination and, perhaps more so, of gratitude. ‘Somebody who does not have diabetes, nor has any family members with the disease is actually coming here to listen to us!’ This did not make sense to them, which meant I had to spend a great deal of time explaining what my interest was and what the reasons were for this interest. The welcome I received from both of these organisations could be characterized as warm and thankful for my attention to their organisations. This, in turn, had a number of positive effects, including free access, talking to whomever I wanted to and studying the organisations’ documents. The local diabetes organisation was chosen as my second case and was thus the one in a major city in Sweden, characterized by a comparatively dense, urban population. I studied this organisation in the same way and on the same issues as in the earlier case. The organisation was studied for a 10-day period in April 2000, also before the questionnaires were sent out in June the same year. Thus, the qualitative studies preceded the quantitative ones in both cases. Both these organisations were purposefully selected as being information-rich cases. There are several different strategies for this according to Patton (1990, pp. 169-183), out of which mine was the one of ‘intensity’, i.e. information-rich cases manifesting the phenomenon intensely, but not extremely (Miles and Huberman, 1994, p. 28).

When I decided to study strong organisations, another important choice was made. Given my interest in collective action, it seemed natural to choose strong patient organisations. If I had focused on weak patient organisations, this would likely have meant that there would be not much to study. (The weak local patient organisation probably has no clear agenda, few meetings if any, few activities, a small staff and perhaps only a few board members (if there even is a board) and with a varying health status.) The decision to focus on the strong organisations was, however, not totally because of methodological reasons, but theoretical ones as well. This is because it felt logical to look for empowerment among local organisations that were both active and successful in achieving their goals and influencing the regional and national level within the diabetes association. There is thus a point with studying extreme cases. If one discovers problems even in success cases, it is likely to indicate that the problems are of general character. Further, extreme cases are rich in information. However, they may lack information that only weak or non-active organisations can provide in their situation. I could also have chosen to study one strong organisation and one weak organisation, which probably would have given me better comparative opportunities in studying the problems and possibilities of collective action. Nevertheless, it was my firm belief that the focus on patient influence and empowerment through patient organisations would gain from only studying strong organisations. Whether I really have studied strong local diabetes organisations or not can be discussed and is considered in Chapter 8. Here it is sufficient to say that by choosing
to study strong organisations, I could not observe the work of the weaker or less active local organisations or the conditions they exist under.

Data Accumulation

The qualitative data in this study is based on relatively small samples of people, some of whom have been studied in-depth in their context within the organisation. The sample has been purposive in the respect that, rather than interviewing passive members, I chose to interview and observe the active and organised people within each organisation.

The quantitative data, on the other hand, have aimed for larger numbers of cases, which would seek statistical significance. Here the sample is full-scale in one case (the North) and random in the other (the City). In the Northern case the questionnaire was sent to all members, whereas in the City case it was sent to every third member, starting at a randomly chosen number. However, in both cases the total sample was roughly about the same (North: n=465; City: n=520). The achieved response rates were 74 per cent in the North and 76 per cent in the City (see appendix 6 for a detailed presentation and analysis of the missing data, which show no clear pattern of systematic bias).

This study combines a quantitative part, where 742 people in two local diabetes organisations answered a questionnaire, with more intense ethnographical studies of these two organisations by the people running them. The quantitative information was combined with the findings from the interviews and participant observations: together, they formed an overall picture of how people experienced the organisation, the memberships and the empowerment. I will now describe the different forms of data I have collected and used.

According to Miles and Huberman (1994) and Patton (1990), qualitative studies rely on three forms of data: interviews, observations and documents. I have used all three forms to varying extents.

Interviews

Intensive interviewing techniques are widely used in organisational studies. In-depth interviewing is usually based on an interview guide, informal probing, asking the respondent to elaborate on what he or she has said and open-ended questions, all of which allow the respondent to talk at length on a topic, which facilitates discussion in a semi-structured or unstructured manner. Intensive interviews are flexible and open, allowing the respondents to elaborate on their attitudes and values and account for their behaviour. In this way they can be seen as ‘guided conversations’ (Devine, 1997, p. 138).

The interviews are often conducted with just a small sample of informants and tend to be rather lengthy. The transcriptions from the interviews constitute the data that are subsequently analysed and interpreted. The field notes can also contain the researcher’s impressions and interpretations from the observations of the setting and the respondents. Characteristic for intensive interviewing is that people are allowed to offer their interpretation of events and to talk freely: they can tell their own story in a language with which they are familiar. Paramount is their perspective (Schwartzman, 1993, cf. ethnographical studies, which are characterised by putting emphasis on ‘the native’s point of view’).

The respondents to interview at the local diabetes organisations were chosen out of their involvement and experience, as I believed that they could provide thick information. In the Northern case this meant interviewing many of the members of the board, the one person employed at the office and two other persons (one diabetes specialist nurse at the hospital and the chairwoman of the County’s Diabetes organisation). I tried to arrange interviews with all members of the board, but unfortunately, this was not possible as three of them declined to participate because of illness, distance to travel or lack of time.

In the case of the City I interviewed many of the members of the board, the two persons employed at the office and two other persons (one diabetes specialist nurse and the group leader of the women’s group within the local diabetes organisation). I tried to arrange interviews with all members of the board, but unfortunately, this was not possible as three of them declined to participate because of illness, distance to travel or lack of time.

In the case of the City I interviewed many of the members of the board, the two persons employed at the office and two other persons (one diabetes specialist nurse and the group leader of the women’s group within the local diabetes organisation). I tried to arrange interviews with all members of the board, but this was not possible here either. Four of the members of the current board declined to participate, because of either illness or lack of time. (This organisation has been struck by many defections during the year and during my visit was faced with many changes (brand new board members were joining after the annual meeting and many of the former members were defecting). This is a noteworthy observation in itself and one that will be more thoroughly discussed in Chapters 6 and 8.)
In both cases the selection of who to interview was made by me in collaboration with the organisation’s representative. By describing the purpose of the meeting and interviewing active people within the organisation, I was given names of persons that might be of interest to contact.

A total of 15\(^1\) actors were interviewed during the periods January 31 – February 6, 2000 (the North) and April 4 – April 11, 2000 (the City). Board members, ex-board members, group leaders and staff, representing different administrative and interest areas, were included, as well as two diabetes specialist nurses (see Table 2.1).

Table 2.1 Interview sample from the local organisational level

<table>
<thead>
<tr>
<th></th>
<th>Local board members</th>
<th>Local ex-board members</th>
<th>Group leaders</th>
<th>Staff</th>
<th>Diabetes specialist nurse</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case study 1: the North</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Case study 2: the City</td>
<td>4(^*)</td>
<td>1</td>
<td>1</td>
<td>3(^*)</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>16</td>
</tr>
</tbody>
</table>

(\(^*\): one person is counted in both of these groups, which explains why there is a total of 16 people in this table, though the total number of persons being interviewed was 15.)

To gain a more complete understanding, the interviews were undertaken using an open-ended approach. By using open-ended questions, the respondents are not forced into rigid categories that have been established a priori. Nevertheless, a general interview guide (Patton, 1990, p. 283) with basic questions was used, which served as a checklist\(^{12}\), although some argue that it represents ‘mental laxity’ (Kristensen, 1995, pp. 120-121). The advisory guide is, according to Gubrium and Holstein (1995), more of a conversational agenda than a procedural directive. The questions in the guide focused on the respondents’ experiences and opinions on the organisation’s activities, both towards their members and towards actors in the society they wished to influence, as well as the Diabetes Association in Stockholm. The interviews were semi-standardised (Lundahl and Skärvad, 1992, p. 92), meaning that I, as the interviewer, was free to adjust to the respondents and to more freely chose the exact formulation and the order of the questions. The active interview guide was never completely static, however, as it varied from one interview to the next, depending on at what stage in the research process the interview was conducted and who was being interviewed. Sometimes it constituted the core of the interview conversation; on other occasions, it was more or less abandoned when the respondent staked out and developed “narrative territory” (Gubrium and Holstein, 1995, p. 76). The guide was influenced by my personal and professional experience, as well as by my literature studies, i.e. my theoretical sensitivity (Strauss and Corbin, 1990).

Although impossible to completely fulfil, I tried my best not to direct the respondents’ responses in any directions, being aware of the importance of not being too directive and to question informants in as neutral a way as possible. Inevitably, the nature of the interaction at the interview setting between the interviewer and the informant will have some impact on what is said or not said, and on how it is said. It is difficult to judge my (in my role as an interviewer) influence on the course of a conversation, but I acknowledge my role and its (hopefully minimal) impact on the interviews.

In addition to formal interviews, informal interviews were conducted, with the latter referring to meetings and chats at coffee breaks, lunches, car rides, etc. According to Patton (1990), during such informal interviews, the respondents seldom realise that they are being interviewed. Formal interviews, on the other hand, mean those meetings that we had agreed upon in advance and where I asked certain questions and took notes. Both types of interview were formative in the sense defined by Madge (Gubrium and Holstein, 1995, p. 7), as the respondents were “given some sort of freedom to choose the topics to be discussed and the way in which they are discussed.” Informal, non-directive interviews and life histories are all examples of formative interviews. My ambition was to create an atmosphere of open dialogue during the interviews.

I always started the formal interviews by presenting myself to those who did not already know who I was. I also briefly presented my research project and its general purpose. I always mentioned that the study had been sanctioned by the SDA. All interviews conducted were in depth interviews. The purpose

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1 One person filled two functions, both as the treasurer and one of the office staff.

12 The interview guide, however, was not applicable to the interviews with the diabetes specialist nurses in both cases.
of this was to bring forth the respondent’s valuation of the situation, opinions, attitudes and ideas as well as the pure facts. Instead of having only information-seeking questions, I also used dialogue-developing questions, i.e. questions that stimulate the respondent to develop his or her answers and thoughts (Lundahl and Skärvad, 1992, p. 93). The interviews started by asking the respondents something about their background, usually concerning the outbreak of their disease (if they had diabetes) and the reason why they had chosen to join the diabetes organisation. Some examples of the questions being asked were of the following character: How do you experience the work within the diabetes organisation? What do you think is important for the organisation to focus on? How is the collaboration with the individual members and do you believe that they are able to influence the organisation? What does your membership mean to you? Do you feel you have become empowered as a member of this organisation? The SDA think that your organisation is one of the strongest ones in terms of activities and influence. What is your personal opinion on that?

The average interview lasted about 1 hour, but the interviews varied from 30 minutes to 3 hours, depending on the information obtained. I had decided not to use tape recordings during the interviews because this might make the respondents nervous and more reluctant to share information. Consequently, I took notes and transcribed the information almost immediately after each interview. All the interviews with board members and office personnel concluded with me summarising my major impressions of what had been said from my field notes. This procedure encouraged the respondents to immediately correct or add to my notes and allowed them to react to the validity of my notes (cf. Lincoln & Guba, 1985, p. 271).

In both cases the interviews with the diabetes specialist nurses were of a somewhat different character. Neither did they follow any interview guide nor did they end with my summary. They were also the shortest interviews, lasting only about 30 minutes. The interviews mainly focused on their reasons for membership, their involvement in the organisation’s work, their impressions of the respective organisations and their involvement / commitment to recommending their patients to join the organisation.

Data from formal interviews were gathered by using field notes. I chose not to use a tape recorder, even though it has been claimed to be necessary for the credibility of qualitative interviewing (e.g., Patton, 1990). However, there have also been opposite claims, i.e. tape-recording may influence the respondents such that they may behave differently from what they would have had they not been taped (e.g., Lincoln and Guba, 1985, Sekaran, 2000, Kristensen, 1995). Taped interviews might thus bias the respondents’ answers because they know that their voices are being recorded, i.e. their anonymity is not completely preserved. For this reason, tape-recording was not used in the interviews or in the formal observations. Instead, I took extensive field notes, both from formal observations and from the interviews, sometimes including people’s observed feelings or reactions when they were obvious and acknowledged by the person in question, but mostly of what people actually said. I kept from making notes on people’s feelings and reactions in other situations, as it is difficult to interpret people’s facial expressions and gestures correctly. Almost immediately after the interviews, the detailed ‘process notes’ were transcribed (Gubrium and Holstein, 1995, pp. 78-79), which were clarified and elaborated upon as soon as possible after completion of the each interview.

In the first case study eight formal interviews were undertaken with 6 persons; in the second case study 11 formal interviews with 9 persons were undertaken.

The interview included two forms: the open personal interview with an interview guide and the questionnaire. These two forms, which are different concerning structure and content, provide different information and knowledge.

All forms of written information of interest to the study are referred to as documents. Examples of documents are annual reports, the organisations’ magazines, newspapers and other magazines, minutes of annual general meetings, minutes from board meetings, letters, notes, internal messages, brochures, study material and other written materials of interest. These types of material have been used to give a better understanding of the different cases. In this study, an effort was made to use written documents when this was possible because I did not want to take up the respondent’s time unnecessarily during an interview. Only where there have been obscurities or contradictions in the written material, has this been brought up during the interviews.
Observations

Patton (1990) claims that data for qualitative analysis usually come from fieldwork where the researcher spends time in the setting under study. Fieldwork, as defined by Van Maanen (1988, pp. 2-3), is “the stiff, precise, probably too visual, but nonetheless double-edged notion of participant-observation.” This, however, is, as Van Maanen points out, more of an amorphous representation of the researcher’s situation during a study than it is a definition of a method. Another definition of fieldwork is the one by Denzin: “The method that throws the researcher direct into the life-worlds under investigation and requires the careful recording (through field notes) of the problematic and routine features of that world” (Van Maanen, 1988, p. 117). The researcher makes firsthand observations of activities and interactions during the fieldwork. Sometimes the researcher takes on the role of a participant observer and engages personally in the activities. Action research refers to situations where the researcher actively works with the people involved in the study in order to solve one or several problems. This joint collaboration, however, has certain ethical considerations of importance to the researcher, a role that can easily become problematic. In my case, I chose not to do action research as I thought it would be difficult given that I planned to include at least two cases with geographically dispersed actors, i.e. more time is required than when studying only one case. Both limited resources and time further set heavy constraints on my ability to perform any action research.

I have undertaken both formal and informal observations. Formal observations refer to those times when I was present at meetings and observed respondents’ interactions. I never ‘went native’, nor did I get ‘an insider’s’ point of view (see, e.g., Schwartzman, 1993; Law 1994). Naturally, in some sense “we all go native, we all interact with what we study”, as Law puts it (1994, p. 39). The degree that this happened in this study was very limited, however. This was partly because of the time constraints, i.e. the limited periods I spent at each organisation, and partly because I am not diabetic, nor do I have any close family members or relatives with diabetes. Moreover, I am from Stockholm, something that clearly differentiated me from the people at the organisations I studied. Not so much from my own perspective, but at both organisations, I was introduced as ‘the researcher from Stockholm’, which also was emphasised by them several times during my stay there. Thus, there was no risk of me ‘getting too involved’, which can lead to becoming ‘too close’ to the research setting. The informal observations (cf. Yin, 1994) are my experiences from having been at the settings, including observing how people worked, how people related to each other, their interactions with each other, their interactions with their members, the way they were dressed and the look and function of the location of the organisation’s office.

I have tried to take on the role of a passive observer, although I am aware that my presence, to some extent, has affected the situations I studied. My direct participation has not gone further than ‘direct onlooking’, i.e. there has been no interference from my side. As Patton has pointed out, the “purpose of observational analysis is to take the reader into the setting that was observed” (Patton, 1990, p. 26.).

I conducted six formal observations. In both cases, I was granted access to all kinds of meetings the organisation was engaged in during my stay. In two cases, external permission for my presence also had to be granted from the people involved at a Hospital and at the County Council’s patient representative. Both organisations met me openly, granting me free access to documents and letting me make contacts with whomever I wanted for interviews. Three of the formal observations were carried out at study circle meetings, whereas the other observations concerned one board meeting, one annual member meeting and one meeting with the health services.

The surveys and the questionnaire

Survey research is based on a standardised approach to interviewing with a predetermined questionnaire and mostly standard closed questions. The main advantages of mail questionnaires are that a wide geographical area can be covered, the respondents can complete them at their own convenience in their homes and at their own pace. The interaction between the respondent and the interviewer is limited, which avoids the respondent reacting to the interviewer. Therefore, considerable effort is put into the formulation of unbiased questions that do not lead the respondent to react in a particular way. The aim is to iron out ambiguities, making the meaning and intention of the question clear and thereby reducing re-
response errors. With survey research, every respondent is asked the same question in the same order. The questionnaires are reliable in reproducing similar facts and can be easily replicated. The replies are coded and subsequent the statistical analysis produce observed regularities.

The planning and the construction of the questionnaires took place during March and April 2000. The first version was to casual sample of about 20 persons at Södertörn University College. This led to several improvements. I brought the revised version with me to the City while carrying out my fieldwork there. I was then granted permission to carry out a pilot study using the questionnaires. Fourteen questionnaires were completed by the participants (members of the local diabetes organisation in the City) at two study circle meetings on measuring techniques, one for type 1 diabetics (n=8) and one for type 2 diabetics (n=6). This pilot study indicated that there were a few unclear formulations of the questions. These questions were eventually revised to get the most reliable and valid data possible. Consideration was also given to the comments made by the participants in the trial study. The final version (Appendix 1) was thereafter sent to members of both organisations (in case 1 to all 479 members in May and in case 2 to 533 randomly selected members in June\textsuperscript{13}). Thus, construction and planning were done before beginning the data gathering phase (Hellevik, 1984).

The construction of the questionnaire has importance, both as to how the questions are posed (i.e. the formulations) and in what order they are administered. In the case of getting the results from the questionnaires, we depended on the recipients’ benevolence. Belson (Holme and Solvang, 1997, p. 173) states that if the questionnaire is too comprehensive, if the structure is unclear, if we use an unintelligible language or if it seems careless and less serious, the probability is low for the recipient to devote time to answer it. Therefore, it is important that the questionnaire and the enclosed letter motivate the recipients to respond to the questions. In this study, two letters accompanied the questionnaire, one from me and one from the concerned local diabetes organisation. In my letter (Appendix 2) and in the reminder letter (Appendix 4) emphasis was placed on how important it was to get their responses.\textsuperscript{14} The letter from the local organisation (Appendix 3) also stressed the importance for the organisation as a whole, to take part of the results from the survey. In this respect the individual respondent would indirectly benefit from the findings (e.g., through changes of the organisations’ activities and services), which was pointed out to the respondents. Another factor of importance is that the respondents could trust the promise of anonymity (Holme & Solvang, 1997, p. 174). In this study all the questionnaires were coded with a number so that in the event of missing data I would know the identity of the respondent. This was used only once, namely at the time of arrival when I checked off the respondent on the members’ list.

Questionnaires differ in many ways from interviews. One difference concerns keeping the respondent’s interest alive. In both cases there are limits to how comprehensive the questionnaire/interview guide can be. If it is too long, missing responses will increase greatly and the answers will be less serious (Holme and Solvang, 1997). Several authors have presented different orders of questions in a questionnaire (e.g., Hellevik, 1984; Holme and Solvang, 1997; Wärneryd ed., 1993). Most authors, however, agree that the questionnaire should start with factual questions.

The formulation of the questions can affect the answers. According to Holme and Solvang (1997), questions concerning values will always lead the respondents. In minimising this effect, the questions should be formulated in such a way that all respondents get the same meaning and the same associations from the question (Davidsson and Wärneryd, 1993, pp. 60-100).

In the present questionnaire I chose the response form suiting respective question (cf. Wärneryd, 1993, pp. 101-121). There were questions and response alternatives (both structured, semi-structured and un-structured) of varying character (Appendix 5). When mailing questionnaires, it is important to leave a good deal of space for comments. Thus, plenty of space was provided for respondents to elaborate their responses (Appendix 1). I had tried the questions out in advance in a pilot study in order to see if they worked. I carried out the full-scale survey with the incorporated changes and corrections that were based on the results from the pilot study. At the same time, I tried to formulate the questionnaire to make it easy to code and transfer information from the respondent directly to a computer.

The response alternatives generated different levels of measurement, ranging from fully quantitative or interval data (e.g., number of years of membership) through ordinal or ranked data (e.g., ‘what do you think about your organisation’s ability to influence the Diabetic Association: very big, big, neither big nor

\textsuperscript{13} Of a total of 1601 members (i.e. a third) of the City organisation.

\textsuperscript{14} After two weeks, a reminder was sent to those who had not responded with a second copy of the questionnaire.
small, small, very small?’) to nominal or categorical data (e.g., ‘in what way can the organisation improve the diabetics’ situation?’)

The purpose of the quantitative research in this study is exploratory. I wanted to get the opinions of the members and their views regarding their local organisation, the SDA and their membership in the patient organisations. When presenting the data, the primary aim is to describe the findings in terms of what the members feel and think of their membership, their influence, the local organisation and its work and influence. Thus, the purpose is not to test any specific hypotheses, i.e. the survey is descriptive and exploratory.

Data Processing

During all phases of data gathering, I only took notes purposefully, covering what was deemed relevant at the time. Thus, the qualitative data presented in this study are data as I have experienced them, and thus were obviously influenced by my preunderstanding and personal concepts.

Because it is impossible to note exactly everything that is said or done, selection of what to study began at an early phase in the study. When going through my field notes and process notes, I chose only those statements that seemed important to the study. Basically, the same reasoning applies to the survey study. Thus, I chose only those comments to the questions that seemed important for the study and the coding of the data is characterised by my interpretation. However, most of the responses were coded into categories, which made it easier to present the results.

The reliability of a study seeks to minimise biases and errors, i.e. to assure that the operations of a study can be repeated with the same results. I have in both studies in this thesis conducted and documented the research methods and procedures so that they can be checked and repeated by others.

Table 2.2 presents the various studies of this thesis.

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15 More specifically the questionnaire aims at clarifying the individual member’s interest in, if any, and ability to influence the organisation and participate in its work and/or activities. This is done with detailed questions regarding the reasons for joining the organisation, the local organisation’s and the national association’s (SDA’s) ability to improve the situation of people with diabetes in the society, the possibilities of influence within the organisation/SDA, the individual member’s ability to influence the branch and the branch’s ability to influence SDA and the most influential actors in the branch’s work etc.
Table 2.2 Outline of the studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Type</th>
<th>Point of time</th>
<th>Form</th>
<th>Technique</th>
<th>Number of resp. / Missing data</th>
<th>Time / Interview</th>
<th>Respondents</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fieldwork in the North, organisational level</td>
<td>Qual.</td>
<td>10 days, Jan-Feb, 2000</td>
<td>Interview, observations</td>
<td>Semi-standardised, extensive process notes</td>
<td>6 (formal interviews)</td>
<td>30 min – 3 hours</td>
<td>The local diabetes branch in the North</td>
<td>To map out the organisation’s work in terms of driving forces, membership empowerment and influence</td>
</tr>
<tr>
<td>Fieldwork in the City, organisational level</td>
<td>Qual.</td>
<td>10 days, April 2000</td>
<td>Interview, observations</td>
<td>Semi-standardised, extensive process notes</td>
<td>9 (formal interviews)</td>
<td>30 min – 3 hours</td>
<td>The local diabetes branch in the City</td>
<td>To map out the organisation’s work in terms of driving forces, membership empowerment and influence</td>
</tr>
<tr>
<td>Pilot study, questionnaire*</td>
<td>Quant.</td>
<td>April, 2000</td>
<td>Questionnaire</td>
<td>Direct</td>
<td>14</td>
<td></td>
<td>Participants from two study circles</td>
<td>Testing the questionnaire.</td>
</tr>
<tr>
<td>Member level in the North</td>
<td>Quant.</td>
<td>May, 2000</td>
<td>Questionnaire</td>
<td>Mail</td>
<td>345 / 120</td>
<td></td>
<td>Members of the local diabetes branch in the North</td>
<td>To map out the members’ motives, attitudes and relations to the local diabetes organisation and the national association.</td>
</tr>
<tr>
<td>Member level in the City</td>
<td>Quant.</td>
<td>June, 2000</td>
<td>Questionnaire</td>
<td>Mail</td>
<td>397 / 123</td>
<td></td>
<td>Members of the local diabetes branch in the City</td>
<td>To map out the members’ motives, attitudes and relations to the local diabetes organisation and the national association.</td>
</tr>
</tbody>
</table>

*=The purpose of this study was to check the feasibility of the survey instrument (i.e. the questions in the questionnaire).*
Although this study is mainly micro or meso oriented, this chapter’s focus is more on the macro level and should be seen as a background chapter presenting the larger trend of which the focus of this thesis is part of. This is important for how patient empowerment has been studied in this study. First, in order to illustrate the forces active in the field where patients need to increase their influence, it is necessary to give a short orientation about the organisation of health care in Sweden.

In addition to the United Kingdom and the Nordic countries, Sweden has one of the most socialized health care organisations in the world. Most of cost is paid through taxes but patient fees amounted to 4 per cent of county council revenue in 1999, the highest percentage of UK and the Nordic countries (World Health Organisation, 2000). The organisation of health care is largely decentralized, but each of the three political levels that exist in Sweden has some responsibility for the health of their part of the population.

The central government, through the department of social affairs, introduce laws governing the health care, is responsible for the follow-up of the care through the Board of Health and Welfare (BHW) and may sometimes increase the locally levied resources through specified grants to the councils or municipalities. In 1982, the present health care law was passed by parliament, for the first time introducing the right of patients to be informed and decide about their treatment.

The second level, county councils and regions, is directly responsible for implementing most of the health care. The county councils and regions are the owners of hospitals, including the teaching hospitals, and most of the facilities for primary care. The third level, the municipalities, were charged with responsibility for care of the elderly (through a law in 1992, Ädelreformen) and for patients with mental diseases (through a law in 1995). Both responsibility and money were then transferred from the county councils to the municipalities through an agreement following these laws.

All three of these levels have a right to levy taxes from their respective populations. The consequence of this organisation is that both taxes and services differ in different parts of the country (although the government always claims that the availability of health care should be the same for all citizens). As the political majority in all governing bodies may change at the four-year elections (to parliament, county councils and municipalities at the same time), details in the distribution and running of the health services may change according to political ideology every fourth year, with dissatisfaction from workers and patients alike. This has been the case especially in Stockholm County and in the Stockholm municipality during the past decades. Suggestions to lift the responsibility for health care above the political level have never been seriously considered. Furthermore, many county politicians have the attitude that the influence of patients on the running of health care is sufficiently governed through the four-year general elections. They are not alone, as Van de Ven (1991, p. 53) stated: “In principle a structure of elected local politicians responsible for local health care, provides the opportunity for expressing consumer preferences at a local level.” Many Swedish patients, however, are no longer satisfied with such a limited influence on the delivery of health care, which is an important issue for their wellbeing.

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16 At present, 18 county councils, one municipality and two regions are in charge of health care. In some places in the country pilot projects with regional self government were started in 1999. The Region Skåne was then formed by merging the county council of Kristianstad County, the county council of Malmöhus County and the medical health care in the city of Malmö. At the same time, the region of Västra Götaland was formed by merging the Bohus county council, the Älvsborg county council, the Skaraborg county council and the medical health care in Göteborg.

17 During many decades, all responsibility for health care rested with the counties. In the last decade of the twentieth century Ädelreformen changed this pattern. First, the care of the elderly was moved from the counties to the municipalities in order to get this care closer to the patients. However, not all municipalities had an organisation that corresponded to the new responsibilities. Furthermore, the anticipated co-operation between counties and municipalities and between medical and social services did not occur except in some places. Both the main change and the follow up have been a question for civil servants and politicians with very little, if any, cooperation from patient organisations (The National Board of Health and Welfare, 2005).
When the above-mentioned reforms were launched, both government and the public anticipated some difficulties, but even now (ten years after the reforms started) the cooperation between counties and municipalities is far from perfect. This is the case both at the personal level (between civil servants and social or medical workers) and at the level of the ruling political boards. The BHW is continuously evaluating the effect of these reforms, but it can only advise the government about its findings. The divided responsibility between the different political levels invites problems, especially as the details are not clearly defined. This has led to an inability for rapid decisions and getting agreed changes working in daily routines. This situation is one important reason why patients and their relatives feel the need to have more influence on the running of health and social services.

A health service in constant financial changes

The development of new medical knowledge during the past decades has contributed to an increase of the costs of health care. In Sweden, the cost increase was contained for a long time, but during the past 10 years, the cost increase has again started to escalate. In this situation the county councils have tried different ways of cutting down or rationalising the service, but usually without any great success. When one kind of reform has failed, another reform replaces it, always without any evaluation of the results of the failed attempt. As the different counties have tried various ways of changing the health services, this ought to have been a fertile field for scientific studies regarding the value of various organisational methods and the difference between them. The way the changes have been done and followed up has made it impossible to make such comparisons, however. Consequently, the councils know today as little as they did ten years ago about the best (and cheapest) way of conducting health services.

Each county council has a pronounced freedom to develop the pattern of health service. Although varying from county to county, the county politicians, administrators, heads of clinical departments and primary care physicians all have some influence on the health care budget. The formation of policy and resource allocation is seldom based on a clear-cut set of priorities. During later years, priorities for change have usually considered the economic situation more than medical advances. Many of the decisions are delegated to politicians on subordinate levels in the organisation and to health professionals a lesser extent to (Thorslund et al., 1997, p. 204). In the daily exchange with patients the doctors enjoy a comparatively high level of freedom (within the budget set by the county council).

Some counties have a comparatively rich and prosperous population; others have more earners of low salaries and others a large elderly population. This means large differences in the health care budget. The decentralized responsibility for health care thus leads to a growing difference between the output of the health care in different county councils. The increase of these differences can be seen as a “definite threat to one of the basic principles of the Swedish welfare state: equity” (Thorslund et al., 1997, p. 204). The difference has continued to increase since Thorslund’s statement nearly 10 years ago.

Complacent patients

Traditionally, the Swedish decision-making model has been characterised by a “lack of violent conflicts and focus on compromise and consensus” (Peterson, 1991, p. 176). During the past decade, however, the public has become more informed through the activities on the Internet and the mass media, both on general medical matters and on matters concerning their own illnesses and symptoms. This has led to a more informed and inflamed general discussion with increasing criticism of how the health services are conducted, especially regarding long waiting times for diagnostic procedures, seeing a doctor or being admitted to surgery. The politicians have countered by making an official rule of the longest allowed waiting time. Nevertheless, the health services have not been equipped to keep the promise of shortening the times for these services (The National Board of Health and Welfare, 2005).

The suggestions of closing smaller local hospitals have led to public demonstrations protesting this measure and even occupation of the threatened hospital, sometimes causing the responsible politicians to change their decision, especially during an election period (Björk and Rosén, 1993, p. 151). Largely, however, the citizens have silently accepted changes in the health care deemed necessary by the politicians. According to the Commission of Inquiry on Power and Democracy, the health care system has been an area of ‘quiet powerlessness’ (Peterson et al., 1989).
As stated above, all through the end of the past century and the first years of the new, Swedish health care has been criticised, especially for lacking accessibility. Little has been done to remedy this shortcoming. Besides public demonstrations, one way for the citizens to exercise power is through withdrawal. During the past years, more patients have used the opportunity that the membership in the European Union has provided, and thus have travelled to foreign countries for treatment. This has become a sore spot for both county councils and the Swedish Health Insurance Organisation that are asked to foot the bill for such treatments. To date, this problem has not been resolved.

Many patients are frustrated by their lack of real power (Petersson, 1991, p. 187). Even if the patients have the legal right to decide on their treatment, this does not mean that they have any say about the organization of the medical services, except when voting at the four-year general elections.

The increased interest from the media and the public regarding the shortcomings of the health services during the past years has led to several attempts to increase the influence of patients. One such attempt was the shortening of waiting times; another attempt concerned increasing the possibilities to choose treatment outside their own local county, a measure that many do not consider helpful as it requires travel for both patient and relatives. As might be expected, these minor changes of the rules for the health services are not considered adequate.

In the contact between doctor and patient in the therapeutic situation the patient’s influence on choice of treatment has increased, sometimes to a level where the patient would prefer to avoid this responsibility and instead follow the doctor’s suggestions. The general position of patients has gradually become somewhat stronger. In the age of consumerism it has been stated that increased individual influence on health service is an important objective (Anell et al., 1997, p. 158).

The Swedes are socializing individuals

For a long time, the citizens in Sweden have established numerous societies and associations to further various interests. The political party that has been responsible for governing Sweden for the most part of the past century started as a minor association before the First World War. It has since not only grown to be a strong political force but has also created many other organisations aiming at increasing the knowledge and power of the workers (for example the workers’ unions (Landsorganisationen, LO) and the workers educational society (Arbetarnas BildningsFörbund, ABF).

Many of these organisations have become nurseries for the parent political party. Some of the members of these ‘daughter’ societies have had a keen interest in the health of the workers. This interest, however, has primarily focused on health in the working place as opposed to health care. Sweden has become a model for other countries in both research and prevention of accidents and diseases occurring in the working place. Several leading persons in these ‘daughter’ organisations have become politicians and then been recruited to parliament, county councils or municipalities, where they have then had the opportunity of influencing the health care (have they been interested in health. However, this has been done from above than from below as representatives of the citizens. Furthermore, the presence of different interest organisations on the boards of public agencies has been questioned, resulting in decreased influence on public policy through commission reports (Petersson, 1991, p. 178).

The people change their general views in the new millennium

General changes in many attitudes in society over the past years have led to a diminishing interest to take part in different organisations and institutions. This has been observed for political parties as well as associations and seems to have concerned younger citizens in particular (except for athletic associations). This general trend may be of importance also for patient organisations (Statistics Sweden, 2003, p. 33ff).

One important item regarding the health services has been whether the public service can afford to provide all types of health care in the future, especially as the medical services have increasingly become responsible for many social and existential problems. Another reason for questioning the affordability of medical services is demographic. The Swedish population lives longer than almost any other population in the world, leading to a marked increase of older persons needing various types of care. As this trend will be even more obvious in the future, planning the care of the elderly and very old has to start now.
Consequently, the government has had several working groups addressing general health care problems. Partly because of these problems, a parliamentary commission on priorities in the medical services was appointed in the 1990s called The National Priority Commission (1995). After several years of hearings and discussions, the commission presented a basis for a law on medical priorities. Following this, the parliament agreed on principles for the prioritization of medical care, principles that those responsible for health care should adhere to: the principles of equality, solidarity and cost effectiveness (SOU 2001:8). It was implied that health care should be conducted using these principles, but they have continued to be more of a theoretical framework than a real base for decisions in daily work in the health services. The Center for Medical Technology assessment at Linköping University has studied how these priorities in health care are followed and conclude that “the knowledge of the ethical platform for setting priorities, supported by the Swedish Parliament, is very restricted” (Mårtensson et al., 2006, p. 6). At the same university, Garpenby demonstrated the difficulties responsible politicians feel in following official priority rules (2006, pp. 58-59).

Much of the general political discussions in Sweden at the end of the last century and the beginning of the present did not address the details of care. Instead, the discussions concerned delegation of responsibility, responsibility of ruling the services and to what extent private enterprise should be allowed to provide services rather than official public resources (Thorslund et al., 1997, p. 202, SOU 2002:31, Ds 2003:56).

Although Sweden’s health system is based on solidarity, fairness and public participation, most of the county councils have not shown any interest in lay participation in decisions regarding health care until recently. It is significant that none of the above-mentioned official investigations or scientific studies have had any patient participation: “In the study the perspective of patients are lacking. We need more research that illuminates which procedures that are important for patients” (Garpenby, 2006, p. 60).

The activities of local governments and the increasing amount of studies from scientists have been self-sufficient. The exclusion of local patient groups or societies in local health care planning has become a target for criticism from both patients and the public.

Contemporary examples of a few county councils’ participatory efforts

All through the latter part of the twentieth century, the activities of the politically appointed governing bodies have dominated the management of the health services. Some county councils, however, have eventually initiated co-operation with patients in different forms. Study circles, conferences called “Dialogues of the future”, medical care programmes aiming at prioritization, and local interest groups have recently been tried in some counties. Most of these activities are so recent that it is impossible to judge how experiences from these exercises will influence the conduct of health care now or in the future. This is not the place to give a full description of these activities that still must be judged as experimental. The reader is referred to the rather sparse literature that gives a description of and presents some results from these activities. (See North and Werkö, 2001a and b, and 2002 for examples of lay participation in local health care planning in Sweden.)

The first county using study circles for discussion of priorities in health care was Västerbotten County Council (SOU 2001:8, p. 59), followed by the Västernorrland County Council 1998, Västra Götaland Region 1998, and Kalmar Län County Council 1999 and 2000. Of these, the Kalmar County Council seems to have been most successful, creating a fruitful dialogue between government representatives and citizens.

Dialogues on the future have been organised by two county councils (Jönköping County Council in 1997 and Västerbottens Län County Council in 1997). In these dialogues politicians and citizens meet to discuss the future of the Swedish health system. Some information from these meetings has been mentioned in the daily press, but no official report of the outcome of the meetings has appeared.

The most organised attempt to stimulate citizens to take part in discussion with those responsible for health care has been taken by the Östergötland County Council (1999). For many years, this council has tried to get an agreement between politicians on varying levels, administrators, the professions and the

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public regarding a defined priority scale to be used in health care within the county. These extensive discussions led to an increased understanding between the different parties, but the attempt to use the established priority scale in the real world met resistance, especially in the media and particularly outside the county. The general conclusion from this ambitious exercise was that neither the citizens nor the responsible politicians were ready to accept that the delivery of medical care should adhere to a detailed priority list, even if the different parties had agreed upon it.

Long before the counties expressed interest in asking advice from patients, local interest groups had assembled around some specific questions. Such groups play a role in the present National Priority Commission that follows up the parliamentary priority guidelines (Calltorp, 1999, p. 16). Most disability and patient organisations have jointly created the Disability Association (Handikappförbundet), which is partly supported with a yearly state subsidy. Altogether, around 470 000 members in more than 70 organisations represent specific disability groups, with about 2 000 local organisations nationwide (The Swedish Institute, 2000, p. 1). The disability movement therefore influences both national and local decision makers through these organisations.

One illuminating example of this is the Swedish Diabetes Association. For a long time, Sweden had a policy that lifesaving medicines for treatment of most chronic diseases were provided free. In order to decrease the drug bill, in 1995 the government wanted to change this, making all prescription medicines available only at a reduced cost. All disease-oriented patient organisations lobbied to keep ‘their’ medicine free of charge in the future. However, only the Diabetes organisations were successful in keeping medicines for treatment of diabetes free of charge in the future. There is currently a renewed discussion in the government about further reductions of the drug bill. The Diabetes organisations are again mobilising their lobbying efforts so that the present decision will still be in effect in the future.

Conclusions and Contemplations

All through most of the past century, patients in Sweden had very little influence on the conduct of health care. The same was also true about their treatment, but this is no longer the case. Some of the county councils are now interested in trying to develop a more democratic approach to health care planning and conduct. The earlier attitude, which was present for a long time, in which most social and medical services organised from the top down, may be in a flux towards contemplating a bottom up approach, at least to a certain extent.

The Swedes are used to leaving societal discussions and decisions to elected politicians. Despite the Swedish culture of taking part in several organisations, the citizens are usually passive regarding social and medical services. Even if they were more than minimally interested in these issues, they left the action to the political bodies.

The majority of active members in patient organisations have usually been people directly dependent on the health services. To increase their influence in the future patients, their relatives and other concerned citizens must work together both locally and centrally in getting a strong common voice that the politicians have to consider. The willingness shown by some county councils to listen to local patient groups has thus far caused little change in the behaviour of the council politicians or administrators. To achieve more substantial changes citizens, patients, administrators and politicians have to realise that times are changing. The increasing penetration of the media, the extensive use of the internet for information of both professionals and patients, and the increased education of the general public have completely changed the general attitude in society. It is necessary for the governing bodies to listen to public opinion and the wishes of patients, whether expressed individually or through patient organisations. It is no longer enough to rely on the confidence of the citizens expressed at the four-year general elections; the public in general and patients in particular must have a genuine influence regarding the health services more often and much more directly.

The examples given above about co-operation between county councils and citizens are only a starting point for such a co-operation. Very little, if any, meaningful decisions regarding the health care have been the result of these experimental activities. Even high levels of activity in some of these endeavours do not necessarily indicate a successful process wherein the dialogue is perceived as useful to all parties. As earlier experience has shown, the ruling persons may not gladly abandon their near dictatorial power. The citizens and patients must continue the fight that has just started for more influence both locally and centrally.
The increasing need for more resources for the health service constitutes an important reason for making the planning and conduct of the health services more pluralistic. Some county councils have begun to establish channels of communication for their local population. So far, the initiatives have been experimental. The positive experience of these makes it imperative to continue on this road. There is no going back: “On the whole, it seems as if the citizens' participation in the decisions that concern their own lives will be one of the issues that demands special attention in the future” (The Federation of County Councils, 1995, p. 55).
4 Membership and Empowerment

This chapter deals with a traditional issue in organisations in the field of non-profits or the third sector, i.e. volunteerism and the question why people join voluntary organisations. By asking for the reasons for membership, selective incentives, reasons for active participation, empowerment, the concept of co-production and patient empowerment, I attempt to give an overview of the general issues relevant to this study.

In my study of patient organisations and patient empowerment it is necessary to ask why people join organisations, why they become active and how this is relevant to empowerment. The following theories are of particular relevance to this study’s research questions.

Why Membership – Collective action? Why do people join organisations?

There are several theories about why citizens engage in common matters and join organisations. The theories focus on the various reasons why people become members of organisations.

Just as individuals often were expected to act on behalf of their personal interests, so were groups of individuals with common interests expected to act on behalf of their common interests. It was often taken for granted that members of a group sharing an interest or objective would, assuming they were rational and self-interested, act to achieve that objective. In 1965, Olson systematically questioned this notion in his theory of pressure and special interest groups. He argued that unless the number of individuals in a group is quite small, or unless coercion or selective incentives exist to make individuals act in their common interest, rational, self-interested individuals will not act to achieve their common interests. To the participants the decisions of the meeting are public goods. New members are usually welcomed by organisations that supply a collective good and sometimes such associations even attempt to make membership compulsory.19 No other member will be significantly affected in large groups if one member does or does not help provide the collective good and therefore no one has any reason to react. An individual in such a group cannot, by definition, make a noticeable contribution to any group effort and since no one in the group will react if the individual contributes or not, he or she has no incentive to contribute. Accordingly, here we have the basis for the famous free-rider phenomenon: since the outcome of the collective action is a public good that can be enjoyed by all regardless of prior participation, the individual is tempted to withhold his or her contribution in the expectation that others will exert themselves on his or her behalf. As a result, everyone waits for the next person to jump first with the result that nothing happens.

Selective incentives

In a latent group only the existence of a separate, selective incentive stimulates a rational individual to act in a group-oriented way.20 Group action can only be obtained through an incentive that, unlike the collective goods, operates selectively toward the individuals in the group. To treat those who do not join the organisation differently from those who do, the incentive must be selective. These incentives can be ei-

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19 An increase in the size of the group does not bring competition to anyone, but may lead to lower costs for those already in the group (Olson, 1965 & 1971, p. 37).
20 In Olson’s terminology large groups are called ‘latent’ because of their latent capacity for action. Only through selective incentives can that potential capacity be mobilised (see Olson, 1965 & 1971, p. 50ff, for further details).
ther positive (inducements offered to those who act in the group interest) or negative (punishing those who fail to bear an allocated share of the costs of the group action).

Although the most common incentives are economic, there are also social and psychological objectives. For example, people are motivated by a desire to be seen, to win friendship, respect and prestige. If a small group of people who had an interest in a collective good also wanted to belong to the same social club, or be personal friends, and some of the group left the burden of providing that collective good on others, then the consequence might be that even if they gained economically by this course of action, they would lose socially, a social loss that might outweigh the economic gain. As a result, the social club might exclude them, or their friends might use social pressure to encourage them to do their part toward achieving the group goal. Such action can indeed be effective, as most people value personal prestige, social status and self-esteem, as well as they the fellowship of their associates and friends (Olson, 1965 & 1971, p. 60f).

Organisations with strong selective incentives may be able to retain their political power and membership, even if their leadership uses some of the organisation’s economic or political power for objectives other than those desired by the members. This happens when the members of organisations have a strong incentive to continue belonging to the group, even if they disagree with the organisations’ policy. By offering its members benefits that, in contrast with the political achievements of the organisation, can be withheld from non-members, it accordingly provides incentives for joining the organisation.

Olson’s theory on collective action has been criticised by, among others, Udéhn (1993) who argues that collective action is not a function of group size and that the assumption of self-interest is inadequate. Rather, people co-operate, contribute and participate out of mixed motivations. Additional to self-interest, these motivating factors could include morality, social norms and altruism. Because of different social values and orientations, people differ in their will and to what extent to co-operate when “rational egoism suggests free-riding” (ibid, p. 253). Therefore, other motives than self-interest must be included when explaining collective action.

**By-product theory**

Olson’s theory of pressure groups states that the membership and power of large pressure-group organisations do not derive from their lobbying achievements, but are rather a by-product of their other activities. An organisation that has no function apart from its lobbying function obviously cannot legally force individuals into becoming members. However, if this organisation can justify having a compulsory membership because of some other non-political function it performs, or if through this other function it has obtained the power needed to make membership in it compulsory, that organisation may be able to get the resources needed to support a lobby. The lobby then enables the organisation to have a captive membership and is thus a by-product of whatever function this organisation performs. Many economic lobbies obtain their support mainly because they perform some function besides lobbying (Olson, 1965 & 1971, pp. 132-167). Many organisations have lobbying functions and economic or social functions, or even all three functions at once. Characteristic for all economic groups with significant lobbying organisations is that they are organised for some other purpose. A further incentive to membership is thus offered by performing additional functions. This by-product theory is relevant to this study’s research question regarding reasons for membership in local interest organisations.

**Dissatisfaction**

Greater attention has been paid in recent years to the phenomenon of customer dissatisfaction (e.g., Wallin Andreassen, 1997) and patient dissatisfaction (e.g., Coyle and Williams, 1999). On the other hand, to move from individual customer dissatisfaction to collective expressions of customer dissatisfaction is not common. Influence can be exerted on different levels, both on the individual level (e.g., through the right of voting or through the market) and on the collective level. It is principally this latter form that is referred to when user-influence is discussed in Sweden (Möller, 1996). The user should be

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21 e.g., providing individual assistance and help, publishing informational journals wanted and needed by its membership, providing education and politically lobbying for its members’ interest.
able to exert influence over the activities in the capacity as member in a collective (the user-collective) and not as a separate individual. Consumer co-operatives and various forms of consumer organising are examples of how consumers unite in order to exert influence (Pestoff, 1984). According to Hirschman (1985), disappointment is also a reason for membership. Hirschman showed how a pattern of change, when individuals and groups moved like pendulums from private to public action and back again, is inevitable. Acts of participation in public affairs, as well as acts of consumption sometimes yield dissatisfaction and disappointment, although they were undertaken because they were expected to yield satisfaction.

According to Hirschman (1970), there are two possible options for the individual to show his or her dissatisfaction, either by withdrawal of demand or by protests: the concepts of ‘exit’ and ‘voice’. The exit option is the possibility that the private consumers have to show their dissatisfaction. In this case, the consumer simply stops buying a product or a service, or for members to leave an organisation. The voice option is the option that can be used in the public sector that is run by political decisions, such as the Swedish health care system. It means expressing the dissatisfaction directly to management, the county council or through protests addressed to anyone who cares to listen. Hirschman’s theory, however, has been criticised (Agevall, 1998) within certain of the activities of the public sector where the exit alternative is problematic (such as in the health and social services). For example, people with severe disabilities, serious diseases, dementia and many of the elderly do not have, disregarding the information problem with finding alternatives, the resources or the strength needed to make an exit. The sick patient is very often unable to “shop around” to find the best treatment alternative and it is more or less impossible for patients with a serious disease to change hospital and physician when they are under intensive treatment (Guldvog, 1994, p. 52f). Furthermore, a relationship of dependence is often developed between the caregiver and the patient. Möller (1996, p. 349) drew the following conclusion:

The direct and daily meeting with the front staff means that a relationship of dependence occurs, which makes the possibilities of influencing through the “voice”-channel difficult. The users thus tend to avoid the confrontation with the staff that is necessary to affect their situation. (Free translation).

Having the ability to make an exit should increase the ability and the strength to voicing a protest. For a person with a chronic disease, another possible consequence of dissatisfaction with the health services or even with the society could be to join an interest organisation and this way influence the actors or issues one finds dissatisfying.

Consumption of publicly financed services is likely to generate disappointed consumers. The services governments provide in such fields as recreation, health and education are funded by higher general and social security taxes. The existence of these services and the fact that one has paid taxes to support them create expectations of entitlement. Hirschman argues that just as in the case of consumer durables, the disappointment potential of these purchases is likely to be quite high, but for different reasons (Hirschman, 1985, p. 39f). Publicly financed services in general are more strongly and more often criticised than private services. Perhaps, Hirschman argues, this has to do with the form of payment (directly or indirectly through taxes) and the impact it has on the clients (1985, p. 62). A common notion is that the customer would be more quality-conscious and critical if he or she paid for the service directly than if it was paid for by taxes. Nevertheless, payment in itself presumes the receiving of adequate counter value, therefore clients may very well remain silent and blame themselves in transactions with unsatisfying results. Another aspect is that private purchasers generally have choice of product and therefore more easily can satisfy their preferences, whereas clients in the public sector have less choice and therefore tend to use ‘voice’.

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22 According to Hirschman, this dissatisfaction explains systematic changes in both citizen activities and consumer behaviour. If the disappointment is not fully eliminated by instant downward adjustment of expectations, then any pattern of time use or consumption is bound to eventually bring dissatisfaction.

23 The problem with consumer durables was their failure to bring pleasure to the extent consumers were expecting, given their prior experience with nondurable purchases, and not their performance which overall is rather reliable. When educational and health services are concerned, however, the performance is uneven. In comparison with more traditional purchases, this new and harsh experience has a high degree of variability in the efficacy and quality of the thing acquired. Thus, the likelihood is high that many consumers will be disappointed.
Turning to the public – abandoning private concerns

When private consumption fails to deliver a state of well-being the consumer searched for, the disappointment can lead to an exit in the private arena, and for some, entry into the public. Voice is often public action by definition. Disappointing consumption experiences cause voice reactions, which in turn will reinforce the exit reaction and increase the likelihood of a turn toward public action. In situations where services involving the recipient’s collaboration are concerned (e.g., educational or various professional services), consumers may well blame themselves for not being able to take advantage of the services they have received (e.g., in cases of ineffective psychotherapeutic advice). What action dissatisfied consumers will take depends also on the nature of the defect of the product. Experiences involving public interest further induce the consumers to question existing social and political arrangements in general. In Hirschman’s words, the customer’s disappointment has also given him “a ladder, which he can use to climb gradually out of the private life into the public arena” (Hirschman, 1985, pp. 65-66). Further, others believe that collectivism arises because of dissatisfaction with the service or the possibilities to affect it, that it is a combination of dissatisfaction and powerlessness that principally impels individuals to unite (e.g., Pestoff, 1998 and Petersson, 1989).

Disappointed consumers in the private arena to whom the choice of action in the public is available and that are conscious of being citizens may be inclined to take up this course of action under favourable conditions. “The extent to which public action is really taken up, may well depend on the ready availability or appearance of a cause” (Hirschman, 1985, p. 64). Thus, the timing and visibility of a cause plays a crucial role of whether the individual will engage in any public action.

Resource mobilisation theory disagrees with Hirschman’s ideas about dissatisfaction as the reason for collective action. Instead, this theory argues that grievances alone do not suffice to create collective action (e.g., Kendall, 2002). Rather, what is important is control over and access to resources. Calculations of costs and benefits explain the individual’s participation in the movement, or lack of it, i.e. only acting when benefits outweigh the costs. However, this theory has been criticised for not explaining the effects of groups with limited resources and for marginalising the impact of, for example, identity, culture and grievances (ibid).

The basis for all organisations is collective resources, according to Ahrne (1994). These resources are produced, maintained and used by the organisation’s members who want and need them. Examples of the organisation’s resources can be its building or other property such as equipment or money funds, or intangibles such as knowledge or personnel. Hence, the property and resources of the organisation make it into something more than the sum of its members (ibid, p. 13). Ahrne argues that “it is the need and wish for all these collective goods, things one cannot get and keep on one’s own, that make people join organisations and also promise to come back” (1994, p. 14). Membership means having rights to the use of resources. However, it also means having obligations to contribute to the production and maintenance of them. All the organisation’s activities rely on its resources, as do its goals. Ahrne (1994) also sees motives for joining an organisation as related to their resources, an important motive being the interest in getting access to or contributing to its resources. Sometimes, however, the motives are only indirectly related to resources and the motives of members of the same organisation may vary (Udén, 1993, p. 251).

Normally, the incentives for joining interest organisations are mixed as the aims and goals of these organisations vary greatly. Activities that are arranged by an organisation and the social contacts that are provided through membership may be important reasons for joining organisations. For example, for people who like to practise a sport, a sport organisation provides both an opportunity to do just this and to meet other persons with similar interests. Another kind of incentive for membership is provided by organisations concerned with political or social questions with the aim of changing the social, economic or political setting in which they and their members live. As pointed out earlier, Olson saw only individual gain as a motivating factor, but other reasons for membership could be a shared interest in political or social change, as well as solidarity. These other factors can provide strong incentives for activating peo-

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24 When a patient is requested to participate and add some of his own input to the medical services, he might believe that the bad result is due to his own inadequate contributions. The disappointment then turns inwards, to disappointment with oneself.

25 Regarding private injuries, if, for example, the consumer believes that he has just been unlucky and bought the one defective item, he is likely to ask for a rebate or return it. The likelihood of a public voice response increases in cases that involve public interest (e.g., if the consumer believes that the product he bought is unsafe and that this is a general characteristic of the product).
people in voluntary organisations (Pestoff, 1979). Joining a voluntary organisation usually means that one identifies oneself with its ideas. The feeling of similarity and belonging is therefore important in a voluntary organisation.

**Active Membership – Why do people participate actively in voluntary organisations?**

Participation can mean that citizens are active in voluntary movements and the member organisations of the political parties. As citizens are active in democratically built up organisations and movements, which in turn try to influence politics, a second channel is established (besides the democratic elections) through which the citizens’ participation is given attention. Participation can also consist of other attempts from private persons to influence politics. Following this perspective of political participation, being a member of an organisation or a political party is just one possible way of influence. Other imaginable ways are participation through political elections, financial contributions to some political purpose, direct contact with politicians, civil servants and media and participation in a demonstration or some other political manifestation (see Kaase and Marsh, 1979, p. 42; Parry et al., 1992, p. 16; Verba and Nie, 1972, p. 2; Verba et al., 1978, p. 46; Verba et al., 1995a).

**Socio-economic status**

There are theories on active participation that focus on individual strength of resources such as class affiliation and level of education. This means that those persons who are active and promote their interests have a high socio-economic status. In accordance with Hirschman’s theory people turning to public action are those who have engaged in private consumption but have been disappointed. This supports earlier empirical findings that participation in politics is highly correlated with socio-economic status, i.e. education, income and occupation (see Verba and Nie, 1972; Olsen, 1982; Nagel, 1987; Verba, Schlozman and Brady, 1995b).

Two perspectives can be applied here. First, there is the traditional view, in which participation in politics is explained by the fact that people with resources participate because they have the resources to do so and because it is in their own interest to take an interest in public affairs, complementing their private pursuits. The reasoning goes something like this quote: “the higher-status individual has a greater stake in politics, he has greater skills, more resources, greater awareness of political matters, he is exposed to more communication about politics, he interacts with others who participate” (Verba and Nie, 1972, p. 126). To Hirschman (1985, p. 75), however, this is not the whole story, which brings us to the second perspective. In this perspective, the reason for middle-class people to be involved in public affairs is the disenchantment with the pursuit of happiness in the private arena. They need a new focus in their lives.

Further, in voluntary organisations high socio-economic status is correlated with participation. There is, however, one notable exception is the Swedish consumer co-operatives, where an unusual relationship between low social status and high membership activity was found (see Pestoff, 1979).

Wood’s (2000) study on patients’ associations in America and Britain indicated that active patient organisations appear to relate to wealth and social class. He found that certain medical conditions (such as Myalgic Encephalopathy and chronic fatigue syndrome) were more respectable than others in society and thus more strongly organised than were working-class ailments like e.g. sickle cell disease.

**The rebound effect**

It is clear that individuals who have been dissatisfied through private consumption are more open to collective action than others. Hirschman uses the rebound effect to explain underestimation of the costs

26 That is, while ‘being on the rebound’ from a relationship that ended badly choices of amorous partners are made that are puzzling to outsiders.
and exaggeration of the benefits of the new action, while still suffering from the old action that hurt. Consequently, when the results of a transaction turn out badly, an opposite transaction could have benefits and be subsidised by the person on the rebound. This effect only explains participation in public affairs to a certain extent, but it questions the argument of the free rider by implying that the happiness which disappointed consumers are seeking when turning toward public action arises not only from the expected results of such activities as the benefits derived from the process of achieving the hoped for outcomes and the results of such action are inseparable. Usually, striving in itself is next best to achieving the happiness--sometimes it is even better than the achievement. Moreover, action in the public comprises the search for knowledge, community, salvation and beauty, and as such, these activities “carry their own reward” (Hirschman, 1985, p. 85). The distinction between the benefits and costs of public action disappears because of the fusion of striving and attaining, as striving, which normally is a cost, becomes a part of the benefit (ibid, p. 86). Olson’s theory on free riding is thus contradicted, as contrary from dodging and trying to get a free ride. This means that a rational individual will be as active as he possibly can.

The inseparability of striving and attaining can also be explained in two other ways. Either public action is seen as the consequence of radical cognitive change or as the fulfilment of individual development. In the first case, the unexpected realisation by people who always felt that the existing political and social conditions would never change or that they at least were powerless in contributing to such change, that they in fact by actions of their own can join like-minded people and help change society for the better is an exciting possibility. Consequently, it would be satisfying just to act as though it is possible to promote change for a while. Individuals who believe they are able to change their situation express this type of strength of resources. In the Public Commission of Inquiry on Power this was called “having political self-confidence.” This means that people with political self-confidence will try to influence their situation more than people lacking this self-confidence. The contrary holds for the other pleasurable experience. Here the insight is gained that my commitment to activities in the public sphere develop and change me, no matter if there are real changes in the outside world or not. There is thus a great deal of fulfilment associated with the individual’s efforts to gain public happiness. This, Hirschman argues, goes against the argument of the free ride, because nobody would want to miss all the active pleasure in the actual striving. In fact, in an age with declining religious interest, public action’s greatest quality is its ability to satisfy “vaguely felt needs for higher purpose and meaning in the lives of men and women” (Hirschman, 1985, p. 126).

Abilities and prerequisites

Not only does an individual have to be willing to participate actively in politics, but he is also required to have certain abilities (e.g., a talent for speaking in public and for dealing with people), i.e. having what generally has been called “subjective political competence” (Verba and Almond, 1963) and “political efficacy” (Pateman, 1970, p. 46). Thus, not everybody interested in public action will actually move on this interest. Instead, citizens and groups in the same society, who are open to involvement in public affairs, will, according to Hirschman, experience two opposite but similar disappointments: over-involvement or under-involvement.28

Apart from engaging in voluntary organisations and political parties, participation includes other types of individual attempts to influence politics (e.g., through elections, by contributing funding to some political cause, direct contact with politicians, civil servants and media, participation in a demonstration or some other political manifestation) (e.g., Parry et al., 1992, p. 16; Verba and Nie, 1972, p. 2; Verba et al., 1995a). Earlier attempts to identify causes of participation often start with political resources. Among others, Verba, Schlozman and Brady have suggested a resource model that can be used to explain political participation. Somewhat simplified, the important resources consist of civic skills, time, money and political interest (Figure 4.1 Verba, Schlozman and Brady, 1995a and b).

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27 Disappointment will naturally set in later should no change be achieved. See further on Hirschman, 1985, p. 90f.
28 Those who are capable of participating actively may experience the perils of over-involvement (e.g., it is too demanding or time-consuming), whereas those who want to do no more but no less than register their feelings on an issue may suffer from under-involvement when they realise that they are basically limited to the vote (see Hirschman, 1985, p. 120).
The model illustrates the main descriptives (institutional types, institutional involvements and education, skill opportunities and skill acts), political resources (skills, time, money) political interest (political interest and self-described skills) and political acts.

**Figure 4.1 A simplified version of Verba, Schlozman and Brady’s Resource Model**

<table>
<thead>
<tr>
<th>Main descriptives</th>
<th>Political resources:</th>
<th>Political interest:</th>
<th>Political acts:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opportunity to develop civic skills</td>
<td>⇐ Civic Skills</td>
<td>⇒ Time</td>
<td>⇒ Voting, Contacting, Campaign Work, Campaign</td>
</tr>
<tr>
<td>\uparrow Family income</td>
<td>⇒ \uparrow Political interest</td>
<td>⇒ Work, Campaign Money, Informal Community, Boards, Protest</td>
<td></td>
</tr>
</tbody>
</table>


Verba et al. have shown the relationship between an individual’s resources in political participation. They found that all of these factors had an effect on the three general categories of activities they formed: those that involve giving time, those that entail donating money and voting. What they call civic skills, i.e. communicative and organisational capacities, are acquired early in life at home and in school, but can also be developed in adulthood, at churches, organisations and the workplace. People who can write or speak well or who are comfortable in organising and taking part in meetings are more likely to get involved in politics (Verba et al., 1995b, p. 273). Just as civic skills differ significantly between individuals, so do time and money. In order to contribute time you must have some free time, and vice versa for money. Reasons for why people do not participate in political life are that they either cannot, (suggesting a lack of the necessary resources – time, money and civic skills), because they do not want to (suggesting a lack of psychological engagement with politics: i.e. a feeling that activity makes no difference, a lack of interest in politics, no concern with public issues or consciousness of membership in a group with shared political interests), or because they were not asked or allowed to (suggesting an isolation from the recruitment networks through which citizens are mobilised to politics) (Verba et al., 1995b, p. 271).

On the one hand, both political efficacy and interest facilitate political activity; on the other hand, activity presumably enhances efficacy and interest as well.

There are in theory preconditions that seem contradictory on the connection between money and time as individual resources. It would seem natural that rich people might have more time that is free since they can hire others to do what most people have to do for themselves. On the contrary, one could also argue that the rich might have less free time because they work long hours in order to get their wealth. An income effect could thus both mean that either more leisure for the rich would be produced because of their ability to purchase it, or that less leisure would be produced because the opportunity cost of free time is increased by their high wages. Verba et al. (1995b, p. 274), however, showed that free time and socioeconomic status were unrelated. What instead had an impact on free time were life circumstances in general. Factors such as “having a job, especially a fulltime one, having a spouse with a job and having children at home, especially pre-school children –all diminish the amount of free time available.” Political participation can thus not be explained only by simple motivation such as interest in politics. The resources of time, money and skills need to be considered as well.

In order to find the compelling psychological reasons that motivate individuals to become involved in volunteer activity, Clary et al. (1986, p. 486f) proclaim that the motivational forces should be identified from theories of beliefs and behaviours. For different people, similar behaviours and beliefs serve different psychological functions. This means that different individuals seek to satisfy different motivations by engaging in collective action and they do so in order to achieve important psychological goals and social needs. For some people, the engagement also helped them to fit in and get along with social groups that are important to them, which would satisfy a social function.
The major function of participation is an educative one in the widest sense, including the achieving of practice in democratic skills and procedures as well as the psychological aspect (Pateman, 1970). Participation increases the participants’ knowledge in a broad sense. According to Pateman (1970, p. 105), participation also leads to an improvement of the individual’s political self-esteem. The more individuals participate, the better participators they become. Therefore, the experience of participation leaves the individual better psychologically equipped to undertake participation in the future (Pateman, 1970, pp. 42-45). Social resources and experience also have impact. An explanation is that active individuals who already take part in the work and activities of organisations tend to continue to engage in other areas (ibid).

Certain psychological qualities are necessary in order to be self-governing in, for example one’s work. What would be required is confidence in one’s ability and the belief that one can be self-governing. Acquiring such confidence is a psychological benefit that comes with participation and grows through it (Pateman, 1970, pp. 45-46). The sense of political efficacy or sense of political competence is achieved through participation. People who have a sense of political efficacy are more likely to participate in politics than those in whom this feeling is lacking.

Resources and incentives are important prerequisites for participation or active membership. Resources are the individual factors that cause a person in different ways to feel capable to participate. Martinussen (1973, p. 21) divides these resources into material, intellectual, social and motivational. Those of Martinussen’s resources that are an effect of empowerment are mainly the social, but also the intellectual. The motivational resources are similar to what here is called incentives, i.e. what triggers or starts the participation.

According to Parry, Moyser and Day (1992, p. 9ff), there are four categories of incentives to political participation: instrumental, communitarian, expressive and educational incentives. The instrumental incentive means that one participates because one wants to influence an issue and the decisions that are made concerning it. One believes that action is likely to bring benefits in excess of any cost involved. The communitarian incentive refers to the fact that the individuals who participate do it out of concern for the community of which they are a part because they care about what happens around them. A community does not necessarily have to be geographic. This implies that participation will be greater where people identify strongly with a community and where they are highly integrated into it. The expressive participation is a way of making one’s voice heard, of showing that one exists and has an opinion. To encourage support for the particular point of view is not as important. The activity is an expression of feelings or taking a stand regarding a certain matter. Education as an incentive means that the educational effect the participation has is a reason for the individual to participate (cf. Pateman, 1970). Self-development, however, is better understood as an effect of participation rather than as a reason for it considering that most people probably participate for other reasons. Nevertheless, political education and self-development are side effects. At the individual level, more than one of these categories of incentives could be represented at the same time. These categories have been considered in the construction of the questions in this study’s questionnaire regarding reasons for membership and participation, as have selective incentives (Olson, 1965 & 1971).

My interpretation of the presented theories of participation is shown in Figure 4.2. The participation/active membership is placed in its context with prerequisites and effects at the individual level. Note that passive participation/membership is not included in the figure. There are varying degrees of participation and it is difficult to say exactly how passive or active it is. Participation in this figure refers to an active membership in which the member participates in the organisation’s activities or in some other way tries to influence the organisation.
The prerequisites consist of the individual’s resources, i.e. what makes a person feel capable to participate and the incentives, i.e. what triggers the participation. Resources such as socio-economic status and abilities (Verba et al., 1995a and b), self-esteem (Pateman, 1970) and incentives in terms of a desire to influence, a concern for the community, expressing oneself and need to learn (Parry et al., 1992), disappointment with the private sphere (Hirschman, 1985) or other selective incentives (Olson, 1965 & 1971).

Participation then has effects in terms of socialising. When participation is motivated by social needs and psychological goals, the effect is also social – it is fun to meet others and self-esteem is improved as a consequence (Clary et al., 1986). The educational efforts give the effects where one learns about the topic and the actual participation process (Pateman, 1970). Another effect caused by the participation and the educational efforts is empowerment. Most important to note when speaking of empowerment is that it is subjective in the sense that it is about the individual’s own experience. Educational efforts and empowerment belong together, i.e. they cannot be separated.

A concept related to that of empowerment is political efficacy. Pateman (1970, p. 46) uses this concept in the meaning of ‘sense of political competence’. Petersson, Westholm and Blomberg (1989, p. 286f) translated political efficacy into political self-confidence (politiskt självförtroende). Empowerment is the process that gives political self-confidence, which in Figure 4.2 is referred to as self-development. Self-development as used here includes all the effects of having participated actively (e.g., in terms of improved self-esteem and confidence, gained insights, knowledge and know-how). Regardless of whether the participant continues to participate, these effects or this self-development remains with him or her.

The individual resources are, among other things, a result of the social and educational effects. These, together with the empowerment that is generated from the process of participation, encourage greater participation and more resources, thus a spiral effect. Participation in turn creates participation.

Just as the motives for joining an organisation differ, so do the motives of participating actively in an organisation. Whether it is due to self-interest, meeting social or psychological needs, fulfilling a political interest, becoming empowered or a mix of any of these reasons will differ depending on the individual, the context and the time.

Empowerment

Empowerment is a relatively new and popular concept. The word empowerment is frequently used with many different meanings ascribed. The Oxford Dictionary states that empower means to (1) authorise, license or (2) give power to, make able. Webster’s II gives the meaning of empower as ‘to invest with legal power. Authorise.’ Nevertheless, these definitions fail to capture the active component which empowerment refers to. The roots of the term empowerment are found in the Latin word potere, which means “to be able to” (Random House Dictionary of the American Language, 1966, p. 168). An impor-
tant feature of empowerment is that a person, individually or collectively, actively takes charge of the situation.

Foucault’s (1983, pp. 210-211) concept of power concerns both positive and negative processes by which power is exercised. Foucault offers insights of power relevant to a theoretical understanding of empowerment. Power as a negative force illustrates the way in which human relations of power work to subjugate persons as subjects. Hence, from this point of view, empowerment refers to the oppositional efforts of people to liberate themselves from dependence on professional control and the negative consequences of that control, i.e. the debilitation resulting from dependence. Foucault (1980, p. 118) is fascinated by the positive productive potential of power (e.g., to create things, knowledge and pleasure). These productive possibilities also concern empowerment. Briefly, Foucault’s negative concept of power conceptualises empowerment as opposing subjugation to institutional and professional control. Meanwhile, the positive concept of power deals with the productive possibilities that emerge from a shift in relations of power.

In the scientific literature the concept started being used at the end of the 1970s, at the same time as discussions on such areas as local development, activism and mobilisation. Mobilisation is important for social movements and is one of many expressions for empowerment. It aims at activating and mobilising human and material resources (Ronby, 1995, p. 223). The idea of empowerment is based in the social activity ideology, which emerged in the USA during the 1960s (Starrin, 1997). Empowerment soon came to be an important concept in the discussions of local development, local governing and in the notions on strategies for prevention and intervention that were launched (Kieffer, 1984). Attempts have been made to document the emergence of the concept of empowerment. Perhaps it is yet within areas such as local development and local community work that the most initiated descriptions are found. Among the first to write about empowerment was Solomon (1976) who focused on the blacks’ mobilisation and Riger (1981) who focused on organising feminist movements. In the early 1990s, the concept of empowerment was used so much in the literature that it became a catchword. The most common uses of the concept of empowerment are as follows: Professional or employee empowerment (e.g., West, 1989; Clutterbuck and Kernaghan, 1995; Kinlaw, 1995; Honold, 1997; Sashkin, 2001; Parker and Stone, 2003), education empowerment (e.g., Fraser, 1995; Freire, 1985; Stromquist, 2006; Walters, 1994), civic empowerment, minorities empowerment (e.g., Alozie and Moore, 2007; McEwan & Bek, 2006; Clark and Morrison, 1995; Madhubuti, 1995; Rozario, 2006; West, 1989) and gender-related empowerment (e.g., West, 1989; Irwin, 1995; McEwan, 2005). Empowerment has been used by social workers, politicians, economists, public health administrators, sociologists, political scientists and others. It has been expressed with more detailed meanings in various fields, although the concept is used broadly in the sense that many unrelated fields adapt the concept to meet their particular needs and aims. Empowerment therefore takes on somewhat different definitions and meanings depending on the context in which it used. These diverse settings are nearly impossible to survey. However, there is a common foundation in all uses of the term, namely that empowerment is ‘good’ and it is worth striving for, regardless of what other meanings it has been given.

Empowerment is a form of participatory democracy (Bachrach and Botwinick, 1992), based on a philosophically grounded idea of equality - that everyone is of equal value and should have the opportunity to decide on one’s own (Renblad, 2003), and thus participate. Some examples of areas where the concept of empowerment has become important are in workplaces, communities and areas such as substance abuse prevention, schools, HIV/AIDS prevention, adult probation, battered women’s shelters, individuals with disabilities, gender and liberation movements and small non-profit organisations. Empowerment may take on two dimensions: individual empowerment (self-empowerment) and group empowerment.

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29 Community empowerment, for example, refers to the enabling of concerned residents to play an active part in the local decision making for the neighbourhood and the community. Employee empowerment concerns the employees’ ability to make decisions about their work and the processes necessary to do the work. Business literature deals traditionally with the form of empowerment that concerns empowerment in workplaces. The International Encyclopedia of Business and Management (1996, p. 5099) describes the concept as a strategy that influences work organisation in a way that promotes employees to become increasingly involved in the maintenance and improvement of their enterprise. In this way empowered employees are able to take more direct control over their own jobs and to initiate and make changes and adjustments. The personnel will, through empowerment, feel responsible and become more involved and interested in their jobs. As a generic concept within liberation movements, empowerment was never precisely defined (McLean, 1995, p. 1055). Moreover, different concepts are used and hold different connotations for people in different cultures. The concept of family empowerment is, for example, used in some non-Westernised societies.
Three levels of empowerment are typically discussed: organisational, individual and community. The latter (also referred to as collective empowerment) is said to include an increased level of individual empowerment (Laverack, 2005, p. 35f). Hundreds of possible markers of individual and collective empowerment applicable in various communities were identified in an American study (Reininger, 1994). Organisational empowerment occurs when an organisation is “democratically managed, its members share information and control over decisions and are involved in the design, implementation and control of efforts towards goals defined by group consensus” (Israel et al., 1994 in Laverack, 2005, p. 35f). Individual empowerment is about the individuals’ control over factors affecting their lives, whereas collective empowerment expands the concept to also include the capacity of others to access resources and make choices (Turnbull et al., 2000). Not only does empowerment now refer to control, but also to capacity building for all participants. Kirk and Shutte (2004, p. 242f) argue that collective empowerment comes from the interconnection of individuals who have a clear conception of their roles in the organisation. The authority to exercise voice is provided by role taking (Armstrong 1988; Reed, 2001) and this perspective sees role as providing the basis for individual empowerment. Krantz (1998) prefers another concept to ‘collective empowerment’, organisation ‘enrolement’, as it better stresses the collective container than the notion of empowerment which focuses on individuals empowered in isolation. By taking up their role, individuals take account of the system they are in and their relations with others in that system, by taking responsibility for themselves in relation to these others, their work and the larger environment (Kirk and Shutte, 2004). Collective empowerment is much about collective identification of individual experiences. Pini (2002) showed that collective empowerment was experienced by women, not only by identification with others through sharing similar experiences, but also by confrontation of others with different opinions and challenges to their views. Collective empowerment can be seen as the product of a team working together well, a group operating powerfully as a unit and sharing a sense of purpose, authority and confidence. This, as stated by Kirk and Shutte “happens best when there is mutual respect and recognition of the validity of all the members’ roles, however large or small” (2004, p. 247). But, as argued by Rogers and Singhal (2003), when individuals organise in small groups at the local level in order to accomplish goals that they cannot achieve as separate individuals, empowerment is most likely to occur.

Not only has empowerment assumed diverse meanings it has also held contradictory meanings (McLean, 1995, p. 1055f). As the concept has become popularised, it has been distorted and diluted, taking on a whole range of meanings depending on who is using it and what concerns they hold. It is used differently by an employer, a politician, the concerned individual, a potential care provider, or staff with either strong or weak connections to values such as influence and democracy. It may refer to a goal to be achieved, a process, or a combination of these. Although it has become “a popular, largely unquestioned goal” (Parpart, 2002, p. 338), it is still a concept that is vague and poorly defined. The concept has been argued to enjoy universal appeal precisely because of its vagueness (Lyons et al., 2001; Sharp et al., 2003). Empowerment carries a wide differentiation of understandings and connotations for different groups of social actors. These groups place different degrees of emphasis on the personal and political dimensions of empowerment. However, most users of the concept appear to agree that empowerment refers to heightened individual control or self-determination. The main emphasis in the literature is put on empowerment through education and learning (Robinson, 1994; Mulligan and Griffin, 1992; Stromquist, 2006). A consequence of this is the importance of literacy for empowerment (Delgado-Gaitan, 1990; Freire and Macedo, 1987). West (1989, pp. 109-110) developed what he calls ‘principles of empowerment’ (or reality principles for political movements). First, the group must be able to maintain some degree of constancy in its intentions and the goals must be relatively long term. Next, the group must be able to generalise the interests of its members. The potential difference between members must be reconciled within broader objectives. Then the adopted aims of the group must be carried out efficiently (which presupposes the satisfaction of the two previous conditions). Finally, the group must have its own methods for the transmission of its insights and experience, both to its own future members and to those outside it. However, fulfilling these principles are not always enough. Any group’s interests are only likely to be realised if they can generate support from the rest of society.

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30 As already discussed, individual empowerment may be particularly connected with the development of self-advocacy skills (cf. Henderson and Pochin, 2001, p. 76f).
According to resource mobilisation theorists, there must be resources for a social movement or a voluntary organisation to emerge. Resources can be people’s time, knowledge, commitment and money. This theory focuses on the ability of the members of the movement to acquire resources and mobilise people in order to advance their goals. For example, this could be to capture the media’s attention, create an organisational structure, attract supporters and money and forge alliances with those in power. Resource mobilisation theorists believe that social movements cannot be effective without such resources as dissent alone is not enough to result in any social change (Kendall, 2002).

Olsson (1998, p. 160f) points out the relevance of three factors that must coincide in explaining the emergence of voluntary organisations. First, there must be discontent, i.e. people must be dissatisfied with some condition. Second, there must be resources. Without resources, there can be no activities. Finally, there must be an organiser, somebody with an ability to organise dissatisfied people. This can be compared with the three reasons to why movements are formed, according to Starrin (1997). First, he argues that groups of people must find themselves in the same distress or in the same critical situation. Second, there must be hope and a vision of getting out of this distress. Third, there needs to be an understanding that the only way this can be done is through collective action. Movements arise out of shared experiences. These experiences can transform a group from being a group that is only described by outer characteristics (such as being sick) to being a group in which the feelings are shared and there is identification and a feeling of community. Collective identity concerns how individuals’ sense of who they are becomes connected to a definition shared by co-participants in some effort at social change, i.e. who we are (Gamson, 1992, p. 55). Unlike most contemporary theories on social movements, Starrin (1997, p. 26) emphasises the importance of feelings associated with distress (such as anger, dejection and shame) and feelings that create enthusiasm in social movements (such as indignation, pride, excitement and joy).

In order for a group to go from being defined by outer characteristics to one with an inner identity three stages of development must take place (Swift and Levin, 1987). According to Swift and Levin, the first stage is the knowledgeable stage, where the individual becomes aware of how power is divided in the social system, what position he or she has in society and what interests he or she has in this system. The second stage is the emotional stage, where the consciousness is widened to comprise feelings of dissatisfaction and loyalty. The individual becomes aware of his or her own feelings towards the dominating social system, what position he or she has in society and what interests he or she has in this system. The third stage is the factional stage, where the consciousness is widened to comprise feelings of dissatisfaction and loyalty. The individual becomes aware of his or her own feelings towards the dominating social system, what position he or she has in society and what interests he or she has in this system.

Feelings, however, tend to be infectious. Turning feelings of shame to feelings of pride is an ongoing process in which groups that feel belittled and that lack power together fight to create respect for their own situation, break down prejudices and achieve rights in society (Swift and Levin, 1987). Voluntary organisations and social movements therefore have importance for turning feelings of shame into feelings of pride. Stigma is often given a face through these types of organisation, by appearances in the public, public demonstrations and statements (West, 1898, p. 77). Feelings of community and belonging arise through participation in such organisations. The organisation’s characteristic feelings of pride are passed on to the members by providing goals and meaning (see Hattfield E., Cacioppo J.T. and Rapson R., 1992).

Resource mobilisation theorists speak of (social) movements and not voluntary organisations. As opposed to organisations, movements are seen as fluid and lacking boundaries (e.g., Ahme, 1994). Social movement is a wider concept that pertains to both networks of supporters, a set of opinions and perhaps lifestyle.
Finally, the third stage is called willingness. In this stage there exists a will to change the division of power with the purpose of changing one’s own social situation, moving one’s own positions forward and aiming at realising one’s own interest.

Levin’s process of development presupposes that people first become aware of their own competencies and interests as well as the current objective social conditions before they can be expected to show solidarity with others with similar interests. The emotional stage then creates the energy that is needed for action. Individuals lacking knowledgeable awareness or emotional energy are most likely not participants in activities that aim for empowerment (Starrin, 1997, p. 27). Every stage is a necessary precondition for the continuing stages and every stage builds on the one before.

The concept of empowerment is elusive since it takes in both psychological and political dimensions. In this way it is similar to some of my earlier discussions on the various motives and incentives of membership. Empowerment incorporates considerations of personal efficacy (i.e. the perceived sense of control over one’s life), human rights, human dignity, issues of social justice and self worth, as well as notions of one’s political efficacy, i.e. the ability to make a difference in the world. It can be seen as a process of capacity building aiming for political and social change in favour of the individuals and groups that seek more control (Laverack, 2005).

Defining Empowerment

Defining empowerment is not easy. Judging from what is written about it, it seems easier to say what empowerment is not than what it is. Antonyms of empowerment could be powerlessness, hopelessness, alienation and helplessness. However, to best use the term, an attempt to define it is needed. This study adopts a broad definition of empowerment.

I define empowerment as a goal or process (or a combination of the two) aiming for improved self-confidence, self-determination and increased control of decisions affecting one’s life. Usually, the aim is to change the individual’s social situation and realise his or her interest by moving his or her position forward. Consequently, empowerment is highly subjective.

I have excluded behaviour/activities that are not, in various ways, directly aimed at helping individuals get control over their lives, such as participation in social activities where making friends, having company or having fun is the sole objective. Only activities aiming at increasing people’s control over their lives are included in the concept of empowerment.

As has been pointed out elsewhere, these strivings can refer to a development of a special way of looking upon yourself (e.g., feeling worthy, feeling that one is able to act, that one trust’s oneself and others) and that one sees that society with its structures actually can be modified and changed (Starrin, 1997, p. 13). Thus, empowerment refers to the subjective experience and to the objective reality, both to feeling and knowledge. Empowerment is both a process and a goal and contains some central components, such as power, control, trust in oneself and pride (ibid).

Empowerment is a person’s ability to achieve what is in his or her interest. The fact that people do things of their own free will and of their own motivation is enormously significant according to Alinsky (1971). People feel satisfied when they reach their own formulated goals through their own efforts. With that in mind, empowerment refers to people’s autonomy in making decisions about their life and their power to choose from among several behaviours. Empowerment cannot be bestowed, it must be gained by those who seek it. For further discussions of the term empowerment, see Werkö (2000b) and Werkö (2006).
A concept of interest to this area is the concept of co-production, which was developed in the late 1970s (see Ostrom, 2002). Co-production can take place on the individual level, as well as on the collective level, but of interest for this study is the collective form. “Co-production is the process through which inputs used to produce a good or service are contributed by individuals who are not ‘in’ the same organisation” (Ostrom, 2002, p. 347). For example, the producer of health services is usually a government agency, although it may not be the only producer of these services, depending on the nature of the service, on the current regulations and on the incentives that encourage active participation of others. Public services are potentially produced by the regular producer and by the client. The use of this passive term implies that the client is acted upon. The use of terms will be further discussed in Chapter 8. What is important here is that co-production means that citizens can play an active role in producing health services of consequence to them. In this case citizen contributions can be either encouraged or discouraged by public officials or health care personnel.

The term co-production was developed to highlight the potential relationships that could exist between the producers and ‘clients’ when it was realised that the production of a service was difficult without active participation of those intended to receive it (Ostrom, 2002, p. 358). For example, what doctors and nurses do may make little difference in the health acquired if patients are not actively engaged in their own treatment and supported and encouraged by their friends and family. Co-production can thus be seen as the synergy between what citizens do and what the government does. Co-production is joint provision of a public service by the public agency as well as by the service consumers (Levine, 1984). This means that the ‘customers’ participate in providing at least a part of their own service. Co-production has also been described as having two parts: first, citizens are involved in the planning of services to be delivered and second, they participate in the delivery of the service. (Cooper and Kathi, 2005).

When the inputs from citizens and a government agency are complementary, the same level of output would be possible to achieve with many different combinations of input from these actors. It is, however, important that it is a combination of inputs, rather than reliance on only officials or citizens (Ostrom, 2002, p. 359). However, what is often the case is that the incentive systems of use in the public sectors send very weak signals about performance to staff who usually are employed on low-paying, long-term contracts with few opportunities for advancement. The signals encouraging citizen inputs are even weaker (Ostrom, 2002, p. 360). Consequently, both sources of input produce much less than what could have been generated if everyone had been more motivated to exert more effort.

According to Ostrom (2002, p. 363f), for co-production to be an improvement over regular government production or citizen production alone, four conditions need to be met. First, both parties must have something the other needs. A complimentary production possibility frontier should be possible to achieve with the technologies in use. Second, both parties must have legal options available and not be restricted by the law. Third, a credible commitment to one another must be established, e.g., through clear and enforceable contracts, so that if one participant increases input, the other will continue at the same or higher levels. At the same time, it is also important to make a credible commitment not to undertake actions. For example, citizens are more likely to break their promises if they believe that a government agency will bail them out if they fail to perform according to their agreement. Fourth, in order to encourage inputs from either side, incentives should be used. Sometimes the mere opportunity for citizens to get to know officials and vice versa in an open forum is enough.

These conditions, and specifically the latter three, are more likely to be met in a decentralised political system. Here the rules can be tailored to local situations if they are written in a general form at the large-system level. Naturally, it is easier to plan incentives that encourage co-production for relatively small units that support contact that is more meaningful among officials and citizens. The small and the large units complement each other as each performs tasks the other cannot perform well. Large units usually lack relevant information about local time and place information, whereas small units are not able to plan the basis of a large network effectively. Achieving the potential synergies of co-production, however, demands that citizens and public officials work together. The productivity could then potentially increase and citizens would be further encouraged by their experience to develop other horizontal relationships.

For examples of co-production, see Ansari et al. (2002) who studied community partnerships in South Africa that brought together communities, academics and health service providers. Other examples are co-production in education (Crowson, 2003), customer relationship marketing (King, 2005) and in customer service (Harris, 2003).
and social capital (see Putnam 1993 and Ostrom, 2002, p. 366). The literature on co-production is characterised by a focus on empowerment (Evans, 1996; King, 2005) and the creation of social capital among citizens through collective efforts (Ostrom, 2002).

Finally, one more area of interest should be mentioned concerning the nature of this study, namely patient empowerment.

**Patient Empowerment**

**The Patient**

In the Oxford Dictionary a patient is ‘a person receiving or registered to receive medical treatment.’ Dorland’s Illustrated Medical Dictionary (1994, p. 1245) has a different definition, where a patient is ‘a person who is ill or who is undergoing treatment for disease.’ This means that a person is regarded as a patient if ill, regardless of whether he or she is receiving treatment, or in other ways uses the medical system. I have not chosen this definition, but the Oxford one, as a patient to me is not only a person who is ill but also an ill person using some part of the health care system.

**Patient Empowerment**

Patient empowerment is a sociological expression describing the right of the patient to decide about the ways and means he or she is being taken care of in the medical context regarding questions of health behaviour or in medical care.

The National Swedish Board of Health and Welfare describes empowerment as a view on humans that sees the patient as a product of his or her own health (2005, p. 148). However, the concept is more complex than that. Patients’ possibilities to exert influence in the health care system and choose a provider of health care have been one of the most debated health care issues in the 1990s and early 2000s. Patient empowerment, as a concept, is also relatively new and in tune with a wider political and cultural emphasis on individual choice. It is not until the past two decades that this concept has developed. This is most likely linked to the recent development of the concept of empowerment. Patient empowerment has developed significantly over the past 20 years in the USA and is growing in importance in Europe as well. It was not until the 1960s and 1970s that empowerment became part of the public health discourse, broadening it from the bio-medical model to also include a behavioural and lifestyle component (Laverack, 2005). The temporal structure of the experience of illness has continuously changed due to the increasing predominance of chronic disease, affecting obligations and social expectations associated with the ‘sick role’ (Crossley, 1998).

Movements are to a degree manifested in patients’ organisations (e.g., the disability movement and the breast cancer organisation). There are also organisations for ex-patients or families of patients. Many patient organisations developed as a result of changing and more open attitudes in the past two decades. Among the major organising principles of these movements from the start were self-definition and self-determination. At present, many groups exist that claim to speak ‘for’ patients and to be patient advocates. Most politicians consider that the four-year general elections give them a commission to represent the patients’ views regarding the organisation and conduct of health care. It is questionable whether people or patients feel the same way. Most probably look at the elections in a more general way. A basic liberation principle is that people must speak for themselves. The vast majority of patients remain unorganised, but groups are now becoming more visible and recruiting more members. The major cause to why patient empowerment has emerged is the fact that the traditional medical model does not fit the reality of specialised care. There are patients today rejecting the role of passive recipient. Patient empowerment has arisen out of widespread discontent with the medical practice and the long-lasting state of patient powerlessness (Weaver and Wilson, 1994, p. 480; Saltman, 1994, p. 208).

33 In the USA, patient activism emerged because of two main influences: the AIDS movement and, to a lesser extent, feminism.
Who ultimately is in charge of an individual patient’s care? The traditional medical model views the physician as the final authority in the treatment of illness (Ottoson, 1999; Evans, 2003). In contrast, patient empowerment posits that patients are in charge of their own care on a daily basis (Andersson, 2002, p. 38). When the illness allows it, they are their own health care providers. Traditionally, the physician is viewed as responsible for diagnosing the illness, deciding on an appropriate treatment and assuring that the treatment is carried out as prescribed (Anderson, 1995, pp. 412-413). Patients only make one initial crucial decision: whether to put themselves in the hands of the physician or not. The physician is looked upon as knowledgeable, active, in control of the care process and powerful, whereas the patient viewed as crucial decision: whether to put themselves in the hands of the physician or not. The physician is looked upon as knowledgeable, active, in control of the care process and powerful, whereas the patient viewed as compliant, accepting, passive and dependent on the physician’s medical knowledge and goodwill. The perception of patient dependency on health care providers who are accorded high social and political status is found not only in the academic literature but also amongst patients’ association activists (Wood, 2000). However, in the case of diabetes, most patients do not want to be ordered, controlled, directed or blamed for how they live (Anderson, 1995, p. 413). They want advice about how to care for their own disease. Most patients want their physicians both to provide adequate information about effective treatment options and to respect their preferences. Therefore, evidence-based medical care makes no sense if patients’ preferences are ignored (Wensing, 2000).

In the early days, the medical establishment was quite hostile to the idea of patient empowerment (Melin, 1996, p. 9). Physicians have been entrusted by society with the responsibility of being in charge of patient care. Consequently, many physicians react negatively to the idea of not being in charge. Today, however, with the growing importance of patients’ influence, many doctors are committed to patient-centredness (Kjeldman et al., 2006) and patient empowerment (Moynihan and Smith, 2002). To the extent that doctors and nurses can regard patients as empowered, there is also a risk that they can regard themselves as being freed from a degree of responsibility for the patients’ treatment (Salmon and Hall, 2004).

The World Health Organisation (WHO, 1978, p. 1) stated, “The people have the right and duty to participate individually and collectively in the planning and implementation of their health care. This is clearly a basic human right.” Although the term empowerment is not used in this declaration, it goes beyond participation to imply that empowerment is a necessary component to primary health care and public health (Laverack, 2005, p. 22). The patient may exercise his or her rights through direct contact with doctors or other caregivers or through a patient organisation that will have an influence on decisions about the delivery of care. The rights of patients to determine what is going to be done with them concerning both body and soul is a relatively recent development which has been emphasised through the Human Rights Charter of the United Nations. In Sweden, the present Health Law introduced the right of patients to be informed about any procedure of which they were going to be the object with the right to determine whether they would be willing to take part or not. As far as I know, there has never been an objective assessment regarding how or to what extent this rule has been used in routine health care.

Patient empowerment involves a transfer of power from the professional to the patient. It deals with the right of the patients to have input regarding their treatment based on an educated selection from various options. Patients play an active role in decisions regarding their treatment and care in a process. Patient empowerment can be expressed in terms of jurisdiction (i.e. laws stating patients’ rights or in terms of education, e.g., the need to decrease the gap of knowledge between the patient and the doctor). Increased participation from the patients means that they in turn need access to adequate information. The choice of treatment method can have major consequences for the individual patient as well as for the care provider (and the financer of the care.) It could concern the choice between awaiting the development of the disease and starting a treatment. A precondition for patients’ ability to decide on alternatives in the health services, regardless of whether these concern care provider or treatment method, is to have access to information and then have the ability to assimilate it. There are arguments in favour of the individual’s right to have access to all information that may be of relevance for his or her own life situation, but arguments can also be found for situations when information can confuse or even harm the individual (the Ministry of Health and Social Affairs, 1999, p. 246). Patients’ right to information was specified in the 1999 Health and Medical Service Act. From the perspective of patient empowerment, access to information is of crucial importance.

Some people have good health despite high levels of stress. Theories on the reasons for this identify factors of importance for good health, one is the ability of coping (Bulsara et al., 2004; Kristenson, 2006) and another is empowerment. Empowerment is defined here as being in control of your own life (Bengtsson and Morén Hybbinette, 2004, pp. 69-78). This happens when patients see how their own
abilities affect their state of health. When turning to the health services, the patients often have chaos in their life and do not feel that they have any power to affect their health. Patients often experience powerlessness, lack of knowledge/information, vulnerability, defencelessness, anxiety and distress (Wåhlin et al., 2006). Therefore, the health professional’s attitude has huge importance for the patient’s ability to mobilise (Ottoson, 1999; Wåhlin et al., 2006). If the health professional alone takes on all the responsibility for making the patient well, the patient’s own resources and strengths will not be noticed.

Depending on the field of medicine, the concept of patient empowerment has been developed somewhat differently. Many articles discuss the concept of patient empowerment, looking at it from a medical perspective; the specific diagnosis of the patients, a specific line of medicine or medical profession, a specific care situation or surrounding, like a specific country, and so on. Other articles focus on different aspects of or prerequisites for patient empowerment. Few focus on the concept of patient empowerment in general. There is a wide range of views on what patient empowerment means and yet there is little agreement as to what meaning this term should incorporate. Currently, patient empowerment is an umbrella term covering a number of issues.

What is an active patient? A French study on patient organisations for AIDS identified four different cases: the patient as manager of his illness, the science-wise patient, the experimenter and the empowered patient. The study showed how patient organisations for AIDS have moved from the approach of patients as “objects of solicitude” to the promotion of patients as “active subjects” in the production of scientific and medical knowledge (Barbot, 2006). The current change of the view on patients as opposed to that of health care consumers is an example of patient empowerment initiated by, among others, patient organisations. Today, we talk about the enlightened health care consumer. In this respect, patient empowerment is gained by treating patients as health care consumers and teaching them to take an active role in determining their health care. As we shall see in Chapter 8, this change in terminology has importance for collective identity (Gamson, 1992, p. 55). (For a discussion on patients vs. health care consumers, see Werkö, 2000a; Levin and Normann, 2000, p. 54ff; Le Grand, 2003; Tomes, 2006).

Both contradictory pressures (to limit costs yet also to secure the best and usually most expensive treatments) and persistent asymmetries (in the knowledge and power bases of the doctor and the patient) have complicated the expectations of doctor-patient partnerships (Tomes, 2007). Patients and doctors become partners in the shared process of health care and the move from ‘object’ to ‘subject’ to ‘equal’ usually corresponds with the idea of patient empowerment (Cribb, 2005), but it could mean even more. Elliott and Turrel (1996, p. 44) developed a model of patients’ different roles in decision making. Table 4.1 illustrates various conflicts and misunderstandings that might arise because of a lack of clarity regarding the patients’ role in multidisciplinary decision making about their care. In this table empowered patients would take on the role of the most important team member (cf. resourceful individual in Eldh, 2006).

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34 Empowerment has recently been described in relation to self-care in chronic illness such as cancer (Björklund, 1999; Bishop, 2004, Chang et al., 2004; Bulsara et al., 2006), HIV (Crossley, 1998), mental health (Townsend, 1998) and diabetes (Adolfsson et al., 2004; Anderson and Fullnell, 2005; Fullnell et al., 2005), but also with focus on other patient groups such as patients with pulmonary diseases (Göransson et al., 2003) and intensive care patients (Wåhlin et al., 2006; Christensen & Hewitt-Taylor, 2007). For instance, patient empowerment in intensive care consists of stimulating and strengthening the patients’ own inherent will to fight and joy of life (Wåhlin et al., 2006). This can be done through a positive environment that encourages feelings of motivation and value and in which the patients receive additional care, feel safe and participate as they wish.

35 For example the USA (Roberts, 1999), the UK (Perri, 2003; O’Cathain, 2005 and Bridgen, 2006), Thailand (Reeler, 1996) or Australia (Pelletier, 2000).

36 This can include communication between the provider and the patient (Clark, 1996), patient choice (Saltman, 1994), seeing the patients as consumers (O’Donovan, 1995), the importance of information (Kane, 2002) and internet (Fox, 2005 and 2006; Broom, 2005 and Cotton, 2004).
Table 4.1 Patient participation and decision making: potential conflicts

<table>
<thead>
<tr>
<th>The patient’s decision-making role</th>
<th>Adviser</th>
<th>Collaborator</th>
<th>Equal partner</th>
<th>Most important team member</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient’s team role or status is:</td>
<td>To provide help, insight, views, recommendations about decisions when requested.</td>
<td>Active involvement in the decision-making process to an extent which may be jointly determined or defined by others.</td>
<td>To be actively involved as much as anyone else in the decision-making process.</td>
<td>To lead / direct / control the decision-making process.</td>
</tr>
<tr>
<td>The patient has rights to:</td>
<td>Give an opinion when it is sought.</td>
<td>Work alongside others in the decision-making process at some level.</td>
<td>Expect equal weight to be given to his or her views in reaching any decisions.</td>
<td>Expect his or her views to be given more weight by others and to be always heeded by others.</td>
</tr>
<tr>
<td>The patient’s power to determine the outcome is:</td>
<td>Nil as of right. Views expressed will be heard but can be legitimately ignored.</td>
<td>Unclear: patient involvement is legitimate, but its influence is not clear.</td>
<td>As great as anyone else’s, but may be outvoted by other ‘partners’.</td>
<td>Right of veto: the final say in all decisions rests with the patient.</td>
</tr>
</tbody>
</table>

Source: Elliott and Turrell, 1996, p. 44.

Why is there such an imbalance of roles in health care? Weaver and Wilson (1994, p. 481) introduce Brody’s explanation that because of their many years of training and education, physicians have accumulated a wide range of knowledge not widely available to the average person (such as the patient) who is dependent on his or her physician (e.g. Strandberg, 2002; Eldh, 2006). This gap in knowledge fosters the imbalance of power, as does the use of professional language (Laverack, 2005, p. 40f). The ability to acquire information is, however, an important prerequisite of empowerment (Kuokkanen and Leino-Kilpi, 2000). Patient education is therefore one of the key factors of patient empowerment.

**Patient education**

Patient education has traditionally focused on giving information regarding preventive care (e.g., stress management and smoking cessation) or information regarding treatment (e.g., how often to take a medication and how to give an injection). The focus has not been on communicating concerns or asking questions. When the physician alone defines the educational aims, the patient cannot become empowered. The patient needs to take part in the goal setting process. According to Weaver and Wilson (1994, pp. 480-483), an empowering education must be based on the desire to enhance the patients’ decision-making capabilities as well as on the right of the patient to be the central member of the health care team. Today, there is a trend to design IT education programs for various groups of patients (Shortliffe, 2005).

In a study that attempted to measure the patient’s satisfaction with health care, the most important factor is the relation between the patient and the physician, including the information that is given at the consultation (Crow et al., 2002). Despite an extensive need for information, patients’ desire for information is often underestimated by their physicians. Many studies demonstrate that patients would generally like to receive more information about their laboratory test, diagnoses and medication. In an American study (Strull et al., 1984, pp. 2990-2994) patients with hypertension were asked how much information they had received about their disease. The majority replied “quite a lot” or “all there is to know”, whereas only 38% of the physicians gave the equivalent answer. Naturally, it is difficult for patients to decide how much information they have received without knowing how much information has been withheld. This one-sided medical view is also illustrated by Ottoson (1999).

37 Many studies demonstrate that patients would generally like to receive more information about their laboratory test, diagnoses and medication. In an American study (Strull et al., 1984, pp. 2990-2994) patients with hypertension were asked how much information they had received about their disease. The majority replied “quite a lot” or “all there is to know”, whereas only 38% of the physicians gave the equivalent answer. Naturally, it is difficult for patients to decide how much information they have received without knowing how much information has been withheld. This one-sided medical view is also illustrated by Ottoson (1999).
by their wishes (Elliott and Turrell, 1996, p. 46). Changes in patients’ conditions also cause difficulties. Information alone is not always enough: patients also need to be supported through the process of making choices, particularly if they are facing life threatening chronic illness, but even in less serious situations (Gustafson et al., 1999). A study on intensive care patients found that these patients were able to experience some form of control over their own life (assuming that they felt certain that the health professionals did all they could to help), through understanding the situation: what had happened, what was planned and what was expected to happen (Wåhlin et al., 2006). The need of continuous, well-balanced and professional information is thus important. It is not only important for the patient to know about all possible options, harms and benefits but also to have the opportunity to convey preferences to one’s physician who should give full explanations to inquiries and never regard questions as intrusive or inconvenient (Rubin, 1995, pp. 24-25). One of the main tasks for patient organisations is to provide essential information to patients regarding treatment options available and their effects.

Patient education is a basic prerequisite for self-management with any disease, an important result being improved self-confidence. Traditionally, patient empowerment or education programs primarily focus on education of physical factors, such as glucose management in the case of diabetes. However, there are two levels of knowledge needed to make informed choices about daily care (ibid, pp. 943-944). The first and obvious level concerns expertise about the disease. The second level is psychosocial skills and challenges. The two levels are equally important. Empowerment education programs are generally based on philosophical assumptions. It is assumed that by reflecting on their lives and given the freedom to choose, patients would be willing and able to select appropriate goals regarding living with and caring for their own disease. Examples of patient empowerment programs are found in Appendix 10.

From the patient’s point of view

Conceptual problems arise when defining empowerment in a health care setting (McLean, 1995). Empowerment can refer to an increasing amount of treatment options or to opportunities for consumers to voice their preferences to help determine future options. On another level, it refers to processes occurring in relation to the larger social structure, the organisation or the individual, or to interrelations among these factors. Finally, it may be used to refer to a service approach (ibid). In her study McLean (1995, p. 1056) found that patient empowerment in the USA takes on different meanings for different groups of people. She had the following to say regarding this matter.

... greater choice of, and control over, treatment options may represent empowerment to providers, families and those private sectors consumers in a position to exercise choice and control over their treatment. For public sector consumers with minimal opportunity to exercise control and choice over their treatment, empowerment could mean heightened access to desired treatment options. But for ex-patients who reject the medical model of expert control, empowerment can only mean the freedom to produce, and choose among, their own options.

Although not defined, patient empowerment has achieved such high status that it is perceived as being above popular questioning and thus commands enthusiastic and widespread support among enlightened practitioners and trusts (Elliott and Turrell, 1996, pp. 43-47). The many benefits associated with patient empowerment are a major cause to this popularity (e.g., moral and therapeutic, socio-political, financial, managerial and legal benefits). Thus, the potential for uncritical acceptance is considerable.

Patient empowerment is high on the political agenda in Sweden and in most comparable countries. It is a relatively new concept, only emerging over the past 15 years. It is widely used. The core issue of the debate the past couple of years in Swedish society is patient empowerment (e.g., SvD, 971104, p. 5; Jersild, DN 020219, p. B2). However, the knowledge of patients’ preferences and possible consequences of increased patient participation are rather limited (Ottoson, 1999, p. 375). Most of the existing studies are American and thus reflect conditions that in some ways differ from the organisation and financing of Swedish health care. How the experience of being ill influences attitudes and values or why and how patients’ preferences change are not known. No reliable knowledge exists about what forms of patient participation create best results, or what effects that follow by different actions.
Seeing patient empowerment as the growth of individual patients’ ability to direct their own actions and influence their environment means that there are strong links between patient empowerment and choice.

**Patient choice**

Saltman (1992 and 1994) discussed patient choice becoming an important touchstone of health care reform across northern Europe. The patient’s ability to choose concerns such activities as choosing a regular health centre, hospital or general practitioner. Market-oriented reforms in Swedish health care in the mid-1990s gave patients more ability than earlier to exercise choice over health services (Harrison & Calltorp, 2000; Saltman & Bergman, 2005). A comprehensive survey of patient choice and public involvement in eight European countries showed an overall high desire for free choice of health care provider (Coulter and Magee, 2003, p. 224), although to a lesser extent in Sweden. Perhaps this is because Swedish patients more or less already have free choice of hospital (ibid, p. 10) and because they have more direct access to specialist treatment, e.g. they can book an appointment with a hospital outpatient department (European Observatory on Health Care Systems, 2005, p. 77). Saltman (1992, p. 43) refers to patient choice as a political factor in which patients help legitimate the underlying authority and appropriateness of the service delivery system. Hence, patient choice stands for democratic rather than commercial rights. The author goes on to discuss the basic issues involved in empowering patients within publicly operated health systems, concluding that ultimately resource allocation and budgetary authority are the only practical surrogates for organisational power. In order to become empowered patients have to have substantial control over these two financial mechanisms from managers and physicians.

According to Dent (2006, p. 453) “‘choice’ has become a rhetoric and set of management practices that is felt by some within the profession to undermine their role as independent, authoritative and expert health adviser.” The process of patient empowerment may result in a proto-professionalisation of people in the delivery of their health care, encouraged by media, the internet and the medical profession. As a consequence, there is a risk that the policies aimed at giving the patients their own voice(s) and choices will be undermined, as well as the public trust in doctors in general (ibid, p. 460).

**What is patient empowerment?**

When presenting this project, I have been asked the following question several times: What is patient empowerment? Is it different things in different contexts? They are relevant questions. In this chapter, I have demonstrated that patient empowerment, like the concept of empowerment, takes on different meanings depending on the context. Generally, patient empowerment means that patients have a voice in health matters; it is the patients’ ability to voice any concerns, ask any questions and make decisions about their medical treatment and care. Patient empowerment is ultimately about respect for the individual patient’s will.

Patient education is an important prerequisite for patient empowerment and may come from different sources, not only from the health services. In order to be educated, the patient must actively seek information and cannot always depend on the health services to provide the adequate information. Its purpose is to ensure that the choices patients make every day in living with and caring for their disease are informed choices. Thus, patient empowerment aims at enhancing patients’ ability to influence their lives through helping them learn how to make informed choices about their health care.

It should also be mentioned that patient empowerment is something one must prepare for. Some patients are always unable or unwilling to assume a significant decision-making role in their treatment (Salmon and Hall, 2004). They might feel they came to the physician so that their care decisions would be made for them. These are patients not yet demanding to be empowered. Therefore, it is important not to insist that patients participate in their care when they are reluctant to do so. But even if patients wish and find it natural to leave medical decisions and treatment principals to the health professionals, it is still important to be taken seriously and be listened to.

Applying Levin’s three stages of development could be difficult when it comes to sick patients, though this will depend on the state of their illness. Even if the requirements of the knowledgeable stage are satisfied (patients are aware of their competencies and interests and they show solidarity with others in
their situation), the energy needed for action may be diminished because of their illness. In that case, neither the emotional stage nor the willingness stage will be attained. However, what is lacking does not necessarily have to be knowledge, emotion or willingness; rather, it could be physical and psychological strength that are the problems (cf. Swift and Levin, 1987). When mobilising patients, their state of health must also be considered.

Summary

Several reasons for joining an organisation have been discussed in this chapter and impact of outer characteristics such as size of the group or membership coercion have also been mentioned, as well as different life situations (e.g., timing and visibility of a cause and disappointment in the private arena). Reasons for membership can be found in the selective incentives offered by the organisations or associations, such as the sharing of information, member activities, social contacts, political or social questions and shared interests. There are many different reasons for why people choose to join an organisation. Members of the same organisation probably have different reasons for joining. Some may be motivated by the opportunity for social contacts, some by self-interest and some by solidarity. Many persons may join a patient organisation primarily for the educational aspect in order to gain a better understanding of the disease. Others may see the organisation as a way of meeting people in the same situation or as an investment in medical research.

The reasons for active participation were discussed with a focus on people’s socio-economic status, their need for higher purpose and meaning, their abilities in terms of subjective political competence, political efficacy, political resources; skills, time, money and political interest. Furthermore, the social functions were described (e.g., to achieve important psychological goals and social needs, to fit in and get along and to become empowered). The prerequisites that were discussed were the individual’s confidence, the feeling of being capable, the wish to influence, the caring about what happens around him or her, the wish to make one’s voice heard and finally the wish for learning the process itself.

The complex concept of empowerment was described and explained. This was found to be difficult because of the elusive nature of the term as it has both psychological and political dimensions. A definition of empowerment was offered.

Co-production was briefly reviewed, which in the present account stressed the equality of the two sides working together (usually a government agency and citizens) in achieving some mutual goal. It also stressed the activity taken by the usual passive citizen. Therefore, the concept of co-production is clearly highly relevant to the field of patient empowerment. This will be further discussed in Chapter 8.

Finally, the patient was in focus when the important concept of patient empowerment was explained. Whether it was patient education, patient choice or taking on the perspective of the patient, this part dealt with patient issues related to empowerment.

There are various inputs in patient empowerment. Some talk of freedom of choice, such as choosing physician and hospital, and some talk of influencing the decision-making of treatment and care. Further, some talk of patient empowerment as a complementary, reinforcing part of patient education, where, ideally, these two forms should be integrated. Others talk of gaining financial power and of letting the patient educate the doctor about living with his or her disease. Creating opportunities for patients to address the psychosocial issues of living with a disease requires a comprehensive and person-centred approach. Physicians can learn to be experts in managing diseases, but only patients can be experts in the conduct of their own lives. Therefore, it is important to accept that some patients may exercise their right not to take part in decision making.

In this chapter I have shown that patients can be empowered in many different ways, legally and through education. This demands access to information as well as a will of the patient to become empowered. Patient empowerment focuses on patients’ preferences and patients who prefer to have choice (Saltman, 1994, p. 218). How much choice, at what level and to what degree might all be secondary to patients’ desire to be empowered in the process itself.

It is thus clear that the concept of patient empowerment is relevant to any study of local patient organisations and their members when trying to uncover reasons for both passive and active membership.
The first part of this chapter describes the disease diabetes in order to illustrate what it is like to live with diabetes. This is necessary in order to achieve a better understanding of this study’s topic. The second part describes the Swedish Diabetes Association (Svenska Diabetesförbundet). This chapter serves as an introduction to the empirical part of this thesis.

Diabetes

Diabetes mellitus is a disease that affects the metabolism, i.e. the turnover of energy in the body. Glucose is the substance in the bloodstream that carries energy to all organs for their proper function. The level of blood glucose is dependent on the proper intake of food regarding kind, amount and time, but is determined through intricate mechanisms maintaining a glucose level without much fluctuation. This means that both energy input (food of different kinds) and expenditure (rest and physical activity) are important for the level of glucose, as well as for the symptoms of the diabetic person. The main aberration in diabetes affects the way the body is handling glucose. That is important for the transport of energy in the organism.

Normally, the level of glucose in the blood is kept within certain limits by the action of insulin—the hormone that is secreted from certain cells in the pancreas. When the blood glucose increases, more insulin is secreted into the blood to help the body deal with the increased glucose. When the different organs in the body increase their activity, the glucose is used for energy, especially in the muscles, heart and brain but also in the abdominal organs. The amount of glucose in the blood going to active organs is quickly consumed. The insulin excretion is then kept low in order to get more energy for the working organs. All organs are dependent on a constant flow of energy, which makes the complicated mechanisms for the control of blood glucose of utmost importance. This fine-tuned mechanism is destroyed in type 1 diabetes through the lack of insulin from the pancreas and in type 2 diabetes because of a disturbance of the action of insulin in the cells for combustion of glucose.

Type 1 diabetes usually develops in children or young adults and has some familiar genetic background. The disease develops rather quickly over days or weeks. If one child in a family has diabetes, the risk of diabetes for siblings is 5–10 per cent. Type 1 diabetes is the second (after asthma) most common chronic disease in childhood and adolescence (Hanas 1998, p. 12). About 6 500 children in Sweden have diabetes and the number is increasing. About 40 000 people in Sweden today have diagnosed type 1 diabetes (DN 010207).

Type 2 diabetes (mature onset diabetes) develops gradually in middle age or later and is related to other metabolic changes, especially overweight. The increased number of fat people in the Western World is thought to lead to an increase of diabetes. More than 85 per cent of all people with diabetes have type 2 diabetes.

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38 Space does not allow a detailed description of diabetes. I only want to give a brief description that shows why it is important that patients with diabetes have the main say in their treatment. The reader that wants to know more about the disease is referred to the many popular or scientific books on the disease (e.g. Pickup & Williams, 1997 and Hanas, 1998).

39 There is an uncommon disease called Diabetes insipidus, which is due to another hormonal disturbance. Therefore, the single word diabetes always refers to diabetes mellitus.
Some women may have a temporary disturbance of the glucose metabolism during pregnancy (gestational diabetes), which may threaten the foetus.

It is estimated that 3–4 per cent of the population in Sweden have diabetes (The Swedish National Board of Health and Welfare, 1999). This makes diabetes one of the major public health problems in the country. Further, research indicates that the number of people with diabetes is escalating in both Sweden and worldwide (Amos et al. 1997, Hanas 1998).

Symptoms

High levels of blood glucose increase thirst in the short time and the production of urine with a risk of dehydration. The patient may lose weight rapidly. In the long term high levels affect both blood vessels and the natural resistance against infections. Low levels of blood glucose affect the delivery of energy to the vital organs. A precipitate drop of blood glucose, as after a too high dose of insulin, influences the brain, heart and the circulation of blood with a risk for acute fainting attacks. These symptoms are due to a combination of low blood glucose and low blood pressure (‘hypos’) that, if prolonged, can lead eventually to death.

Diagnosis

Earlier patients were not diagnosed until they had developed symptoms because of the increase blood glucose levels. Nowadays, patients with diabetes, especially type 2, are usually diagnosed before they develop severe symptoms through the routine determination of the level of blood glucose in the fasting state (before eating in the morning). If glucose is found in the urine, the person has to be investigated more fully. This is because glucose does not normally pass the kidneys. The level of blood glucose that is considered normal, or elevated to a level defining the diagnosis of diabetes, has been determined by expert committees in the WHO.

Treatment

All patients with diabetes have to watch carefully the balance between food intake and physical activity in order not to get too high (food rich in energy) or too low (extreme activity or a high dose of insulin) levels of glucose in the blood.

The patient with type 1 diabetes must substitute the lack of insulin with daily injections of insulin. Several different preparations of insulin are marketed: short-acting, long-acting, combinations, and on the horizon, insulin that may be inhaled instead of injected (Skyler et. al 2001, DN 010207, Ernström 2005). The best way of preventing and treating type 2 diabetes is to avoid overweight. In addition to watching the daily way of life, patients with type 2 diabetes may be treated with tablets that stimulate insulin production or, more seldom, inject themselves with insulin to combat too large increase of blood glucose.

Before insulin was discovered, the patient with diabetes slowly deteriorated until death. Since the discovery of insulin, it has been manufactured and used for the treatment of diabetes. The knowledge of how to administer insulin has continuously increased, an increase that continues today. Earlier insulin was injected once or twice a day; nowadays, special preparations have made it possible to do so several times a day (i.e. before each meal), making life both better (less symptoms) and worse (having to inject several times a day). The optimal treatment of diabetes depends more on the patient than on the medical services. The interested and observant patients can influence both wellbeing and longevity through their way of life, especially diet and activity. Increasing patient knowledge and participation have led to more patients all over the world living a better and longer life. The person with diabetes lives probably longer after the diagnosis has been made than any other patient category in the Western World.

A conscientious patient who follows his or her blood glucose closely, watches the in- and output of energy and uses insulin when needed, can live a long and fruitful life without much fear of complications. Some people may consider that this way of life is close to a normal, whereas others may feel the constant need for medication and observing their body functions lead to a very restricted way of living.
A quote from the survey study presented in chapter 7 nicely illustrates how a member of the diabetes organisation feels about the common view of her diabetes:

There’s an image of diabetes – and the life conditions of diabetics - that I call ‘have a diet-coke and a smile’ attitude, which is something I’d like to change. In my opinion, the picture of diabetes as a disease is quite glossy and if you have complications or feel bad or sick, then it is because you have misbehaved. Give the diabetes disease a few more faces that are different!

Complications

The late complications of diabetes were not observed until after insulin was discovered; before this, the patient died prior to the developing these complications. The complications, which are observed in various organs, occur not until five, ten or more years after diagnosis. This is because the deranged glucose metabolism influences the arterial system – the blood vessels that serve the different organs in the body. High levels of glucose are constantly flowing through these vessels and hence damage the lining of the vessel wall and promote the development of pathological changes. This could increase the risk of blood clotting in the vessel with more or less complete shut down of the blood flow to the organ served by the vessel. The importance of diabetes for the development of arterial diseases has been emphasized during the past decades. Diabetes has been incorporated in the ‘metabolic syndrome’, which seems to be a precursor to or part of the arterial disease that leads to heart attacks, stroke, kidney failure, decreased blood flow in the extremities and leg sores. The increased glucose level of the blood is thus only one of many dangers that the diabetic patient has to face. Derangement of the mechanisms governing the incretion and action of insulin, the regulation of arterial blood pressure and the amount of body fat as well as other disturbances of lipid metabolism all work together to cause serious damage to the vessel walls in the arteries. Thus, the patient with diabetes faces large number of potential risks, including insulin/glucose metabolism, blood pressure control, lipid alterations, and body weight, with the latter being the most important.

Monitoring the patient

Patients with diabetes are treated within the medical specialty of internal medicine. Medical departments in larger hospitals and health centres may have a division that specializes in diabetes with a staff of various specialists, doctors, nurses, nutritionists and others. The patients are requested to show up for control regularly, some patients yearly, others more frequently. As long as the disease is well controlled, nurses can do the monitoring; however, patients with a complicated picture may have to be treated by physicians in several specialties.

The Health Care

This study was done in two settings, where also the health services differed considerably.

In the North the medical service is comprised of only one hospital for the whole county, with one department for internal medicine, within which the patients with diabetes are taken care of when they need hospital care. However, this need seldom occurs and hence most patients are served by the system for general practice, where local surgeries with physicians, nurses and other health personnel are the natural contact for routine control and checks of patients with diabetes. At hospital, there may be one or a few physicians with special interest in diabetes. The county may have organized a special follow-up service for patients with diabetes with one or more nurses active in the control and treatment of diabetes.

In the City the situation is completely different, where a university hospital constitutes the most highly specialized service, with several more or less specialized departments of internal medicine, one or more of which have a special interest in diabetes. Furthermore, there exist several middle size hospitals (similar to the one in the North) with departments of internal medicine, some of which may be interested in
research on diabetes. In the City there are also similar surgeries for general practices as in the North, and some of them may have special organisations for the long-term follow-up of patients with diabetes.

About the Swedish Diabetes Association

The SDA, established in 1943, concentrates today on care, research and information dissemination. Their main task is to gather and organise all those who want to promote medical and social interests for people with diabetes, disseminating information on diabetes and supporting scientific research on diabetes.

The SDA has 20 regional organisations and a little more than 100 local branches throughout Sweden with approximately 33,000 members. The branches work for better diabetes care on the local level. They arrange such activities as meetings, study circles, courses and camps. In most regions there are also regional organisations that function as a collaboration body for common issues within the region. The regional organisations are run by the local organisations within the region. Individuals are members in the local diabetes branches. Furthermore, a number of groups exist within several of the local branches, including specialised groups for young people, parents, ethnic groups and gender groups. The groups are run entirely by volunteers and usually offer care, support and companionship to people with diabetes and significant others. Some groups are also involved in other activities, such as influencing the local health services and fundraising. Many local branches have a youth and family group helping that help children with diabetes, their parents and other family members. Usually, they organise activity holidays for children of all ages, family weekends and parent meetings. Parents of children with diabetes typically run this group. Within the SDA, there is a Youth Council (UngDiabetes) and networks covering various issues and geographical areas. The Youth Council aims at stimulating young people to work actively within the association, with issues and activities formed by and for young people.

The Association’s top decision-making organ, which assembles every other year, is the National Assembly (Riksstämman). At the National Assembly the board of the Association is elected, which consists of 11 permanent members and three substitutes. In 1995, a decision was made at the meeting that the SDA should act from a consumer perspective. This meant a new way of looking at the association’s role in society, where it was decided that it should act as an active patient organisation with a health consumerist perspective. As consumers of health care, we are making specific demands on the health services and want to be able to compare health systems and treatment methods. The goal is to continue carrying out the National Guidelines, to increase the level of knowledge on diabetes within the public health services, to increase the individual’s influence in the health care system and to collect and systemise information on the quality of the health services from a health consumerist standpoint.

Governmental grants, member fees and project contributions from authorities, organisations and companies finance the SDA’s work. Testaments and gifts are other important sources of income. Between the years 2000 and 2005, the SDA’s resources have increased in some areas while they have decreased in other ones. The number of employees working at the foundation’s office decreased from 18 in 2000 to 12 in 2005.

The financial income of the SDA has varied from 17.5 MSEK (in 2003) to 20.7 MSEK (in 2001) and is 17.7 MSEK (in 2005). With diminishing costs over past few years, there has been a positive result, most recently to five MSEK (in 2005).
As we will see in chapter 6, the SDA has much more resources compared with the branch organisations, both in terms of personnel and budget. This point will be further discussed in Chapter 8.

The SDA provides research-based information on all aspects of diabetes to their members and their families, carers, health care professionals, students and the public. Members of the SDA are sent the membership magazine *Diabetes* six times a year. It includes information and advice on care, research, diet, legislation, SDA’s campaigns and practical hints on daily aspects of living with diabetes.

The SDA aims at increasing the individual member’s competence to act as a conscious health care consumer and enhancing the knowledge of the people who in their work affect the care and social conditions for people with diabetes. The association does not only arrange conferences and courses for their members on annual basis but also for nurses, dieticians and chiropodists as well as conferences and seminars on important issues concerning diabetes, often in collaboration with other organisations.

The Foundation’s research fund (*Svenska Diabetesförbundets forskningsfond*) is a large financial supporter of diabetes research in Sweden. On a yearly basis, it funds scientific research on diabetes and the care of patients with diabetes. The research fund currently spends and awards about 14 million SEK (www.diabetes.se) to research projects examining the possible causes, prevention, treatment and cure of diabetes and its complications. Scientific advisory committees with special competence handle and assess the research applications. The fund also supports the development of new treatments, education of diabetes health care personnel and information dissemination activities.

According to the SDA, people with diabetes should have equal access to good care regardless of where in the country they live. Moreover, such care should be based on the national guidelines for diabetes care (the Swedish National Board of Health and Welfare, 1999). The guidelines are aimed at providing a basis for treatment programs at the local level and were drawn up by diabetes specialists in collaboration with governmental authorities, professional bodies and representatives of the patient organisation. In brief, the guidelines emphasise the importance of multidisciplinary diabetes teams and the ambition to establish an individual treatment plan, i.e. a ‘contract’ between patients with diabetes and their doctor. This contract defines, for example, the roles and responsibilities of the patient and the caregiver as well as the individual goals of diabetes treatment.

The SDA also work to influence government policies on the care of diabetes and are recognised by government as the voice of patients with diabetes. The SDA is campaigning continually on patients’ behalf, campaigning for such aspects as the best care, the best quality of life and an end to unfair discrimination. For example, their campaigning has helped to ensure that insulin and aids remain free of charge for people with diabetes, which the SDA continuously work actively for maintaining. As for social and economic justice, the SDA contend that people with diabetes should be able to live under the same conditions and with the same quality of life as do non-diabetics. By actively influencing public opinion regarding social issues on all levels, the SDA aims to get additional costs due to diabetes to be compensated by the social insurance system. The association is also working to give people with diabetes the possibility to contract private insurance policies on the same terms as other people (e.g., without having to pay an in-
increased insurance premium or having to face other restrictions). In addition, the association works to provide patients with diabetes better possibilities of getting and keeping a driving licence.\textsuperscript{40}

\textsuperscript{40} It is a legal requirement for physicians to inform the County Administrative Board if the patient is obviously unfit to hold a driver license (The Swedish National Road Administration’s code of statues, 1998:89). People with diabetes that are taking insulin cannot have a large goods vehicle or passenger carrying vehicle license (i.e. buses and taxis). In some cases, however, it is possible to get an exemption provided certain requirements are fulfilled (The Swedish National Road Administration, 1997 and 1999).
6 The local diabetes branches

This chapter presents the qualitative data of this study. The results from the interviews and the participant observations are presented. The interviews were carried out with staff, board members and a few other active members at two local diabetes branches in Sweden. The text in the chapter comes from the interviews and the meetings as well as other gatherings where I participated (Appendix 8). All the quotations are collected from these occasions and translated by me.

One aim of this chapter is to answer the posed questions in this thesis. A further aim is to describe these two local patient organisations and their work. This must be done in order to grasp their function within society and more precisely for their members. Therefore, I have chosen to present the data with a descriptive intent in order to present an overall picture of the local organisations, their work, activities and the issues that they deal with on a daily basis. I have tried to focus on the issues the members focused on during my stay with them and their view of the organisation.

It is my aspiration to bring the local branch organisations and the people there to life in this text. I have purposely tried to animate the organisations and let the voices of the field speak, so that the natives’ standpoints are heard (cf. Van Maanen, 1988). One research tradition that emphasises the actual writing of the creative text and the native’s point of view in the text is ethnography (Law, 1994). As this view appealed to me, I decided to let the voices of the field speak, hence the many quotations. At the same time, I have not tried to hide my presence as a researcher. As such, I have participated in forming the reality that is described (Ehn and Klein, 1994).

Case study 1: The local diabetes branch in the North

It is a cold winter day, the last of January and early in the morning. It is a quarter to eight and it is −15°C outside. I have put on warm clothes so I can walk for quite some time outside without getting too cold. It is still dark outside, but the sun is slowly rising and with all the white snow around, it does not feel so dark. I am on my way to the local diabetes branch office. It is my second day and I am trying to find my way through the town and towards the outskirts where the branch is located. It takes about 40 minutes to walk on the snow-white streets of the city.

The office of the local diabetes branch is situated in the People’s Hall, in the same corridor as eight other patient or disability organisations. I read their signs when I arrived. The Swedish Federation of Disabled Persons (DHR), the Aphasia organisation, the Asthma and Allergy organisation, the Arthritis organisation, DHR locally, DHR regionally, the Umbrella Organisation for Organisations for Disabled (HSV), and the organisation for Persons with Difficulties in Reading and Writing/Dyslexia. As I walked through the corridor, I noticed that all the doors were open. Here people working at the various organisations do not shut their doors it seems. A first impression is to wonder if they all co-operate with each other or if this only suggests a social need of meeting other people, of having colleagues at work. Later I learn that the sharing of premises at the start had benefits for the smaller organisations, as HSV used to have the responsibility for the premises and the wage subsidy\(^{41}\) to the employees (to persons who were employed by them and not the separate organisations.)\(^{42}\)

\(^{41}\)The wage subsidy is a governmental grant covering (a part of) the employer’s costs for employees with reduced working capacity.

\(^{42}\)Interview with N3.
Background

No one knows when the first diabetes organisation was established here, but the chairman of the board of the local branch has been a member for more than 20 years. His guess is that it is about 30–35 years ago. At first, there was only a local branch, which also was seen as the regional organisation. This organisation then became a local branch organisation in June 1997. Having had only a combined local and regional organisation was problematic and therefore local branches in two other small towns were also started. In 2000, these three local branches become members of the same regional organisation, which was established at a meeting in May 1997. The two new local branches were started on the initiative of the local North branch, which supported and helped them through their start-up phase. Among other things, they were helped with knowledge on how to financially run the branch by the treasurer.

Without any capital of its own, it seems hard for the local branches to calculate on a budget as the grants from the municipalities vary greatly from year to year, if they receive any grants at all. The size of the municipal grants depends upon the number of members the branches have. The local branch I visited had 571 members and the new neighbouring one had 58 members (in 2000). The new local branches received a starting grant from the SDA and from the municipality, usually a few thousand SEK. The regional organisation received a grant from the county council. These organisations depended on this money at the start. The treasurer tells me about the uncertainty of receiving grants.

The grants from the municipality can really differ from one year to another. The last time the local branch got between 26 and 28 000 SEK. We also received 8 000 SEK from the Humane Fund (Humansfonden). The organisation can apply for means from all the municipalities within the region. I did that, but of six municipalities, only one gave some money—3 000 SEK. The highest amount I applied for was 3 900 SEK and the lowest 2 000 SEK. And all the municipalities have inhabitants who are members of the organisation.

Financial resources are not only needed when starting up new branches but also help on how to do it. The plans of this branch therefore include supporting the establishment of new local branches in at least three other areas of the region as well as one in a neighbouring region. There are still locations that do not have any local branch. To the extent their inhabitants are members, then they are deemed members of the branch of this study. According to the chairman of the board:

It is important to establish more local organisations within the region in order to reach out with information in a better way. If I lived in other towns, I probably would not join this local organisation because of the distance.

Thus, the regional organisation and the local branch have been separate organisations for only a few years, which naturally still affect both organisations. They are intertwined in many ways: for example, they share the same premises and meet and collaborate to some extent. Further, some of the people were active in both organisations. At times, it was difficult keeping the two organisations apart.

The Board Members

The board consists of four ordinary members (elected for two years) and two alternates (elected for one year). I was able to interview three of them: the chairman, the treasurer and an ordinary board member. In addition, the chairwoman of the regional diabetes organisation was interviewed. She was also the former chairwoman of the local branch. Of all the board members in the regional organisation and in the local branch, there is only one person who is a family or support member: all the other members are diabetics. This person became an active member because of her son’s diabetes. She is the current chairwoman of the regional organisation and was elected as an alternate on the board of the SDA in 1997 (at national level). However, she claims that the general reason for why people join the board has to do with the pressure of others, i.e. most have been persuaded by someone to join the board.

43 Minutes from the annual meeting of the Northern organisation, April 1, 1998.
44 The start up grant for the organisation is a one-time grant. The local branch needs it during its first year of existence when it does not need to pay any member fees to the SDA.
45 Interview with N3.
46 Interview with N5.
47 Interview with N4.
48 Interview with N5.
Reasons for joining

Most of the board members have been members for a long time. The treasurer is also a member of different boards of one other local diabetes branch within the region, the regional organisation and other patient or disability organisations, such as the Asthma and Allergy organisation. She fills the function of being the treasurer of all these organisations.\(^{49}\) The reasons for joining the board differ. Here are some examples of how the board members themselves described their reasons for joining the board.

I have been a member of the board for a long time because I want to do everything for my son. I would not forgive myself if I did not try everything in my power to make sure that my son will get the best medical services in this County Council. This is where he lives and where he will need health care one day. Therefore, when that day comes, I want to know that he’ll get the best medical services here. That is why I want to influence this.\(^{50}\)

I became a diabetic sometime in 1979, but did not join the organisation until about ten years later and that was because I did not take care of my own health. I was running my own business. I had been working a lot and had not been eating healthy, nor had I exercised. Then my doctor told me that my test results were very poor and he made me go for a week to A.\(^{51}\) When the exact same thing happened again, and after the second time I had been to A for a week, I didn’t think that I could resist being a member any longer. Therefore, you can say that I really became a member because of my doctor. One year after I joined the organisation, I joined the board, where I am now in charge of the newsletter.\(^{52}\)

I am a member of the board because of my wish to teach other diabetics about the disease and the situation and to teach our society to be nicer and friendlier towards the diabetics.\(^{53}\)

The recruitment of people to the board is problematic.

Only a few members are active. This is a problem for the organisation, as we want to get active people to the board. The problem is that when you do find these active people, they don’t have time. Consequently, there are problems of getting people on the board. A common proposal from the members is for us to arrange member meetings and camps for children with diabetes.\(^{54}\)

Especially recruiting young people to the board is difficult, just as it is to recruit young members to the organisation.

It is desirable with younger people on the board; we oldies can’t know what the young ones want to do. But maybe the youth has too much to do to have time for the diabetes organisation.\(^{55}\)

Workload and Remuneration

The great geographical distances have implications for the board’s internal work. This branch does not have board meetings often, mainly because of the travelling distances for all the board members. Sometimes they have meetings over the phone, but that is quite expensive, so they try not to have that too often. A majority of the interviewees felt that much of the branch’s work has largely been dependent on one person, the current chairperson of the regional organisation. In her opinion, this is the case because she does not believe that the other board members, who are older, have understood how much work and time she has put into the branch.

The workload facing the board can be heavy, especially if there is no assistant secretary employed. Only the assistant secretary works with the organisation’s tasks, except for the board. If there is no assistant secretary, the board has to carry out the work, all of which is voluntary and without payment.

\(^{49}\) Interview with N3.  
\(^{50}\) Interview with the N5.  
\(^{51}\) A was a recreational centre where one could spend some time if applying for funded means from the local diabetes organisation.  
\(^{52}\) Interview with N1.  
\(^{53}\) Interview with N4.  
\(^{54}\) Interview with N1.  
\(^{55}\) Interview with N4.
There are working groups in various topics where the members can commit themselves and be active (e.g., a working group for national guidelines, a parent group and other activities). One group made the homepage on the web. You find the members with certain knowledge that can work with that issue unpaid. Perhaps some reimbursement for travelling expenses will be given, but that is all. But, the board members at the national (SDA) level get reimbursement for everything.56

Between 1998 and 2000 remuneration to the board members amounted to 700–900 SEK per year.57 Other compensation included a weekend subsistence allowance of 400 SEK, a weekday’s subsistence allowance of 300 SEK and travelling by one’s own car (15 SEK / Swedish mile).58 Many of the board members were dissatisfied with the financial compensation.

The board remuneration for the chairman is 900 SEK per year, which is nothing! It costs more than that to participate.59

I get 700 SEK per year in board remuneration, but I completely lose on the deal. It is all unpaid voluntary work. It costs more to be a board member for me than what I get. I think I put in one week of fulltime work each month for the three diabetes organisations!60

The lack of financial compensation is one of the contributing factors why the chairwoman of the regional organisation decided to quit. She will leave the organisation at the annual meeting.

I have given them so much of myself and so many years of my life and it is just not worth it anymore. You don’t get credit or compensated for one’s efforts. Now I want to do something else with my life. I cannot pull all of this by myself any longer. I just hope that the current projects and the co-operation continue after I leave the organisation. If you want to get trustworthy within the health services, you have to keep up the work. I refuse to watch how my son becomes blind or gets his leg amputated only because he belongs to the wrong county council, which does not go in for preventive care. That is why I felt that I had to influence the politicians and the health care personnel here. The organisation has become respected and is now looked upon as being trustworthy. I’d like to see somebody take over after me who also can be the driving force, but it doesn’t look good.61

Others fear for her resignation as well.

I am very worried that X will quit completely with all this. She is practically invaluable to us. We need live wires like her!62

From the diabetes team at the hospital, concern is also expressed regarding her resignation.

I’ve understood that they’ve problems within the organisation to find a replacement for X. I’ve also understood that things are not so good considering the internal conflicts they’ve had. But at the same time, now that X will quit I’m worried the collaboration between us that has worked so well will deteriorate. I’ve understood that it’s X who’s the driving force, pushing things forward. I hope it doesn’t stagnate now. It’s really a pity that she’s resigning.63

Conflicts

The composition of the board has caused numerous conflicts. Opinions on how the work is run and by whom vary. Some are satisfied while others are dissatisfied and question and counteract other members of the board. For example:

It is hard having a person on the board who’s an alcoholic who’s drunk and sober in periods. You never know if X is going to show up or not.64

56 Interview with N5.
57 Minutes from the annual general meeting of the Northern organisation, April 1, 1998.
58 A Swedish mile = 10 kilometres.
59 Interview with N5.
60 Interview with N3.
61 Interview with N5.
62 Interview with N5.
63 Interview with N1.
64 Interview with several people: N2, N3 & N5. Quote given by N3.
One explanation to account for all the conflicts is offered by a board member.

You must remember that within the disability movement generally there are many people who didn’t get any retirement post in the trade and industry or in the business world; nor did these people get any positions of trust or board posts. And that’s the reason for why these posts become more prestigious and hold higher status. Some people fight tooth and nail to stick to the positions within the organisations although they [the people] aren’t suited.\(^65\)

Regardless of whether this is the case in this branch, it is clear that there are conflicts. As the chairwoman of the regional organisation expresses her feelings:

Certain people on the board do not like my way of working. I didn’t want to become the chairwoman in the first place. I am a visionary and I’d like to participate in a working group, not the board! But since nobody else wanted to take on the job I felt I had to.\(^66\)

Jantelagen\(^67\) is so deeply rooted in this region, which is the reason why I have not gone out and told everyone about everything I have done; instead, I have kept quiet about it. For example, I never tell people if I go abroad. I think I have paid a high price. I have neglected my family and my own life and that is why I’ll resign in connection with the annual meeting in March.\(^68\)

Other matters concern how the finances have been handled. Money coming into the organisation nowadays is placed in a postal giro account instead of an ordinary bank account. The treasurer is critical towards the treatment of the finances.

I am against how the organisation’s economy has been handled. For example, that the money is placed in bond funds and equity funds. You cannot speculate like that with the organisation’s money. They have let X do as he wants with the organisation’s economy. It is really the assembly at the annual meeting that must decide on how the capital shall be used, but it is rather so-so with that.\(^69\)

Office staff

Many of the local patient or disability branches cannot afford to employ personnel. The only way for the branch to hire an assistant secretary is to use AF Rehab\(^70\) or some other form in which the state pays for the employment. The chairwoman of the regional organisation phoned up the employment office and asked them to check what people in the area that were soon no longer entitled to unemployment insurance,\(^71\) as they are the ones who can be entitled to a wage subsidy from the AF Rehab. This branch cannot afford to hire anyone else. The only requirements the board has are that the person can work independently (as there is a lot of time spent alone in the office) and that he or she can perform office work. They would also prefer that individual has diabetes, although this is not a requirement.

With the only possibility of hiring people who are soon to be uninsured from the employment office, there is naturally is a high level of staff turnover, especially as the unemployment benefit is only valid for

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\(^65\) Interview with N5.
\(^66\) Interview with N5.
\(^67\) ‘Jantelagen‘ (‘the I’m-not law’) is a Swedish expression which describes a phenomena rooted in the Swedish society. Briefly, it refers to the social pressure in a society that nobody should distinguish oneself and means that nobody should think of him- or herself as in any way better than anybody else. The term originates in the ten “commandments” distinguished by the mentality of little towns and jealousy that came from Aksel Sandemose in 1933. “In [Australian]: the tall poppies syndrome.
\(^68\) Interview with N5.
\(^69\) Interview with N3.
\(^70\) The former AMI when the employment office after negotiation with the employer gives the employer a wage subsidy for the employee.
\(^71\) Sweden differs from many other countries in that unemployment insurance does not form part of the national social insurance system. The Swedish unemployment insurance consists of two components: a basic insurance which is the same for everyone (a maximum of 240 SEK per day in 2000) and an optional, supplementary loss-of-income insurance (the maximum is 580 SEK per day in 2000). Anyone who wants to be insured for the higher amount must personally apply for membership at an Unemployment Benefit Society. To be qualified for benefit in the event of unemployment, a person is obliged to meet two conditions: The employment condition means that you must have worked for at least six months during the 12-month period immediately preceding your unemployment. Working hours must have been at least 70 hours per month, or you must have been employed for at least 450 hours during a continuous period of 6 calendar months. Work must have been performed for a minimum of 45 hours in each one of these months. The membership condition means that you must have been a member of an Unemployment Benefit Society for at least one year.
a limited period. However, it is not unusual that the assistant secretary, after the employment period, is recruited to join the board. The board is well aware of the problems that are caused when there are no employees to deal with everyday tasks.

This branch had one person employed in the first half of 2000, who I also was able to interview several times. She was hired as an assistant secretary at the time when I visited the organisation. She chose to work there because she would otherwise soon not be entitled to unemployment benefits. She had been a passive member of the organisation for a long time. Later, I learned that she joined the board, but no new assistant secretary was employed. Today, this branch has no employees.

**Finances**

In 1999, the local branch showed an unusually good financial result, with a revenue of 137 414 SEK and expenses of 136 285 SEK, giving a positive result of 1 129 SEK. This result, however, had to do with the start up grant on 5 000 SEK. (The local branch was earlier namely viewed as the regional organisation, which meant that the local organisation had to start as a new organisation, although it had been around for a long time.) A board member commented on the good result:

> It is foremost during the past 2-3 years that our branch has become so strong. This is partly due to its good financial situation, which is due to a good placement of funded means although different opinions exist. Therefore, we have been able to invest more than other organisations on information and informational meetings, newsletters and now ‘the way to-project’ through which we have been out to all the parts of the region. We’ve many new members. The members support both the organisation and research on diabetes by paying their membership fee.

The organisation has various sources of income:

- The local branch receives grants from the municipality.
- The regional organisation receives grants from the county council.
- The local branch receives means from funds: for instance, the Swedish State Inheritance Fund has contributed to the financing of ‘the way to-project’.
- Sometimes money is bequeathed to the branch and it happens that people give money to the Memorial fund, which goes to the local branch.
- The branch arranges lotteries (e.g., 5 SEK for each sold lottery ticket).
- Sometimes the branch arranges auctions, such as ‘wrapped gifts auctions’, at Christmas time.
- The member fees, of which a major part goes to the SDA. Some of the fees go to the regional organisation and the rest goes to the local branch.

There is also a possibility for the branch to apply for financial support from the municipality when applying for special activities. (The regional organisation can also apply for grants from the county council for special activities such as camps.) Some pharmaceutical companies sponsor the local branch. For example, Novo Nordisk and Abbott sponsor the branch by paying for food and lodging at some meetings, as well as giving blood glucose self-monitoring aids and devices for automatic finger pricking to the branch (these are then used as prizes in lotteries or sold to individual members). Novo Nordisk has also sponsored ‘the way to-project’.

The branch has its capital placed in two funds. At the beginning in the mid-1990s, 493 000 SEK were placed in three funds, mainly in bond funds but also in a mixed fund with stocks as well. At the time of

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72 The annual report for the diabetes organisation in 1999 and interview with N3.
73 Interview with N4.
74 The annual member fee in the North is 225 SEK and for support members 150 SEK. Of this amount, the local branches get to keep 59 SEK while the rest goes to the SDA. Of the remaining 59 SEK, 20 SEK go to the regional organisation. Left for the branch is 39 SEK per member and year. Interview with N3.
75 Reagent strips for blood glucose measurement contain glucose oxidase immobilised together with peroxidase and a chromogen whose colour changes on exposure to the hydrogen peroxide generated by glucose oxidation. This means that reagent strips can be compared visually against a standard colour chart, or could be read using a reflectance meter. Such meters are useful for patients with colour vision defects that are due to retinopathy or other causes. Blood for glucose monitoring is obtained by pricking the sides of the fingertips. The blood drop must be applied correctly to the strip and the reaction timed precisely in order to achieve accurate results.
my visit in 2000, the organisation had one mix fund and one bond fund, which together were worth about 800 000 SEK.

There are funds that generate income to the local branch:
• The Memorial fund is the fund to which one can give money when a person dies. The branch is free to dispose the assets as they like.
• Mats’ 40-year fund (There is a wealthy man named Mats with a son who has diabetes. In connection with his party celebrating his 40th birthday, Mats gave the same amount of money to the local diabetes branch as he spent on the party, which was 140 000 SEK.) The money is exclusively set aside for specific purposes and only the interest can be used for certain activities, half of which should be used for children and youth activities and the other half should be reinvested in the fund. Applications for money, which are often granted, are mainly for hospital wards and children camps.

Funds are essential as they provide resources that have importance for both the further existence of the organisations and for enabling the organisations to produce or contribute to the production of activities. From this aspect, the branch’s resources may also appeal to future members (cf. Ahrne, 1994).

The branch does not reimburse the politicians or health care personnel when they come to speak at meetings, and so on. Concerning activities that staff from the county council participate in, the county council takes that cost for their staff. The diabetes organisation has an agreement with them covering that issue. However, the branch does reimburse for travelling expenses and they give out gifts. The branch usually receives these gifts (e.g., the treasurer mentioned she sometimes gives away paintings that she has painted).

It does happen that the branch pays for a part of special training or a course for personnel within the health services. The prerequisite for this to occur is that the person applying for the grant is a support member of the branch organisation. Individual members can apply directly to the branch for grants. These applications usually concern contributions to stay at recreation centres, aids or other medical costs. Other activities financed by the local branch are the working groups’ activities (those that are not free of charge or funded by the members themselves), other member activities and fees to the organisations the local branch is a member of.

The most recent numbers from 2005 show a financial income of 193 619 SEK and costs of 186 475 SEK, giving a positive result of 7 144 SEK.76

Membership and members

There are two formal types of membership: people with diabetes and support members, such as parents or relatives to someone with diabetes. Further, health care personnel working with diabetes patients often join the branch as support members. The fully paying members receive the diabetes journal from the SDA; the support members, who pay a lower fee, do not receive the journal. Because many of the members are on sick leave, the member fee is expensive for them. The annual member fee of 225 SEK is sometimes criticised by members directly to the office staff. Nonetheless, it is unusual for members to leave the organisation:

You can see a trend – the number of members in the organisation does not increase as a whole because when the members die, the number of members decrease. Members do not leave the organisation, they die.77

Most members are passive and do not engage in the organisation’s activities. Individual members are welcome to participate in meetings and to phone or write to the branch. Nevertheless, initiatives from the members are not that common. An example of an initiative taken by members was for the local branch to contact the police and inform them about how people with diabetes behave after having experienced a

76 The local branch in the north terminated its’ lease a few years ago. The administration of the branch is now done by the chairperson and the treasurer who use their private computers and faxes and let the branch use their private homes free of charge, so there is no rent and no costs for employees, as there are none. Annual report, 2006.

77 Interview with N5.
Another example was to influence schools about their timetables. For instance, physical exercise was not put directly before lunch, as a person with diabetes needs grape sugar or food then.

The board members believe the reasons for membership among their members are to meet like-minded people, to get information about the disease and to feel affinity with others in the same situation. The young generation is not as inclined to join organisations as the older generation.

Young people don’t join the organisation. The parents sign them on as members, which shows on the statistics for the 20-30-year-olds. But then again, it is hard to make them feel a close connection with pensioners.9

The branch tries to recruit new members mainly using personal contacts and by advertising and putting up posters. It is generally difficult to get new members.

In this region only 12 per cent of all the people with diabetes are members. What can we do to make them come to the meetings? This is a neverending issue, which is constantly discussed. But people don’t care anymore. It all started during the times of austerity. People feel they don’t have anything to say any longer, and that they can no longer influence anything. Although people’s commitment sucks, it’s still pretty good here compared with the rest of the country.80

Today’s threat is that the organisation does not get any new members. People are so passive these days. But because of ‘the way to-project’, the diabetes branch has increased the number of members with 10 per cent in six months: never before has the branch done so well in the organisation’s history. No longer do members go to meetings at night. Where are all the people with chronic diseases? Well, of course in the health services at daytime! That is where you can reach people in their own environment. Therefore, the organisation must adjust and work after these prerequisites.81

A problem exists in that the organisation is not allowed to get information about those recently diagnosed with diabetes, but the Secrets Act does not allow that. Therefore, we have to go through the health services. I mean we have to get the health centres to inform their patients about the study circles, which in turn means that the organisation must inform the personnel at the health centres.82

'The way to-project’ has become our recruitment base. Before this project, the number of members was decreasing. But it is important that the patient organisations still exist because it is so easy to kick a man when he’s down!83 [This refers to action that would further oppress the oppressed.]

Issues on the organisation’s agenda

Local issues in focus in February 2000:

- To inform the police that diabetics can behave as if in a drunken state if insulin deficient.
- In 2000, the branch took up the torch for home services: training and education in preventive care for its personnel.
- The driving license. It is common that people with diabetes get their driving licences withdrawn. Nonetheless, several cases have been won in court and the branch works for allowing people with diabetes to keep their driving licences.

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78 This has happened to a member and there have been cases when the police have taken a diabetic with a ‘hypo’ for a drunk and locked him up in prison over night.
79 Interview with N5.
80 Interview with N4.
81 Interview with N5.
82 Interview with N2.
83 Interview with N5.
The care allowance.\textsuperscript{84} Parents can get a full care allowance for children up to seven years old with diabetes and a half care allowance for children up to sixteen years of age. The care allowance is applied for individually. At the local level, the branch is supporting the SDA’s work for care allowance to families with children with diabetes, mainly through informing and supporting parents to apply for such an allowance.\textsuperscript{85}

Usual issues that are discussed at board meetings are the branch’s financial situation, the member activities and how to increase members’ commitment and activity. Another important issue concerns the threat that insulin will no longer be free of charge. The chairwoman of the regional organisation thinks that soon insulin will no longer be free of charge and thus plans to fight this possibility. The diabetes nurse has her doubts. She knows discussions are being held, but no decision has yet been made, so she sees no need for the branch to act yet. The SDA will strongly be lobbying for keeping it free of charge.

The branch also helps individual members with doctor’s appointments and other medical inquiries. Because the branch knows that the membership may only be a matter of money, it even helps non-members. Board members or staff at the branch can give advice on what the person should ask about, help them to write down their questions or even go with them to the doctor. Members are generally appreciative and grateful for this service.

Activities

Each Monday there is a column in the local newspaper and one in the regional newspaper describing all the current activities. The organisation makes sure its activities are reported in the newspapers. Starting in 1996, the local organisation published its own newsletter, but the newsletter was terminated when the wife of the man in charge became sick and he no longer could manage to run it. Nowadays, the organisation sends out a copied newsletter.

Although people with both types of diabetes are seen as the target groups for membership, the activities arranged by the branch are more targeted towards those with type 2.

There are activities that are especially targeted towards either type 1 or type 2. Being more common, type 2 is a much larger group. On the other hand, the type diabetics receive substantially more help and information from the health services. Look at, for example, X. It’s a small village where all they have is the relay doctors\textsuperscript{86}, who go there and work for two weeks. It has higher status to be a doctor in Åre. It is a general problem in the region to find doctors; there are too few and the few that do exist get burnt out and quit, which means even fewer doctors. How interested do you think these relay doctors are in their patients? Therefore, maybe it’s more important for people with diabetes in such communities to be members of a diabetes organisation than it is for others.\textsuperscript{87}

The organisation focuses more on the type 2 diabetics, as they’re a neglected group in the whole country. The problem is that the personnel in the health care centres don’t have sufficient knowledge about diabetes. Therefore, it’s much easier for the type 1 diabetics to be diagnosed: they’re then regularly called to the hospital where they get better care. Look at, for example, X’s son who’s called to the hospital for a check-up every third month. Roughly, 80 per cent of our members are type 2 diabetics.\textsuperscript{88}

84 Sick or disabled children often have greater needs of special efforts than other children. Parents can get care allowance in order to be able to take care of their sick or disabled child in the home. To be entitled to care allowance, the child is required to need special care and to be especially looked after for at least six months, or for the parent to have additional costs, i.e. extra costs that are caused by the child’s disability. The care allowance can be given from the child’s date of birth until the age of sixteen (after that, the child can apply for disability support). A full care allowance amounted to 7625 SEK per month in 2000.

85 The SDA is working for getting a full care allowance up to the child’s first year at school. Thereafter, a half care allowance up to the age of 16 years (with the possibility of individual trial) is possible. Children who acquire diabetes after their first year at school should receive a full care allowance during the debut year and thereafter a half care allowance up to the age of 16 years (with the possibility of individual trial). They argue that children with diabetes need more supervision than healthy children, regardless of age. Even if the child is able to take his or her injection and test the blood sugar level, certain supervision is needed (e.g., controlling that the insulin dosage is the right one after the blood sugar value has been analysed). The way the child relates to his or her diabetes varies with the stage of development. Further, older children need more supervision at certain periods, such as when school starts and in puberty. More supervision is needed because of the risk for ‘hypos’.

86 ‘Stafettläkare’ is an expression in Sweden for doctors who only go to these places for a very short time before the next one comes to replace the previous one. Usually, this takes place at less attractive places where it is hard to find doctors who want to be placed there. Thus, there are constantly new doctors, if any at all, who stay for very short periods.

87 Interview with N5.

88 Interview with N4.
Our educational activities are mainly for type 2 members because type 1 members get more or less the same knowledge and information at the hospital. They’re much better equipped with knowledge themselves.  

Many activities are not only for members: the chairwoman also allows others to participate in these activities.

I’m 100 per cent sure that they’ll become members sooner or later and I don’t want to hunt them down in order to recruit members. Why should one hunt people down?  

Membership activities are mainly constituted by educational, physically active or social purposes. In their activities, the organisation focuses on the three factors affecting the lives of people with diabetes: physical activity, diet and insulin. Focus can sometimes also be on other conditions affecting people with diabetes. This is because the organisation’s approach is that diabetes is not just one disease, but many.

The educational activities arranged by the branch take the form of educational days to which physicians and other health care personnel are invited to speak. Research trips to Umeå are also arranged (the members must pay, however). The branch has good contact with the diabetes research group there and is welcome to arrange study visits. The branch sometimes invites the researchers to speak at member meetings where they can discuss their current research. All the educational activities aim at strengthening people’s meetings with the health services. At times, the branch collaborates with other patient organisations and arranges informational meetings and debates. For example, together with the National Association of Visually Handicapped (SRF) and DHR, the branch has invited politicians from the municipality to debate the grants given to the patient and disability organisations.

Activities regarding physical activity do not mean sports per se. The approach is more modest, for example ‘gå-ing’, which is a shared physical activity in which the participants first get their blood sugar level measured. Then they set off walking a pre-determined distance at their own pace. At the destination, two hours later, their blood sugar level is measured again to compare the difference between the two levels. The regional chairwoman has made this event into a more competitive activity by challenging all the other organisations in the country through SDA’s journal. So far, this region has always had most participants. Excursions such as mushroom gathering and forest walks are also arranged.

Trips are sometimes organised by the branch. A bus trip to Lübeck in Germany with planned stops for regular meals was one of the latest examples. Excursions are arranged in collaboration with other patient organisations such as the Asthma and Allergy organisation. Usually, the members must pay for these types of activities, but sometimes they are subsidised by the organisation.

Many of the members give us some extra money because they think the activity is cheap and they can pay some more. They are grateful to go.

As for parents or children activities, most of these are organised by the parents’ group. This group is formed within the branch by parents. Camps for children are usually planned and arranged at the regional level where the regional organisation and the parents’ group collaborate.

There is a high divorce frequency in families with chronically ill children (e.g., children with diabetes). Therefore, it is important with family and parent meetings with information which can function as an opening for the parents to show their anger.

The regional chairwoman does not believe in traditional member meetings; instead, she means that the local branch must be where people gather.

To think, they only have the courage to go out mushroom gathering! I think too many people with diabetes become passive and afraid of having an active life, but they should have: that’s what gives life a meaning.
When planning activities, the branch faces problems, the major one always being the long distances their members must travel. Most of these activities require having a car and being able to drive.

The problem is that the region is so large. Thus, there are such high costs for everything because of the long distances.95

The way to – project (The way to… a conscious health care consumer)*

In 1998, a pilot project called ‘the way to… a conscious health care consumer’ (Vägen till… medveten vårdkonsument) started in this region. It was led by the chairwoman of the regional organisation and was aimed at increasing the collaboration with the health services. In the rest of the country the local diabetes branches chose to promote only the view of their members as individual health care customers. The chairwoman, however, thought otherwise.

I felt that was meaningless. You can’t only raise one of the scales of a balance; rather this must be done in collaboration with the health services.

The SDA disagreed with her, but when she suggested that she should carry out this project as a pilot project in the region, they accepted the idea. The SDA in Stockholm trained and educated 17 people from this region to become study circle leaders. Other regions only had diabetics (patients) there with them, but the chairwoman of the regional organisation had brought nurses with her as well because she believes in co-operation with the health services. Before starting this pilot project, an inventory of the health centres in the region was made, which the county council authorised her to conduct. The next step was to plan and organise the study circles in the region. This was to be done not only for people with diabetes but also for people with other physical impairments.

The project builds on several study circles, all within the theme of empowering people in their contacts with the medical services and others who they depend on (e.g., the staff at the municipality). The goal of the project is to strengthen the patient’s position.

The regional chairwoman started out by having meetings with the diabetes physicians and nurses within the region regarding ‘the way to-project’. The ABF97 was subsequently contacted and the steps of the project were being planned. The local branch then further trained the study circle leaders and thereafter the ABF took over running the study circles.98

The study material consists of a basic brochure, which helps to explain the fact sheets, but also provides support for both the individual and the group to find the courage to act in the meetings with the health services. There are fact sheets that bring up the concept of quality and consumerism to show people’s action and what affects them when consuming goods and services. The material compares consumers of general goods and services with consumers of medical services. There is no medical information in the study material and the study circles are not meant to deal with disease issues. The material of the study circles covers a number of topics, all teaching the participants about their rights. The study circles also try to strengthen the participants. The five themes are quality- and consumer-concepts, quality of the medical services, rights and duties for patients and health care personnel, the organisation and financing of medical services and the interplay between the individual and the organisation (see Appendix 9 for an example of a typical circle meeting within ‘the way to-project’).

95 Interview with N4.
96 The study circle project has been developed within the national project ‘The Way to…’, which was a three-year collaboration project within the disability organisation. The project started on the initiative of the SDA, the Swedish Rheumatism Association, the Swedish Association of people with stomach and bowel diseases and ABF. The project was terminated in December 2000. The study circles have used the project’s study material ‘The Way to a consciousness’. The project’s evaluation of the study circles indicated very positive results, showing that the majority of the circle leaders/participants had increased their knowledge on health care issues and became more active in their meetings with the medical services. The study circles often led to the circle leaders/participants contacting the medical services in their town with the purpose of starting collaboration to develop the quality of health care (material from the SDA).
97 The Swedish Workers’ Educational Association.
98 The study material is produced by an educational company in collaboration with ABF, the SDA and two other patient associations.
The first year resulted in increased interest from the participants and an increasing number of people joining the diabetes branches within the region. The project has also meant changes for the board members of the branch in their contact with members.

The collaboration with the members used to be limited to traditional member meetings where I didn’t think that I had any direct contact with the members. I felt more like a lecturer. But I feel there is a whole other commitment from the members with ‘the way to-project’. Now, I really have contact with the members; they’re more active, they phone me and ask me about advice and ideas. Many of them were, for example, upset that a local dealer didn’t sell sugar-free food at the local grocery. I advised them to invite the dealer to a meeting, which they did and it turned out very well. It is great to gather in smaller groups because you get more personal contact that way and people acquire the courage to phone you about minor things. ‘The way to-project’ only started about a year ago and it had a direct effect. Just look at the number of members, which has increased with 10 per cent.

Nine study circles are currently active in two regions here. The one in the other region is doing best right now, as the people there want to start their own local branch organisation. They haven’t had a branch of their own earlier. Instead, they’ve been members of our branch. But of course the members from that region have felt that it’s a bit too long to travel 20 miles to come here. The only problem is that several of the study circle leaders have become sick now.

‘The way to-project’ has since been copied by other branch organisations throughout Sweden. A common feature in the material is the focus on the term patient versus the term health care consumer. The SDA and the diabetes branches are trying to influence their members to think of themselves as consumers rather than as patients.

The patient patiently suffers and endures, whereas the health care consumer takes an active part in his or her treatment and care.

The word patient has a negative, unpleasant ring to it. The term health care consumer has higher status. But the difference is really zero.

The diabetics call themselves patients within the health care system in situations concerning the health services and at the hospital. But in situations concerning, for instance, rights, they call themselves health care consumers.

For further elaboration of the consumerism aspect and the differences between the two terms patient and consumer, see Werkö (2000).

Co-operation and networks

The local diabetes branch is a member of various organisations and collaborations: the HSV in the municipality, the ABF, the SDA, the community council for the disabled (KHR), the regional diabetes organisation and, from time to time, is a member of an employer’s association.

The organisation’s networks of contacts are, among others, the disability coordinator at the county council, the patient ombudsman, politicians at the municipality (the regional organisation has contacts with the politicians at the county council) and health care personnel, both at health centres and at the hospital. The network contacts are sometimes invited to come to meetings with the branch organisation, and members of the board go to them to introduce themselves and the branch. Most of the contacts are related to a person in the board, with personal contacts rather than the organisation’s contacts.

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99 Interview with N5.
100 20 Swedish miles, i.e. 200 kilometres.
101 Interview with N2.
102 Interview with N5.
103 Interview with N1.
104 Interview with N2.
105 The Community Council for the Disabled (KHR) is an advisory organ and a forum for consultation between municipal committees and disability organisations. In the council there are representatives from different disability organisations, politicians and employees. KHR functions as a pressure group regarding disability issues within the municipality. The Council does not handle matters concerning individual persons.
There are no problems for me to get in touch with them informally to discuss and work on ideas, to have a dialogue and get an informal green light. After that, you can, for example, start writing an application to them once you have the go-ahead.\textsuperscript{106}

Foremost it seems the board members think their personal contacts are most important. When I asked about any bureaucratic obstacles, the answer I got was representative of all of them.

No, I don’t think it’s an unwieldy system. I’ve established such good relations with politicians and the county councils. Many probably experience the bureaucracy as well, but it depends on how you treat the bureaucrats. But it has taken time to establish good, personal contacts. Then there’s also the change in the times; nowadays, it’s more modern and popular to listen to the patients as users. They also see the service in listening to us because we pass on the information and have very good contact with our members. Having ‘the patient in focus’, has been the motto for several years. But personal contacts are more important.\textsuperscript{107}

The chairman of the local branch also has private contacts with people at the municipality and municipal politicians who are friends. Thus, these close contacts allow him to raise issues at informal gatherings. Because of this relationship, the organisation has a good chance of receiving extra grants from both the municipality and the county council. (Because this region is very large, the costs are higher than for other local or regional organisations.) Otherwise, most formal contacts with the municipality take place when the branch educates politicians in diabetes or when they apply for money for various purposes.

Many of the board members are members of other organisations or associations, which are of help to them in their work for the diabetes organisation. The treasurer is, for example, one of the representatives in KHR in another town. She feels that the organisation’s collaboration with the municipality has worked out well since she started there. She is also a member of a political party. At one time, the diabetes organisation was one of the arrangers of a panel debate to which local politicians were invited.

I got really pissed off when it seemed no politicians were going to come to the panel debate they were invited to. Then I phoned the representative of my own party, the Centre, and told him he’d better show up. That usually works. Finally, someone from each political party showed up.\textsuperscript{108}

The chairwoman of the regional organisation is the organisation’s representative in the diabetes team at the hospital. The chairman of the local branch is a representative in the HSV, which ensures that he has many municipal contacts useful to the branch. He is also participating in the DYR – delegation (Direkt Yrkesinriktad Rehabilitering, ‘Direct Professional Rehabilitation’).\textsuperscript{109} At their meetings, he usually lobbies for the diabetes organisation. Still, he knows it is up to each organisation to make sure that they not only get a representative but that they can also nominate a representative.

Many voluntary organisations are bad at nominating representatives, so it is their own fault. You must keep ahead, be active and find people to nominate as representatives in various places.\textsuperscript{110}

Board members have participated in UR programs on TV\textsuperscript{111} and radio programs in which they talk about diabetes. The chairman of the local branch has participated in regional radio programs several times, sometimes in debates with the county council as the other party.

When the hospital arranges diabetes courses, the diabetes organisation is invited to market itself and to inform others about its work. The chairwoman of the regional organisation is often speaking at colleges of health sciences and at the nurse’s or paramedical training at the municipal adult education with future health care personnel.

\textsuperscript{106} Interview with N5.
\textsuperscript{107} Interview with N5.
\textsuperscript{108} Interview with N3.
\textsuperscript{109} Professional rehabilitation is for people with reduced working capacity. The aim is that the individual shall be able to stay in or enter the working life. People with diabetes can get professional rehabilitation when the capacity for work and the financial support are essentially reduced. This is always individually investigated. The physician’s opinion is important. Professional rehabilitation can be initial education for the first profession, vocational training or university studies, but also complimentary education, further education and retraining. When a person with diabetes has a good adjusted insulin level, i.e. has good blood glucose values, the disease is not assessed as reducing the working capacity. Then no rehabilitation is necessary.
\textsuperscript{110} Interview with N4.
\textsuperscript{111} As part of public service operations, UR (utbildningsradion) provides a wide range of educational programmes on TV and radio. The purpose is to help to bridge the gaps in educational levels within society.
I think the result is quite good. Even non-members approach me in the street to talk to me. All of us on the board are known among the diabetics and we are often approached on the streets and asked about all kinds of medical and health care issues.\footnote{Interview with N4.}

Sometimes the branch co-operates with other patient organisations (such as applying for funding for common purposes). At the time of my stay, they had just applied for funding from the EU together with the ABF and the SRF for a shared computer room for blind people and people with visual impairments.\footnote{These kinds of computers cost about 100 000 SEK each, so not many members can afford to buy one themselves.} They also co-operate with the Asthma and Allergy organisation, arranging common bus trips or other activities with the purpose of increasing the understanding for each other’s disabilities. Yet, the reactions from the other organisations are not always positive. A few years ago, the branch tried to co-operate with the local organisation for the visually handicapped since the branch does not have knowledge on visual defects/blindness (which is a complication of diabetes) and they wanted to give their members that knowledge. The whole co-operation was discontinued, however.

The visually handicapped organisation didn’t want to co-operate with us. They thought that we would take their members over to our organisation! I couldn’t believe it!\footnote{Interview with N5.}

Obviously, there is some kind of competition among the patient organisations.

I can’t look at it that way. I don’t think there’s any competition when it concerns disabled people. But other patient organisations see competition and threats: for example, the visually handicapped organisation, but not me. Those who potentially could be competitors are the visually handicapped organisation and the organisation for kidney patients, I suppose. Also DHR versus HSV. DHR receives more grants than HSV, but HSV has more activities than DHR, which means that the grants probably will increase, respectively, decrease for these organisations. Other competition is naturally everything that takes time, TV programs, hobbies, etc.\footnote{Interview with N5.}

\begin{flushright}
An example of a project with the health services
\end{flushright}

One afternoon I attend a meeting together with the chairwoman of the regional organisation at the hospital. It is a meeting with the diabetes team, which included one senior physician from the medicine department at the hospital, one district medical officer, one diabetes nurse from the hospital, one nurse from a health centre and the representative from the diabetes organisation in the region. The topic is the national diabetes registration (see Appendix 11), a group that directs the registration in the region and that meets twice a year.

The registration of diabetics in Sweden started in 1995. Because care was (and still is) unequal, the purpose of registering diabetics was to get an overall picture of diabetes care within the country. Therefore, each person with diabetes should be registered. It started on an initiative from the National Board of Health and Welfare, the Swedish Association of General Practice (SFAM) and the Swedish Society for Diabetology.\footnote{This organisation is only open for diabetes physicians and is led by a diabetes doctor in the region.} It is estimated that there are about 330 000 people with diabetes in Sweden, of which approximately 33 000 were registered at the time of this meeting (January 2000). This group has reason to be satisfied as they are successful with the registration here compared with the rest of the country.

Mainly the practical work lies with the medicine clinics that register and primary care. The medicine clinics register 50 per cent of the patients, whereas primary care only registers 5 per cent of the patients and there are a 28 health care centres within the region. Therefore, one of the issues discussed at this meeting was how to improve the registration? How should one market the registration to doctors and other personnel within the primary care? An internal computer system within the health services that caused practical problems regarding the registration was also discussed. Mostly, however, there was a great deal of discussion concerning some persons. The chairwoman’s resignation in March was also discussed. There was general scepticism from the health care personnel towards the new representative from the regional organisation because nobody knew who that was going to be.
Within the National Guidelines for Diabetes care, the national registration makes up a very small part (the National Board of Health and Welfare, 1999). A problem that was discussed was that not all patients are called to annual controls at all health centres. The chairwoman was asked to push “her” members to demand to be called: alternatively, that the diabetes branch calls its members.

**Contributing to Empowerment**

As we have seen so far, this branch can contribute to the empowerment of its members in several ways. In addition to ‘the way to-project’, which explicitly aims for empowerment, all of the branch’s educational activities offer keys to empowerment. They do that by giving the participants knowledge and insights about diabetes or other issues of relevance when living with diabetes. The physical activities can also contribute to empowerment since in a way they are educational. The participants learn how their bodies react to physical activity and in what way physical activity is good for them. It should be mentioned that social activities could be of importance here (e.g., participants improving their self-esteem through socialising); however, this is not included in the definition of empowerment in this study. Here such effects are mainly attributed to educational efforts.

Society’s changed views on diabetics indirectly affect the empowerment of people with diabetes. These changed views are mainly the result of the local branch’s work at the local level as well as the work of the SDA.

The work carried out by the board members in co-operation and co-production (see Ostrom, 2002) with other organisations, authorities or the health services also have impacted on the empowerment of people with diabetes. This is made possible not only by the actual work and what is achieved but also by raising the level of knowledge and perhaps changing the attitude among members as well as health personnel, politicians or other partners.

**Case study 2: The local diabetes branch in the City**

It is one of the first days in April and I have just arrived to this city. In contrast to Stockholm, there is a big difference in the climate. Here you can tell that spring is in the air and the sun is shining brightly from a clear blue sky. I am walking down a city street and the difference from the North is obvious. This is a big city with a great deal of traffic and many people everywhere. Big streets are crossing small streets, one part of the city is turning into another and it seems the city continues in all directions. I am following the directions I have for the diabetes organisation. Their premises are situated right on the border to the old part of the city. As I approach it, I realise that they are accommodated in what must have been a shop before because other shops cover this street and their premises look more or less the same. They also have big windows facing the street, but these are partly concealed with curtains. You walk straight in from the street, and if it hadn’t been for the signs saying “Diabetesförbünden”, you would not have known what this place was. During the week I am there, I check out the neighbourhood for other patient organisations but could be found in these quarters. It seems the location of the diabetes organisation is the only one in existence here. This is different from the North where people from several organisations were placed in the same corridor and met on a daily basis.

**Background**

People with diabetes, their families and friends established the local branch in 1943. The initial aim of the organisation was to improve the lives of people with diabetes. Its purpose is stated in the annual plan for 2000.

The organisation, which shall be connected to the Swedish Diabetic Association (SDA) and be a part of the regional organisation, has the purpose of looking out for the diabetics’ interests.

The organisation shall especially work
to disseminate knowledge on diabetes

to work for increased publicity on diabetes

to represent the diabetics at local authorities and institutions

to promote the diabetics’ social-medical interests

to co-operate with organisations with similar alignment and

to support scientific research regarding diabetes

The organisation shall have no political or religious affiliations.\(^{117}\)

As the city branch is three times as big as the North branch regarding numbers of members, perhaps it is only natural that this branch is organised in several sections and working groups, in addition to the board.

The Parent’s section works with special support for parents of children with diabetes. It also organises various activities for the children. The Youth section (for people aged between 15 and 25 years) arranges sport activities and study trips. The Women’s section meets socially, arranges thematic nights, works with a female health project and offers courses in Qi Gong.

The Girl’s section meets socially and exchanges knowledge and experiences. The Adult group arranges monthly meetings, thematic nights, courses and ‘open house’\(^{118}\) in collaboration with the study and health care consumer group. The Market group clarifies the organisation’s work to the members and presumptive members. The Newsletter group produces the branch’s newsletter. The Health Care Consumer group participates in projects and meetings with the medical services, informs patient groups organised by the medical services, informs about the organisation and one’s personal experiences with diabetes at health science colleges. works to influence diabetes education and training for home services personnel. Finally, the Study group arranges thematic nights, wine-tasting nights, study circles, meetings for new members, walks and ‘open house’.

One of the group leaders made the following comment on having the possibility to work actively for the organisation without being in the board.

I’m one of these organisation persons, so it was natural for me to join this organisation 20 years ago. But the bureaucracy, the boring stuff, does not suit dedicated driving forces very well. Now, it’s possible to do things and be committed without getting stuck in the board.\(^{119}\)

The women and girl groups are different. This difference has nothing to do with the age, but with conflicts. The leaders of these two groups cannot agree or be on good terms with each other.\(^{120}\) This is the same impression I get during my stay there. There seems to be many conflicts within the organisation. People generally do not get along.

The Board Members

For a long time, the board of this branch has dealt with the problems of people leaving the board and recruiting new board members. The annual meeting is coming up in only a week and there are going to be changes within the board. Of the present one, only three people will remain, so large parts of the board will be changed. This is mainly due to people getting sick. One board member, however, is resigning because of the long way she must travel to and from the organisation’s office.\(^{121}\)

\(^{117}\) Annual plan for the branch organisation for 2000.

\(^{118}\) To have an open house means to receive guests who, within certain time limits, decide themselves when they will come.

\(^{119}\) Here the Swedish word *eldsjäl* was used, which refers to a real enthusiast who is intensely dedicated to a cause. Interview with C1.

\(^{120}\) Interview with C6.

\(^{121}\) Interview with C3.
The old board consisted of six ordinary members and three alternates, but in the new board there will be seven ordinary members and four alternates to deal better with members who get sick. This branch has experienced that being sick is a common reason for leaving the board. This branch has a history of many board members resigning and this is a problem.\(^{122}\)

**Workload and Remuneration**

Within the board, there is a work committee (arbetsutskottet, AU) which is made up of the treasurer, the chairman and the secretary. Their task is to prepare the issues to be discussed and decided upon at the board meetings, as well as recommending decisions to the board. The work of this committee is often problematic. The former chairwoman often had to fill all the positions herself (i.e. she served as the treasurer, the chairwoman and the secretary) which later proved to be one of the reasons for her resignation. When she worked actively in the organisation as the chairwoman, members constantly called her at her home, causing her to eventually obtain an unlisted number. She estimated that, on average, she spent about two hours per day working for the organisation.\(^{123}\) The workload seems quite heavy for the board members who are also in the AU, with both board meetings and AU meetings every third week.

The remuneration to board members in 2000 was 50 SEK per meeting attended plus travelling expenses.\(^{124}\) Many of the board members were dissatisfied with the financial compensation in relation to the workload.

Last year I got 1951 SEK BEFORE TAXES! That didn’t even cover my costs. I ran at a loss. But you don’t do it for the money. By Wednesday, I’ve usually done all my weekly working hours. But then Thursday and Friday remain.\(^{125}\)

The problems of recruiting board members were apparent at the time of my stay. With the approaching annual meeting and change of the board members, there were problems of filling the board positions up to the last minute.

**Conflicts**

On a Friday afternoon (the annual meeting being on Monday), there were huge problems for the selection committee, as three people were threatening to defect the board nomination in the last minute (the treasurer and two other board members). This caused conflicts and gossip about their reactions and nothing else was discussed at the office that day. There were many speculations about the resignations. One example was why X, who was supposed to be the new treasurer, decided to withdraw his nomination so late. Perhaps this had to do with Z being asked at a meeting the night before if she could consider being the treasurer, provided that she would take a suitable class in accounting? However, X was not informed about this, which probably hurt his feelings.

This position is important to him because the organisation is his life. He has almost been living there on the premises.\(^{126}\)

After the weekend, X was happy. During the weekend, he had been subjected for what he called “operation persuasion” and he decided to stay on.

You cannot have a completely new board with no support and one must see to the organisation’s best interests.\(^{127}\)

This organisation has had a fair share of internal conflicts. Minutes from the City board meetings in 1998 and 1999 include comments from several board members and even a letter from the treasurer\(^{128}\) accusing

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\(^{122}\) From several minutes of the board of the organisation, 1999.

\(^{123}\) Interview with C5.

\(^{124}\) In order to be paid, at least six ordinary board meetings must be attended.

\(^{125}\) Interview with C4.

\(^{126}\) Talk with C6 and C8.

\(^{127}\) Interview with C4.

\(^{128}\) For example, minutes from the board of the organisation, January 15, 1998.
other members of lying. Other internal controversies also occurred. In other minutes from the board\textsuperscript{129}, the external accountant brought up statements from board members, which were lies. A few of the board members back then are now about to be re-elected to the board.

The ex-chairwoman (now a rejoining board member) has worked actively in different diabetes organisations from the age of 17. She acquired diabetes in her teens and joined the organisation in order to get information and knowledge, not for any social reasons. She thinks this depends on how the health services work where one lives.

I think that doctors and nurses still want to make the decisions for the patient. But there is some safety with the medical services in that they tell the newly discovered diabetic how he or she should treat his or her disease.\textsuperscript{130}

She has stayed away from the board in this organisation for a year now because she thinks that it was disloyal and that there were many intrigues and conflicts inside the organisation.

Generally, it seems that the contact with the members is satisfactory, but there are a few instances of dissatisfaction. In 2000, the branch received several anonymous post cards from dissatisfied members. The cards were critically written, asking: “Who is the organisation really for? Why does the organisation only care about the strong and not the weak? Is it only there for XXX?” (counting names of people from the old board). These postcards are expressing the general dissatisfaction with the both the old and new board and the various intrigues within the organisation.

**An example of a board meeting**

The present board is having a board meeting that week, which I attend.\textsuperscript{131} The meeting focuses on the annual general meeting and all the preparations for it. The ordinary board members are elected for two years, whereas the substitutes only for one year.\textsuperscript{132} Five board members are present at the meeting, but two of them will resign at the annual meeting.

Throughout the board meeting, the tone is quite jocular, but feels somewhat strained. The major part of the meeting is devoted to discussing who should get flowers from the branch at the annual general meeting. The details around the meeting are discussed. Then applications for money are discussed; a few strange applications have been received. For example, there is an application from a woman seeking compensation for pain and suffering. Her husband has committed arbitrary conduct and the police report was enclosed. A spontaneous laughter fills the boardroom as this letter is passed around.

At this point, the board decides to take a coffee break. I am surprised that they have not eaten dinner (most of them had not had the time to eat anything before the meeting) considering they are diabetics. The meeting started at 6 pm and they stay to at least 9.30 pm. During this time, all they have is a sandwich and coffee.

After the break, more difficult and important questions are forwarded to the organisation. For example, the branch has received a letter from the University Hospital regarding diabetes care. The board also discusses the placement of the funds that have to be replaced this year. There is a problem with a lack of articles for the branch’s newsletter and it is hard to find editorial staff to the journal. The organisation has had ads out in the four latest issues, but there have not been any replies.

**Office staff**

The office staff consists of three people, two employed half-time and one who works within the Work Experience Scheme,\textsuperscript{133} as he would otherwise be unemployed; he only had half a year left until he would retire. The working conditions, however, seem a bit relaxed and it appears as though the staff is running the office more or less on its own.

\textsuperscript{129} For example, from February 5, 1998.

\textsuperscript{130} Interview with C5.

\textsuperscript{131} Board meeting of the organisation, April 4, 2000, 6 pm – 9.30 pm.

\textsuperscript{132} During the two-year period for the ordinary members, the chairman and the treasurer change roles with each other after one year.

\textsuperscript{133} The Work Experience Scheme (at the time it was called ALU-tjänst – Arbetslivsutveckling; today it is called arbetspraktik). It is a scheme only for the unemployed, giving them work experience, supported by the state.
We don’t have a formal supervisor. It’s been rather so-so with that. The chairwoman of the board often has to take on the role of the supervisor but we’ve had lots of intrigues and we haven’t really had a supervisor. We look after ourselves here at the office and the board doesn’t really know what we do. The board members don’t have any training in being a supervisor either; maybe they don’t even have any education at all and definitely less of being leaders. They have let things go as they please and that is very tough…. I don’t want to let things go as they please. I want to know that this person is my supervisor and that he or she is the one I should go to when I want to take vacation leave or am wondering about something. I myself have pestered the board about letting me attend the board meetings because people phone and ask questions. Because I can’t call all the board members at their work, it’s better that I go to the meetings myself and know what is going on.  

Further, this branch employs unemployed people with some form of subsidised employment by the state. The person who has worked the longest at the office was employed six years ago. Both of the employees were unemployed when they were given the jobs and thus were entitled to wage subsidies.

Conflicts

I overhear a phone conversation of a conflictual nature between one of the office staff and a group leader. During the conversation, X repeatedly states that he cannot go against the board’s decision: “I, who only have primary and secondary school can’t go against someone (the chairwoman of the board) with a university degree and say have you understood this?” The group leader is upset and everybody in the room can hear her screaming in the phone. X throws down the receiver and the group leader instantly phones back to another person on the office staff. This incident takes up the entire morning for all three of the office staff. Usually, the conflict is passed on to the board who then makes decisions and directs the office staff on how to act in the matter.

Finances

In 1999, this branch had a surplus of 29 101 SEK. The revenue was 417 967 SEK and the expenses 388 866 SEK.

The branch has several sources of income.
• The organisation receives grants from the municipality. In 1999, it received 92 000 SEK from the municipality and 4 000 SEK from the neighbouring municipality. The organisation also received 8 100 SEK from Humanfonden (the SDA) in 1999.
• Sometimes money is bequeathed or given to the organisation from members.
• The organisation receives member fees, of which a major part goes to the SDA. The annual member fee is 260 SEK and the supporting members pay 200 SEK annually. Thus, the member fee is somewhat higher in this branch than in the North branch.

Furthermore, this branch has its capital placed in funds. At the time of my visit in 2000, the organisation had placed their capital in bond and money market funds, a mix-fund, bonds and shares, which together were worth about 4.4 million SEK at the time. 90 per cent of the returns of the funds are given out and 10 per cent are reinvested. The Gift Fund (Gåvofonden) does not have these restrictions: that money is used for the organisation’s work.

134 Interview with C8.
135 They have a 90 and an 80 per cent wage subsidy, but both are doing an excellent job, of which they must keep quiet. In principle, one office staff claims that she is working ‘normally’ and should probably only get a 50 per cent wage subsidy. However, she must pretend that she is worse off at the time of the yearly checkout, so that the organisation will get the money; otherwise, they cannot afford to have any staff. This is a requirement from the organisation, i.e. that the employees get wage subsidies so that the organisation does not have to pay full salaries.
136 Conversation at the branch’s premises, April 6, 2000.
137 Minutes from the board and the annual reports of the organisation of 1999. Interview with C4.
138 Minutes of the board of the organisation, December 1, 1999.
139 Of this amount, 71 SEK goes to the SDA in a general fee and 59 SEK to the SDA for each member who receives the journal. Left for the local organisation is 130 SEK per member and year. Interview with C8.
140 The annual report of the branch 2000.
We have a lot of funded means which we’ve been given from wills (and gifts). 90 per cent of the income from the capital is given to recreation and so on, but these activities usually mean quite high fees for the individual as well. Maybe you have to pay 5 000 SEK for a camp or a trip and then you get a grant on 1 000 SEK from us. This means that you still have to pay 4 000 SEK yourself. Those who need it the most can still not apply for a grant, as they cannot afford the rest themselves. A woman I talked to had seven diseases that separately would be considered as awful by ordinary people. Her husband was also not well and they could never get away for anything! What if you could start up a fund only for those needing it most?141

There are constantly a large number of applications for money, including blood glucose self-monitoring aids and devices, children’s camps, congress fees for dieticians and research.

The expenses for the branch includes the rent for the premises (including heating and cleaning), insurances, remuneration to the board (in year 2000, a total of 17 000 SEK), financial compensation for parking and mileage, stamps and administrative costs, salaries (approximately 180 000 SEK annually for the two employees at the office), fees to the SDA and to other organisations that the branch is a member of, conferences, camps and the activities of the working groups.

As most of the branch’s capital is placed in funds, these funds are of great importance. The interest from the funds means that the branch can finance or contribute to the financing of activities.

The most recent numbers from 2005 show a financial income of 349 328 SEK and costs of 338 222 SEK, giving a positive result of 11 106 SEK. Two assistant secretaries are employed half-time at the office.142

When a member does not pay his or her member fee, then someone from the office makes a phone call to that member. The main reason members do not pay is that they cannot afford the fee, but sometimes it because of carelessness, i.e. the invoice is not prioritised.

I’ve an idea about the organisation starting a phone duty, as my experience of calling members is that many of them cry. They are so happy when someone listens to them. They are so lonely. And the task could be good for the members who’d like to be more active, but who are too sick. Those who can’t get out and come here, can perhaps talk on the phone.143

Membership and members

Members of the diabetes organisation are not only people with diabetes and their families, but can also be health care personnel, pharmaceutical companies, hospitals and health centres. The diabetes journal is sent free of charge to the medical services without them having to be members. This is because the branch thinks it is important for the organisation to get out with its message.144

The local branch had 1921 members in 2000, which is assessed to be approximately 10 per cent of the total number of people with diabetes in this city. The number of members is growing every year concomitantly with the increasing number of people with diabetes.

A diabetes specialist nurse who also is an active member and participates in some of the organisation’s study circles, comments on her membership:

I pay full membership because I want to get the journal Diabetes and because there are genes for diabetes in my family, so I know I might get it later on. I like to support the organisation and I meet many diabetics in my work. I’ve gathered that the organisation’s role is very important for the members around here. My interest as a member is to get the latest information. The way the health services are today more and more organisations such as this one is needed, which target information and takes in competent people. That’s how it is with all organisations. This way one knows where to turn.145

Another active member of the branch, who is also active within the sports movement, joined because he wanted to get more information about diabetes. He is the only one in his family with diabetes and he became afflicted with diabetes type 1 when he was 40 years old. He directly joined a study circle when

141 Interview with C4.
142 Annual report 2006.
143 Because of complications associated with diabetes, about 15 members of the organisation have visual impairments: every month. These people receive the journal on a cassette. However, not all want the cassette in that some have family members who read to them. Interview with C4 and C8.
144 Interview with C4.
145 Interview with C9.
he found out that he was sick and now he is on the board. Another board member notes that he was privileged to get a good doctor at the Diabetes centre when he was diagnosed with diabetes.

But I didn’t have any family member, relative or friend who had diabetes. I had no one to talk to. I’ve been active in the trade union movement but when I got an early retirement pension, I thought it was time. When you suddenly don’t have a job or a union, and then you see information about the organisation’s meetings at the hospital, well, then, you join. I did. Looking back on it now I can say that it was all for social reasons. I became involved in different activities and that’s how I made my face known. Then I was asked by the election committee [to join the board]. At that time, the board was full of conflicts and was split into two parties. I thought new people had to come in – away with all the old ones! We got rid of some, but people also left and that’s how I became a board member.146

One of the potential new board members, who is 29 years old, has focused on the problem of recruiting and keeping the young members. Her experience is that when she went to a meeting as an ordinary member, there were “only a lot of 80-year-olds there”. According to some board members, one reason that young people avoid the organisation could be that many of the young diabetics refuse to acknowledge their disease.

I’ll never accept that I’ve got diabetes. I don’t want to have it. I’m so tired of it. I cannot consider getting an insulin pump that would make me feel so handicapped. I’ve never before felt so handicapped in my life as when I became active in the organisation. Here I feel like I’m handicapped. I never looked at myself that way before. Then I just used to think that I had a minor deficiency.147

I joined because of my mother. I didn’t want to join [the organisation]. I was 15 years old when I got diabetes. I’m the only one in the whole family who has it. I was ashamed of my disease when I was young. The young ones aren’t committed. Look at the organisation now. It’s the first time in history we’ve arranged a disco and nobody shows up! No one entered their name for the disco. The young ones don’t want to let on that they have diabetes. They are ashamed to be diabetics. The youth group is quite passive; they don’t even read the journal – they just throw it out.148

When looking back on their time as young persons with diabetes, two of the active members tell me that they joined the organisation mainly because their parents wanted to get information and later because they wanted to get information about the disease. They acquired diabetes at a young age and can relate to having diabetes as a child. Both of them were ashamed of their disease and did not want to show it in front of others. When they were asked why they did not want to eat what was offered, one of them used to say that she was on a diet and wanted to loose some weight while the other said she did not like the food or the beverage. Both of them were told by their parents not to tell the rest of the family or their relatives about the disease. Although being a diabetic is more accepted today, they can both well understand that young people may not want to join the organisation.149 For many years, they were uninterested in attending meetings and activities. Then something happened: one became unemployed and the other retired. They both felt that now they had the time and therefore became active members. They started by going to some lectures arranged by the diabetes organisation (and it was really the lectures that were interesting, not the social activities). This way they became committed. In principle, they first became members because they wanted to get the journal Diabetes, which has a scientific approach regarding its findings. None of them wanted to join the organisation because of solidarity or financially supportive reasons. However, now that they have become active members, their attitude has changed where they now desire financial support and feel sympathetic toward the organisation and its members.

The major problem is that the members are very passive. It’s us leaders and the board who’re committed. Several young people have said that ‘I went to a meeting but there were only pensioners there.’ But it’s for the sake of the members that we’re here, not our own. It gives so much to work at the grass-root level. We meet and we talk, not only about the disease, but about other things as well. You get the social part. There’re so many different needs, both social and for empowerment. It’s this whole issue with the live wires, the real enthusiasts. They’re the driving forces.150

146 Interview with C7.
147 Interview with C6.
148 Interview with C6.
149 Interview with C6 and C3.
150 Interview with C1.
When I ask about the recruitment of new members, board members reply:

We threat them. [sic!] I take all the chances, trying every means of persuasion by any means. You meet diabetics in all contexts. For example, I went to a meeting about equity funds at Länsförsäkringar (an insurance company and bank) and it turned out that the chairman’s wife was a diabetic. ‘Are you a member of the organisation?’ I asked instantly and got her to join. She was an old principal and very attractive for the organisation. ‘You must join’, I said, ‘we need you’.

I don’t believe in traditional recruitment techniques with direct mail advertising and brochures, etc. It doesn’t give that much. A personal conversation gives more. The newly diagnosed are in need of the same information. We have to make them feel that they need us.

Only 10 per cent of the assessed diagnosed diabetics in the city have joined the diabetes branch. The diabetes nurse provides one explanation for this low percentage.

Several of my patients answer my question if they want to join the organisation with ‘No, my wife takes care of me’ or ‘No, we don’t need that, as we can take care of ourselves’. They are happy with the information they get from their doctor.

The organisation does have problems with recruiting new members. Although the number of members is increasing, it is not increasing to the same extent as the number of diagnosed diabetics. There are also members who leave the diabetes organisation in order join another patient organisation for their complication (e.g., the heart and lung organisation or the organisation for kidney patients). It is also hard to recruit active members.

It is very difficult to get people to work on a voluntary basis. You’re not paid. So why do some people still volunteer? Well, I think this depends on two factors. The first is that you believe that you provide something and the second is that you want to get the latest information yourself about research on the disease and the organisation.

Empowerment issues

Since it is difficult for people with diabetes to keep their driving license, the organisation is trying to get the attention of concerned politicians and administrators.

The issue with the driving licences is unfair; you can be 80 or 90 years old and keep your license, but we can’t!

The health care consumer group participates during the year in projects and meetings with the medical services and informs patient groups organised by the medical services. This group is continuously working to influence diabetes education and training for home services personnel. Sometimes people from the board are invited to present the organisation. The ex-chairwoman was, for example, often out informing colleges of health sciences and the medical students who wanted to “see a diabetic and see if he looks sick”.

The local branch’s ability to influence the SDA takes place at the yearly national convention where they can raise various issues. Most of the members I interviewed think the SDA is doing good work, but not all are positive to the change of labels from patient to health care consumer that was initiated by the SDA.

I refuse to be a health care consumer. I refuse to consume health care. I want to be outside of the health services. I don’t want to lie in the hospital and consume health care. To be called ‘a health care consumer’ is

151 Interview with C3. This board member did use the word ‘threat’ in answering the question, but I think she did so only to stress how eager she was and how persuasive she was trying to be in convincing appropriate candidates to join the board.

152 Interview with C4.

153 Interview with C9.

154 Interview with C5.

155 Interview with C5.

156 Interview with C5.
negative. It implies that you should consume and use something, but I don’t want to consume. I want to stay away from this. I don’t want to consume, I want to be a healthy diabetic. Some mean that patients are those who suffer, but I don’t think that patient is such a negative word, although it implies that I’m in the health services, not outside of it. I haven’t found a good word yet. But ‘user’ (brukare) might be good. I ‘use’ food and I ‘use’ insulin even when I am well. One just has to use it the right way. To have diabetes is not to have a disease, but to have a life-long condition. I’m a diabetic. I’m NOT ‘sugar-sick’ (sockersjuk).157

One member thinks it is important that the family members are interested, but not too much. Consideration from people in our immediate surroundings can be both positive and negative. The relation between the individual patient and his or her physician is also important.

My doctor wanted to make the decisions for me without asking me about my opinions. We haven’t worn out the older generation’s doctors yet. As users, we must question the health services more and ask about alternatives. It’s important for the organisation to discuss this problem. I think I’m the typical example of an active user. The relation between the doctor and the patient used to be like the one between a parent and a child; now the relation is more like an adult to an adult.158

The local diabetes branches fill an important function by offering to accompany and support the individual member when meeting with the health services.

It is common that people are weak in the meeting with the health services. It’s an important task of the organisation to inform about this [people being weak in meetings with the health services].159

Activities

Regarding exposure in the journals, the branch uses very small ads, which are free of charge in two local newspapers. They also produce their own newsletter.

The branch arranges a number of educational study circles and lectures each term. These circles and lectures cover different aspects of the disease or of living with Diabetes. During my stay, I attend two such study circles on the topic “measuring techniques”, one for type 2 diabetes and one for type 1 diabetes. The first circle meeting, which takes two hours, is for persons with type 2. My impression is that the participants endlessly talk among themselves. There are eight participants (six women and two men). They are comparing the national guidelines when the meeting begins. The circle leader can speak without being interrupted, but to judge from the questions that are posed, it is difficult for the participants to grasp the technique. As one participant comments, “it’s a lot of work only to learn about the diet and the cholesterol.”

The fact that a few participants instantly said, “can we continue then?” when the circle leader mentioned that he is starting a new round of the circle in the coming autumn (and therefore wanted their evaluation of the course) implies that there were participants who mainly wanted the social get-together and meet other people. At the break, the participants exchange experiences. The leader tells me that being an active member of an organisation is social. A few elderly members in this group go to all the courses time after time. They have taken the same study circle several times.

The most widespread national disease is loneliness. We have elderly and members that are so lonely that they start crying when we phone them.160

I take the opportunity to carry out a pilot study, testing my questionnaire on this group. Some of the participants want to comment about my presence after the meeting. Most are wondering why I am interested in the diabetes organisation? It seems none of them can understand why I would be interested in their

157 Sockersjuk is the old term for diabetes in Swedish, literally translated to ‘sugar sick’. This word has been eliminated for two reasons. First, the connection to sugar is somewhat misleading and makes people with diabetes feel as if they are described as a candy. Second, people with diabetes do not wish that the word ‘sick’ is used to describe a chronic condition, which healthy people can live with for a lifetime. Even the word ‘diabetic’ is not desirable as that word implies that it is something you are. Instead, we should say ‘people with diabetes’, so that it is noted that it is something (a condition) you have. Interview with C5.

158 Interview with C5.

159 Interview with C5.

160 Interview with C4.
thoughts and opinions. They are so used to being ignored that they are touched by the idea that I am there to learn about them.

In the other study circle, which focuses on persons with type 1 diabetes, there are seven participants (five women and two men). At this meeting, as in the other, I am given permission to test the questionnaire. This meeting has the character of a therapy group. The participants share their experiences, mostly bad ones, of the health services (e.g., doctors ordering blood sugar tests). The meeting centres on what the participants want to say and thus it is mostly social talk. Yet, because of my presence, there is also a general discussion in the group about why so few people with diabetes join the organisation. The group thinks that this might depend on denial of the disease: that people think it is a shameful disease and do not want to acknowledge it. Because of old prejudices about becoming blind, they cut off your foot, and so on. There are those who hide their disease. Another reason could be that you cannot afford to pay the member fee or that there is a lack of knowledge about the organisation or even of its existence. People do not know what the organisation does, how it works or that it exists.

Considering the entire member base, there are few participants at the study circle meetings.

It can be unbelievably hard to recruit members to the study circles. Those who participate in the circles are very satisfied. It’s partly the societal climate, the individualisation, and partly the individual level, which makes it hard to get members to the circles. To become involved is a very long process. A characteristic of being active is that you’re a pioneer.

Every year the branch arranges its annual Diabetes day for the public. This includes a whole day with activities: lectures, stands with representatives from the pharmaceutical industry, panel debates and dieticians. For this occasion, they arrange some entertainment and provide coffee and lotteries. The aim is to reach all diabetics and, by preventive information, help many people not to become diabetics. The Diabetes day is for all people with diabetes in the city, media, politicians, health care personnel and others interested in diabetes. In 1999, there were more than 350 visitors.

This branch arranges study visits to a pharmaceutical company (Novo Nordisk), evenings devoted to a particular theme and trips for the members (e.g., health trips have been arranged to Poland). The thematic evenings are quite popular, with about 60 people usually attending these events.

Some members attend every activity we arrange, but the majority of the members go to different thematic meetings. Usually, there are quite a lot of people at these meetings. The best so far [in terms of attendance] was the Diabetes day.

The branch sponsors their participants in Vårruset, a yearly running race. It also arranges meetings for new members, but the last time attendance was low (of 100 invited only 10-20 people showed up). One of the more popular activities the branch arranges is Chi gong, but generally, not many people come to the meetings or activities that the branch arranges.

Many elderly are afraid to go out at night: that’s what you hear more and more these days. That’s why we arrange a welcome meeting both at daytime and at night.

It’s difficult to get people to be active because they have so many other things to do. It’s harder to get the young members to be active in that they have so much else to do with sports, and so on. There were youth leaders who arranged all kinds of activities earlier, but when nobody showed up, these activities were no longer any fun to arrange. Two young girls, 13 and 15 years old, tried to arrange a meeting for the youth, but only one person came.

In contrast, the Christmas party is very popular, especially for families with children.

The parent group arranges a Christmas party every year for about 160 people, but more people than that would like to come; however, the premises cannot take more than that, so that party is really popular.

161 Study circle meeting in “Measuring techniques” at the organisation, April 5, 2000.
162 Interview with C1.
163 Interview with C5.
164 Interview with C8.
165 Interview with C8.
166 Interview with C8.
167 Interview with C8.
The board, the office staff and some of the working groups invite lecturers such as physicians or other health care personnel to come and speak at meetings arranged by the organisation. These meetings are open for the public, so everybody who is interested can come.

The organisation’s activities mainly focus on information and the financing of research, but also on physical exercise and diet. The group of people who actively participate in the study circles is fairly mixed. One of the most important groups is the health care consumer group who has contacts with doctors and research. This way the research can move forward and you can find alternative ways for new insulin production.\textsuperscript{168}

Not only are the activities important, but the existence of the local branch organisation is also important. There is someone the members can phone if they need it. Thus, the branch fills a comforting and supportive function during office hours.

I believe that you have to do something yourself. We could make a lot of people happier if we only had time to just talk with them. The most widespread national disease is loneliness.\textsuperscript{169}

The worst problem is that many people don’t have anyone to talk to, and they don’t know anyone with diabetes. That’s where we’re doing a good job in that we inform, comfort and talk to them. From this aspect, I believe that patient organisations play an important role and that we could do a lot more if we only had more resources, both money and people. To market the organisation costs money, you know.\textsuperscript{170}

If you can show that this works, it’s much easier to get money. However, we often go about it in the opposite way and seek money first and ‘do it’ later. Few people are active, as they don’t have time.\textsuperscript{171}

The only way for individual members to influence the organisation’s work is by participating at member meetings. The committed members are active and the various working groups arrange their own activities for their members. Those passive members are satisfied with receiving the journal.

One of the benefits of meeting other people with diabetes is experiencing situations ‘from the other side’. Although this was not intended, it was the consequence (and benefit, as experienced by some participants) of a study circle meeting. It is common for people with diabetes to get notions of ‘hypos’. Some people with diabetes get it once or several times a week. Low blood sugar can affect a person so that he or she becomes childish, defiant and obstinate. Some of the members felt that it was instructive to see and experience somebody else getting a ‘hypo’, as this actually occurred during a meeting. The experience helped them to understand their families’ concerns when they themselves get ‘hypos’.

Another effect of the social aspect of the meetings is that members can teach and empower each other, with the result of opening up new experiences of life for one another. When learning about the experiences of others, people sometimes get the courage to try themselves.

I’ve pretty much tested all my limits. You have to change the insulin dosage when you fly to the USA or other places when you cross the ‘date boarders’, so in a way I guess I’m a fairly unusual diabetic. Many people with diabetes hesitate and are unwilling to go on long trips. This makes them more handicapped than what they need to be.\textsuperscript{172}

\textbf{The annual meeting of the City branch}\textsuperscript{173}

The annual meeting of the City branch starts at 7 p.m. there about 70 persons at the meeting. The chairwoman is absent (at home sick), which leaves the other board members unprepared for the presentation of the organisation’s finances. The meeting started with a lecture by a doctor from Astra-Zeneca. He talks about the new medications for diabetes and related complications, bringing up the problem that the most interesting literature is in English rather than in Swedish.

\begin{flushleft}168 Interview with C2. \\169 Interview with C4. \\170 Interview with C8. \\171 Interview with C4. \\172 Interview with C5. \\173 Annual general meeting of the organisation, April 10\textsuperscript{th}, 2000.\end{flushleft}
The doctor’s discussion is followed by a coffee break. During the break, I notice that there are almost no young people at the meeting at all (only three as far as I can see). Most of the persons attending the meeting are 50 years or older. I am not surprised as this was my experience from the North organisation as well and I remember what a board member told me earlier that day:

When you are young, you don’t want to be sick. Our organisation has rotten youth activities.\footnote{Interview with C3.}

The annual meeting continues according to the agenda. At this time, the members are participating quite actively. Perhaps not many people come to these meetings, but those who do come are active. The consumer groups discuss the 50,000 SEK in increased grants from the municipality being earmarked money, which the organisation should use to work actively for co-operation with the health services and find new collaborative forms. This has so far been done through the “the way to-project” and the health care consumer group, but other attempts are needed (e.g., care programs).

A new member in the organisation, a young man who appears to be in his 30s who has had diabetes for 17 years (but was not a member earlier), introduces himself. He works as a management consultant, focusing on organisational aspects. He begins by posing questions about the marketing of the organisation and the market group within the organisation. He questions many things, such as the target groups, the lack of strategies and focus and the near absence of campaigns. The instant response from the audience is fantastic. Several people are waving their hands in the air and an excited murmur is heard throughout the room. This is just what the organisation needs! Several offers come thick and fast from respondents to his questions. They asked him if he would like to join the market group. He is exactly the force they need. When declining the offers, it seems he anticipated this reaction. Unfortunately, he says that he has a demanding job and has no time to be an active member of the organisation. However, he has just become a passive member and will continue supporting the organisation through his passive membership. After the management consultant decline the organisation’s invitation, the meeting tended to run out of steam. The disappointment of some members is visible and soon thereafter people are starting to leave. The new board has almost no time to present themselves after being elected. Many members have pre-ordered transportation service for the disabled and because it did not say on the invitation how long the meeting would last, people assumed that it would be over earlier. Therefore, the meeting ends abruptly. They have 10 bouquets to hand out, but almost no one who is supposed to get one is still at the meeting, so these are handed out to whoever wants them.

The way to – project

Moreover, this branch has run study circles within “the way to-project” (here called The way to consciousness – dare to be a health care consumer). The study circles aim at strengthening people in their meetings with the health services. The idea is to increase awareness and knowledge and thus create a more active participation within the health services. An important intention is to start a dialogue with the health services in order to develop the care quality that patients experience.

One such circle was arranged for the board and the health care consumer group. This meeting resulted in the branch inviting several managers, directors and chief physicians from the University Hospital, the primary care in the city and the Health and Medical Care Administration to a meeting about the city’s diabetes care and its planning. The branch wanted to discuss several issues, including the division of responsibility, health care costs, the right to specialist care and strengthening patients in meeting the health services.

Further, other meetings were arranged among the circle participants, physicians and the Health and Medical Care Administration.

Co-operation and networks

The branch has representatives in the regional diabetes organisation and in the local and regional Diabetes Councils. The Councils have an advisory function in co-ordination and development of the diabetes care
in the city/region. The branch is also represented in two separate local Health and Medical Care Committees (HSN). For instance, issues discussed at the HSN meetings are the consequences of cut-downs in the health services and closure of health centres, care quality and insufficient registration of the diabetics to the national register. Furthermore, the branch has two representatives on the board of the HSO, one in the Chair Committee and three in the Disability Council. When asked about co-operation, one of the representatives in the HSO noted the following:

I haven’t seen any co-operation with other patient organisations, as they arrange their own activities. We’ve such a high number of members and yet more than half of all the people with diabetes here aren’t members. Perhaps they have complications and have joined the organisations for those diseases instead. I have a friend with diabetes that also has a heart and lung problem and therefore has joined the heart and lung organisation. You really can’t be a member of several organisations. It’s like with the unions, why join? You pay but they don’t do anything! It’s as if people are afraid; they hide the disease and ask questions privately but they don’t want to join the organisation.175

You don’t say competitors; rather, you say colleagues. Competitor is such a negative word. But, of course you are competitors in the sense that you compete for the same money with all the disability organisations within the HSO for example. Therefore, we’re competitors about money, but otherwise we’re partners and colleagues. Those who we compete with about members are for example the Heart and Lung organisation and the organisation for Kidney Patients.176

The city branch has a collaboration project with lectures together with the organisation for struma patients. According to a board member, members of the diabetes organisation tend to leave and join other patient organisations.

They start out as diabetics and join the diabetes organisation. Then they get some complication, which they feel is worse than the diabetes and then they join that organisation instead. Then they get yet another complication, which is worse, and so they join yet another organisation. My opinion is that we should give a quantity discount because it costs to join organisations. If you’ve been a member for a long time in an organisation, you should also be able to get a reduced rate.177

The organisation is also a member of the KFO (Kooperationens förhandlingsorganisation), which is an employers’ association primarily servicing co-operative businesses, voluntary organisations and popular movements.

Projects with the health services

The branch arranges meetings with the county council in the region, primary care within the municipality, physicians and dieticians. The branch argues that the state saves money when investing in prevention, information and diet guidance. These meetings are not so frequent, however.178

During the late 1990s, a number of working groups made an inventory of the diabetes care in the region. The city branch was then represented in four (of the nine) groups. Since 1998, the branch has had a representative as a member of the User Council at OTA, the orthopaedist division at the University Hospital.

The branch also has representatives in the Insula project, which concerns the development of diabetes care focusing on the patient in a part of the city. The company that owns a hospital there started a project in 1998 aiming at improving diabetes care. The goal is to develop methods for activating the patient in his or her treatment and to develop measurements of the quality of the medical services from a patient perspective. The Care programme, Diabetes 2000, which is within the Insula project, would be developed practically in four areas: information, patient participation, clinical expertise and care system. Together with representatives of the health services, four people from the branch participate in the project group.

The VVV (We Value the Health Services, in Swedish, Vi Värderar Vården) project is a quality instrument for people with diabetes and has been discussed by the board of the city branch, the Health Care

175 Interview with C2.
176 Interview with C4.
177 Interview with C4.
178 Interview with C4.
Consumer Group, an associate professor at the University Hospital and researchers from the Nordic School of Public Health. The discussions have concerned evaluation of the quality of diabetes care in the city and in the region. The issue was submitted to the regional organisation at the time of my stay.

The Diabetes Council handles the development and co-operation issues regarding diabetes care within the city and region. The organisation has had an ordinary representative and a substitute there. They have discussed the development of the care program Diabetes 2000, the diabetes care’s profile areas, the National Diabetes register and other educational and collaboration issues.

The health care consumer group within the local branch acts as representatives of the branch and participates in most projects with the health services and other collaborative efforts. Sometimes board members also take part. When the branch is invited to participate in various meetings concerning diabetes care or educational activities in the health services, usually someone from the health care consumer group serves as its representative. This group is also trying to influence the health services to produce information material about diabetes in common languages among our immigrants.

**Lobbying**

In 1996, the branch sent in letters to the media editor. The branch also tried to petition the politicians in other ways. The focus was already then on ‘the diabetes organisation’s way from patient to consumer’.\(^{179}\)

Letters were sent to the Public Health and Medical service Committee, the Primary Health Care Committee and the City regarding diabetes medical care. Two physicians also discussed these letters in their own letters to the recipients.\(^{180}\) Further, meetings with politicians occur. One of the board members on several occasions has written letters to the health services.\(^{181}\) The organisation arranges meetings about once a year for politicians to attend.

People with diabetes need insulin and sometimes there is impatience with medical science.

> Medical science does indeed move forward but we’re still injecting insulin! I remember telling a friend that it’s amazing how science develops and moves forward. I remember the big bulky syringes and how you had to clean them. Today, we only need a small pen! ‘Is that what you think?’, my friend said, ‘but you still have to take insulin’.

Insulin was discovered in 1921 and ever since then this substance has had to be injected.\(^{182}\)

However, as long as diabetics need insulin, it is not enough to finance medical research. The organisation must also convince the politicians to ensure that insulin remains free. Some of the board members are afraid that syringes and insulin will stop to be free of charge.

As soon as there’s any sign of this being threatened, one has to take an active step.\(^{183}\)

In the beginning of the 1990s, the organisation was lobbying for keeping insulin free of charge. They sent many postcards (which the SDA had produced) to politicians. The postcard showed a little girl sitting with a syringe in her hand with the text: Do I have to pay to survive?\(^{184}\)

The ex-chairwoman believes that the organisation’s possibilities to influence the medical services and politicians are very good.

> We must exist and we must be seen! Preventive care is shut down and people with diabetes are affected; we must work against this. The organisation must show the politicians with numbers what the society can save if the organisation teaches, for example, the type 2 diabetics.\(^{185}\)

\(^{179}\) Minutes of the board of the organisation, November 7, 1996.  
\(^{180}\) Minutes of the board of the organisation, January 15, 1998.  
\(^{181}\) Interview with C5.  
\(^{182}\) Interview with C5.  
\(^{183}\) Interview with C5.  
\(^{184}\) In Swedish: *Måste jag betala för att överleva?*  
\(^{185}\) Interview with C5.
Contributing to Empowerment

Further, this branch can contribute in many ways to the empowerment of its members. The explicit aim for empowerment in ‘the way to-project’ is manifested in the health care consumer group’s work. As in the North branch, member activities with educational aspects provide keys to empowerment. For members wishing to become active, the City branch offers a big selection of member groups with different emphasis and activities. Furthermore, the branch organises many thematic nights and information meetings, making it possible for active membership and participation.

The health care consumer group is actively working for changing views on people with diabetes within the health services and the medical education. The result of this work will naturally affect the empowerment of diabetics, as will the result from the co-operation and co-production with other organisations and authorities.

Summary

This chapter has presented the two branch organisations of this study: first the Northern branch (which is still intertwined with the regional organisation) and then the City branch. These were described from several areas of interest, starting with the background of the branch and its board members, who expressed their reasons for membership and why they were active. Leaders in both branches, but mostly in the North, were driving forces who had been intensely dedicated to the branch, but were now resigning for various reasons. Several of the board members were found to be active in other organisations. Their opinions on the workload, the nature of the work and their financial compensation were presented. Although many of the board members were dissatisfied with the compensation and the workload, most still continue to work on the board. For some, being in the board gave status and a position in society. Nevertheless, it is difficult for the branch to recruit new board members. It is especially difficult to recruit young members, both to the board and to the branch in general. Possible reasons for this were discussed. In both branches, although to a greater extent in the city case, a number of conflicts existed. These and their impact on the office staff’s work were described. Both branches had employees when this study was carried out, but they could only afford to employ persons who are entitled to wage subsidies from the state.

The finances of the branches differed somewhat. Briefly, the City branch is wealthier as it has more funded means, but this organisation has three times as many members as the North branch and is thus entitled to larger municipal grants and is allowed to keep more of its member fees. The funds are important in that they ensure the branches’ continued existence and contribute to their activities.

A number of issues were considered on the agendas, including the problem with diabetics retaining their licence, care allowance, training home services personnel and other information activities. Membership and members, and the board members’ thoughts on those issues were also presented. The North branch mainly focused on activities for the members with type 2 diabetes. This was not as explicit in the City though most activities concerned the older members. There are three types of activity: physically active, educational or social. In both branches, but to a higher extent in the City branch, there are working groups for different purposes that members can join. Parent, youth and the health care consumer groups are examples of those. In the North branch travelling distances has implications for board meetings and member activities.

The networks and co-operative projects with the health services or other partners were described. In the North many collaborative efforts were related to personal contacts, whereas in the City a large part of the collaboration was delegated to a special working group, i.e. the health care consumer group. When needed, the branches engage in lobbying efforts to ensure that insulin remains free of charge. However, this is mainly organised at the national level with the SDA.

Both branches have worked with an empowerment project called ‘the way to….a conscious health care consumer’. The Northern branch has worked much more with this project, with a positive outcome regarding new members joining this branch. In the City this project was one of many and did not get the special attention it received in the North. Empowerment issues were not limited to this project alone, but rather permeated all educational activities and much of the work carried out by the board and other active groups within the branches.
The purpose of this chapter was to give an overall presentation of the local branch organisations of this study, their active members and the work they carried out.
7 Membership in a patient organisation

This chapter reports the results from the survey that was completed by members of two local diabetes organisations in Sweden. The aim was to determine the members’ opinions about their membership in the patient organisation and their reasons for having joined it. In the presentation of the data the aim is to describe the findings mainly in terms of what the members think about their membership, their influence, the local organisation, its work and influence. Hence, the survey serves exploratory and descriptive purposes only.

The chapter begins with a description of the survey study and the social background (e.g. age and gender of the respondents, the types of membership and types of diabetes) of the respondents of the two branch organisations. Whether the respondents were also members in other organisations in addition to the diabetes organisation is also described. As mentioned in Chapter 4, these background factors can have an effect on participation. They are therefore included here and some will later be analysed in Chapter 8. Next, the reasons for membership are presented and the different profiles of the studied branches are discussed. Then a number of issues are raised, including the influence of the association/branch organisation on the diabetics’ situation in society, the local branch’s ability to influence the association and the members’ influence in the local branches. Further, opinions on who has the most influence on the local branch’s work are delineated. The following section deals with membership participation ranging from reading the membership magazine, participation in activities and holding an office. Members’ satisfaction with their branch organisation, its performance, their own membership and their suggestions for improving the situation for diabetics are subsequently discussed. Finally, the respondents’ opinions on the change of status of diabetics in society if the diabetes organisation did not exist and the possible alternatives to the SDA, as well as suggestions for improving the local branches, are presented. The comments to the survey are also presented before this chapter is summarised.

In the presentation to follow, five background factors were considered in all the survey responses to find significant differences. Comments on the background factors are made in all cases where there is a clear and significant difference (in cases of a minimal difference, no comments are made).

- Age: younger or older than 50 years
- Type of diabetes: type 1 or type 2
- Gender: male or female
- Membership in other organisations: member in no other organisation or one other organisation or member in two or more organisations
- Level of education: those with higher education compared to those with a gymnasium level or below

Some of these factors have been discussed in Chapter 4 and, together with the findings here, are analysed in Chapter 8 (e.g. about the youth, education and membership in other organisations).

Description of the Survey Study

Typically, the return rates of mail questionnaires are low. Sekaran (2000, p. 234) states that a 30 per cent response rate is considered acceptable. Others aim for higher rates and according to Trost, an acceptable response rate for questionnaires should be from 50-75 per cent (Trost, 2001, p. 118). In this survey a very high response rate was achieved in both organisations: 74.6 per cent in the North and 76.5 per cent in the City (Appendix 5). This return rate is satisfactory for such a study. The analysis of who dropped out (non-participants) showed no significant differences in the background data of the participants versus the
The two studied organisations differ regarding membership data, as shown in the following sections.

**Age and gender of members in both areas**

First, the age and gender of members in both regions are given, noting some differences between them. Then the type of membership is noted and after the type of diabetes by region is presented. Here there are some considerable differences. The relation between age and type of diabetes are discussed before presenting the main materials from the survey.

The age and gender distributions of responders in various age groups from 1–80 years old are shown in Table 7.1. As can be seen, most of the members are in the age groups from 41–80 years of age. In the North women dominate both in the younger (11–40 years) and in the two oldest age groups, whereas men dominate in the middle age groups (41–70 years). In the City the women dominate the age groups from 21–50 and 71 years and over.

**Table 7.1 Age and gender distribution of the respondents (per cent of each area and gender)**

<table>
<thead>
<tr>
<th>Age in years</th>
<th>The North</th>
<th>City</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
</tr>
<tr>
<td>1-10</td>
<td>1.8</td>
<td>1.1</td>
</tr>
<tr>
<td>11-20</td>
<td>4.2</td>
<td>8.4</td>
</tr>
<tr>
<td>21-30</td>
<td>4.8</td>
<td>5.1</td>
</tr>
<tr>
<td>31-40</td>
<td>8.4</td>
<td>10.1</td>
</tr>
<tr>
<td>41-50</td>
<td>12.0</td>
<td>8.4</td>
</tr>
<tr>
<td>51-60</td>
<td>24.1</td>
<td>19.7</td>
</tr>
<tr>
<td>61-70</td>
<td>27.1</td>
<td>24.2</td>
</tr>
<tr>
<td>71-80</td>
<td>14.5</td>
<td>17.4</td>
</tr>
<tr>
<td>81-</td>
<td>3.1</td>
<td>5.6</td>
</tr>
<tr>
<td>Total (N)</td>
<td>100.0 (166)</td>
<td>100.0 (178)</td>
</tr>
</tbody>
</table>

Note: N=738.

The members’ age distribution is summarised in Graph 7.1. As can be seen, the respondents are somewhat older in the North branch.

**Graph 7.1 Age types per city of the respondents (per cent of each organisation)**

Note: N=739. N for (N)=282 and N for (C)=457.
Different types of membership

Table 7.2 focuses on the type of members: ordinary or supportive. It shows that there is a clear majority of ordinary members in the organisation. Few respondents are supportive members and of those who are, women are in the majority in both of the branches.

Table 7.2 Types of membership and gender distribution of respondents (per cent within each organisation)

<table>
<thead>
<tr>
<th>Type of membership</th>
<th>The North</th>
<th>City</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
</tr>
<tr>
<td>Ordinary member (Diabetic)</td>
<td>47.4</td>
<td>45.0</td>
</tr>
<tr>
<td>Support member</td>
<td>1.8</td>
<td>5.2</td>
</tr>
<tr>
<td>No longer a member / has left</td>
<td>0.6</td>
<td>-</td>
</tr>
<tr>
<td>Total (N)</td>
<td>100 (331)</td>
<td>100 (377)</td>
</tr>
</tbody>
</table>

Note: N=713. The answer “don’t know” and missing data are not shown in the table.

Type of Membership, Types of Diabetes and region

Table 7.3 shows that in the Northern organisation, there were 10 per cent more members with type 2 diabetes than in type 1, whereas in the City the opposite was true, with over than 20 per cent more members with type 1 diabetes than with type 2. Both organisations had fairly low numbers of family members who do not have diabetes themselves, and only a very small number of the members work within the health services.

Table 7.3 Reasons for respondent membership (per cent within each branch)

<table>
<thead>
<tr>
<th>Type of membership</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetic members</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type 1</td>
<td>40.2</td>
<td>57.6</td>
<td>49.6</td>
</tr>
<tr>
<td>Type 2</td>
<td>50.6</td>
<td>36.0</td>
<td>42.8</td>
</tr>
<tr>
<td>Support members</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family member</td>
<td>7.7</td>
<td>4.4</td>
<td>5.9</td>
</tr>
<tr>
<td>Work in health care</td>
<td>1.5</td>
<td>2.0</td>
<td>1.7</td>
</tr>
<tr>
<td>Total (N)</td>
<td>100 (338)</td>
<td>100 (394)</td>
<td>100 (732)</td>
</tr>
</tbody>
</table>

When looking at the type of membership and type of diabetes, Table 7.3 shows that nearly half of the members have type 1 diabetes. As mentioned earlier, nearly 85 per cent of all diabetics have type 2, whereas only 20 per cent of the members claim to have type 2 diabetes. Thus, type 1 diabetes appears to be over-represented among members of the SDA. However, there are considerable differences between the most prominent form of diabetes in these two branch organisations. Half of the members in the Northern branch have type 2 diabetes, two of five are type 1 and nearly one of ten is supporting members. In contrast, in the City nearly three of five members are type 1 diabetics, more than one third are type 2 and only one in twenty are supporting members. We know that age and type of diabetes are related.\textsuperscript{186} The majority of type 2 members are found in the age categories 51-80 years old. Most type 1 members are found in younger age categories (Graph 7.2).

\textsuperscript{186} As shown in Chapter 3, type 2 diabetes generally comes with age.
Graph 7.2 Age and type of membership (proportion of members in different age groups and type of membership)

![Graph 7.2](image)

Note: N=729.

As for the length of the membership in the SDA, it varied from six months to 70 years.\footnote{In the North, the mean of the respondents’ length of membership was 10.4 years and the median 8 years. In the City, the mean was 13.1 years and the median 9 years. Given the dominance of type 2 in the North and that it starts later, it is not surprising that the length of membership is shorter there.}

**Membership in other organisations and SDA**

I also wanted to explore whether membership in the SDA was cumulative (e.g. are members of the SDA also members of other organisations)? Graph 7.3 addresses this issue.

The left part of Graph 7.3 shows that the overwhelming majority of the respondents in both branches were previous members in other organisations. The right part shows the same finding, although to a lesser extent, for the respondents who currently are members of other organisations.

**Graph 7.3 Proportion of members who were previously in other organisations and who are now current members of other organisations (per cent within each organisation)**

![Graph 7.3](image)

Note: N=726 (previously) and N=720 (currently). N for (N) previously=341 and currently=340. N for (C) previously=385 and currently=380.

The findings indicate that a clear majority of the respondents have been and are now members of several other organisations. In both organisations there is a higher proportion of respondents with a higher education (i.e. over gymnasium level) who are now members in other organisations compared with those with
an education below gymnasium level. In both organisations there is a higher proportion of type 2 diabetics as compared with the type 1 diabetics, who have been members of other organisations.

Generally, the proportion of respondents who are now members of other organisations is lower than the proportion of those who were members in other organisations. About a third of the respondents are now members of a trade union and about one fifth of the respondents are members of a residential organisation. Only 11-16 per cent of the respondents are now members of a pensioner, consumer, cultural organisation or a life style organisation. Only one of ten respondents is a member of a political party. Of the rather few respondents who are now members of other types of organisation, most are members of an organisation with a special interest. Almost eight per cent of the respondents are also currently members of another patient organisation, of which the organisations for rheumatics, disabilities and the visually disabled were the most common.

The total percentage on membership in other organisations corresponds well with the national-level statistics in Sweden. In 2000, the majority of the Swedish population (almost 70 per cent) was members of several organisations (Statistics Sweden, 2001, p. 4).

Finally, the characteristics of the members’ social background in the branch organisations in these two regions can be summarised as follows: The smaller Northern branch is characterised by members (both men and women) that are somewhat older and where the majority have type 2 diabetes. The larger City branch, on the other hand, is characterised by younger members with a very small majority of women, usually with type 1 diabetes. Members of both branches are mostly diabetic members and a clear majority is or has been members of several other organisations as well.

Reasons for joining the organisation

Two clearly different profiles are found in the North and in the City

We now turn to the reasons for joining the Diabetes Association. The respondents were allowed to choose several alternatives. The importance of each alternative is indicated by the rank it had (in parentheses) for each branch. There are regional differences regarding the reasons for joining the local branch organisation of the SDA (Table 7.4).

In both organisations information and knowledge is the most frequent single reason for joining the diabetes organisation. Two thirds of the respondents in both branches gave this reason for joining. However, quite different profiles were observed. Members in the North give social and political reasons as the next most frequent reason for joining, whereas members in the City give medical reasons. This reflects the different social profiles of the two regions. To the older and more isolated members of the rural areas in the North, social and political reasons could be more important for joining than for the younger members in a major urban area, where diagnosis and type 1 diabetes come second and third, respectively, i.e. medical reasons are more important as reasons for joining. Here social and political reasons come in fourth and seventh place, respectively. Very few report dissatisfaction with the situation for diabetics as a reason for joining.

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188 80-89% compared to 66-70%.
189 85-89% of the type 2 diabetics compared with 74-77% of the type 1 diabetics.
190 12% and 10%, respectively.
191 In total, the respondents provided 1, 589 response alternatives, which gives an average of 2.1 alternatives used per respondent.
Table 7.4 The respondents’ reasons for joining the organisation (per cent within each branch). Rank within parenthesis.

<table>
<thead>
<tr>
<th>Reasons for joining</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information &amp; knowledge</td>
<td>Wanted more information and knowledge about diabetes</td>
<td>67.4</td>
<td>65.7</td>
</tr>
<tr>
<td>Medical reasons</td>
<td>Diagnosed with diabetes</td>
<td>26.2</td>
<td>36.4</td>
</tr>
<tr>
<td></td>
<td>Type 1 and my parents signed me up as a member</td>
<td>13.0</td>
<td>24.0</td>
</tr>
<tr>
<td></td>
<td>Recommended to join by someone in the health service</td>
<td>26.2</td>
<td>23.5</td>
</tr>
<tr>
<td>All with medical reasons</td>
<td>65.4</td>
<td>83.9</td>
<td>75.1</td>
</tr>
<tr>
<td>Social reasons</td>
<td>Wanted to meet other diabetics and share their experiences</td>
<td>28.2</td>
<td>16.4</td>
</tr>
<tr>
<td></td>
<td>Wanted to take part in the branch’s activities</td>
<td>21.0</td>
<td>17.2</td>
</tr>
<tr>
<td>All with social reasons</td>
<td>49.2</td>
<td>33.6</td>
<td>40.9</td>
</tr>
<tr>
<td>Political reasons</td>
<td>Wanted to influence politicians and the health care</td>
<td>27.1</td>
<td>23.7</td>
</tr>
<tr>
<td>Dissatisfaction</td>
<td>Dissatisfied with the status and influence of diabetics</td>
<td>2.3</td>
<td>2.8</td>
</tr>
<tr>
<td></td>
<td>Dissatisfied with the care of diabetics</td>
<td>3.7</td>
<td>3.7</td>
</tr>
<tr>
<td>All dissatisfied</td>
<td>6.0</td>
<td>6.5</td>
<td>5.8</td>
</tr>
</tbody>
</table>

If various answers are grouped together, many more respondents joined for medical reasons in the City branch than in the North, but again there is a notable variation between the two regions. Approximately one fourth of the respondents in the North and one third in the City joined the organisation because of being diagnosed with diabetes. The third most given reason for having joined the organisation in the City branch was having been registered as a member by a parent. This reason was only in sixth place in the Northern branch. Approximately every tenth respondent in the North and every fourth in the City answered that their parents signed them up as members when they were diagnosed with type 1 diabetes.192 As expected, a higher degree of those younger than aged 50 years answered this question positively in both organisations.193

Another medical reason to join the local diabetes organisation was to follow a recommendation from someone within the health services. In both areas, about 25 percent of the respondents answered that they joined the organisation because they were recommended by the health services to do so. In both organisations it seems as though a slightly lower degree of those with higher education (above gymnasium level) joined because of this reason.194

Table 7.4 shows that for two thirds of the members in both organisations the most important reason for joining the organisation was to acquire information and knowledge about their disease. The membership magazine providing this is thus clearly an example of a successful selective incentive (cf. Olson, 1965 & 1971). In the City there was a slightly higher degree of women than men who joined for this reason.195

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192 Of the respondents with type 1 diabetes in the North, 32% joined the organisation this way, as did 41% of the respondents with type 1 diabetes in the City.
193 Between 40 and 50% of those younger than 50 years and between 1-5% of those older than 50 years.
194 From 19-22% of those with higher education as compared with 25-27% of those with less education.
195 72% women compared with 58% men.
both organisations age also made a difference. A higher proportion of the respondents above 50 years of age joined for this reason. 196 This finding might be explained by the fact that younger people with type 1 diabetes receive better help from the health services, as was stated in interviews at both organisations. 197 Thus, their information need might be satisfied elsewhere. The same explanation could also apply to the observation that a higher degree of members with type 2 diabetes in both branches joined the organisation for the reason of getting information and knowledge. 198 While membership in other organisations had no impact in the City case, it made a difference in the Northern branch. Here about 50 percent of the respondents who are not members of an organisation or who are members of one other organisation joined because of this reason. This figure can be compared with about 75 percent of the respondents who are members of two or more organisations. 199 This means that a higher degree of respondents who are already members of several organisations have joined to get information and knowledge.

Concerning social reasons for joining a diabetes organisation, it is interesting to find that in the North the second most given reason was to meet other diabetics, which fulfils social needs (cf. Clary et al., 1986). This alternative was only in seventh place in the City. Thus, members in the North, in comparison with members in the City, are more interested in the social activities of the branch. Less than a third of the respondents in the North and only half as many in the City answered that they joined the organisation because they wanted to meet other diabetics and share their experiences. 200 The level of education made no difference in the City, but in the North nearly twice as many with an education level below gymnasium joined to meet other diabetics. 201 Approximately 20 per cent of the respondents in both areas reported joining the organisation because they wanted to participate in the organisation’s activities. The type of diabetes made no difference in the City, but in the North there was a small difference. A slightly higher proportion of the respondents with type 2 diabetes joined the organisation because of the activities. 202

The third most given reason in the North (in fourth place in the City) for their membership was the desire to influence politicians and the health care system. In both organisations approximately a fourth of the respondents joined the organisation for this reason. More older than younger members stated that they joined the organisation for this reason. 203 For those who are members in several other organisations, the proportion is almost twice as high as those who are only members of one or no other organisation, 204 a finding that may indicate that people to whom it is important to influence, for example, politicians see this as a reason for why they joined several organisations. This notion is consistent with theories that were discussed in Chapter 4, i.e. political interests and resources are cumulative (cf. Almond and Powell, 1966; Verba and Almond, 1963; and Verba, Nie and Kim, 1978).

The remaining two reasons (of dissatisfaction) for joining the organisation are of minor importance (and very few respondents chose these alternatives). Almost nobody joined the organisations because of their dissatisfaction with the status and influence of diabetics. 205 Similarly, the members did not join the organisations because they were dissatisfied with the care of diabetics. What is intriguing with both of these statements is that an overwhelming majority rejected them. Although very few are dissatisfied with the status, influence and care, nevertheless a fourth of the respondents answered that they joined the organisation in order to influence politicians and the health services, suggesting the need for more power and influence.

Other important reasons for joining the organisations concerned four areas:

- this was a way of accepting and taking responsibility for the disease

I’m curious about my disease, which in the beginning I didn’t want to accept.

I realise that I should take responsibility for my disease, but [I] also get good supervision from the health services.

196 71-73% of the elderly compared with 56-58% of those younger than 50.
197 The findings from these interviews are presented in Chapter 6.
198 From 55-59% of type 1 diabetes compared with 75-77% of type 2 diabetes.
199 55% and 74%, respectively.
200 28% and 16%, respectively.
201 31% and 17%, respectively.
202 26% of those with type 2 diabetes compared with 16% of those with type 1.
203 29-32% of the elderly, but only 17% of those younger than 50.
204 28-33% of those who are members in several other organisations compared with 17% of those who are only members of one or no other organisation.
205 Only 2-3% and there is nothing specific that characterises this group.
• and even finding sponsors

I needed support and sponsorship to an all around the world sailing race with a crew of only diabetics, ‘the diabetic conquest’.

• supporting research on diabetes

A part of the member fee goes to research, which I want to support.

• and to support the organisation

I think it’s natural to support such an organisation when you have diabetes.

The next section concerns the members’ evaluation of their local branch and the national SDA’s ability to impact the diabetics’ situation in society.

**Collective action – together we are strong?**

For many of the questions in this section, a large number of respondents used the ‘don’t know’ alternative, possibly indicating that the respondents are passive members, or they are uninterested in these matters, or that they are lazy when filling in the questionnaire, or that they found these questions hard to answer. Hence, this alternative response has been displayed in the following tables in this section.

**The influence of the SDA and the branch organisations on the diabetics' situation in society**

As Table 7.5 reveals, the SDA is more important and has greater influence on the situation of diabetics than the local branch organisations. More than half of the respondents feel that the ability of the SDA is good or very good in affecting the diabetics’ situation, whereas only one third of the respondents feel the same about the local branch organisations. Consequently, this finding suggests that the respondents have more faith in the national organisation. Fourteen per cent of the respondents reported that the ability of the SDA was appropriate versus 20 per cent for the local branch. Not many of the respondents felt that the ability of the SDA or local branch was poor or very poor. Thus, positive opinions on the ability of the SDA and local branch are substantially higher than the negative ones. A third of the respondents in both areas and for both questions responded that they could not assess the ability of the organisations to affect the diabetics’ situation in society.
Table 7.5 Level of ability of the SDA and the local branch organisations in affecting the diabetics’ situation in society as assessed by the respondents themselves (per cent within each branch)

<table>
<thead>
<tr>
<th></th>
<th>SDA</th>
<th></th>
<th>Local branch</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>The North</td>
<td>City</td>
<td>Total</td>
<td>The North</td>
</tr>
<tr>
<td>Very good / Good</td>
<td>49.5</td>
<td>52.9</td>
<td>51.4</td>
<td>36.4</td>
</tr>
<tr>
<td>Appropriate</td>
<td>15.6</td>
<td>13.0</td>
<td>14.2</td>
<td>21.1</td>
</tr>
<tr>
<td>Poor / Very poor</td>
<td>2.8</td>
<td>2.9</td>
<td>2.8</td>
<td>10.2</td>
</tr>
<tr>
<td>Don’t know</td>
<td>32.1</td>
<td>31.2</td>
<td>31.6</td>
<td>32.3</td>
</tr>
<tr>
<td>Total (N)</td>
<td>100 (327)</td>
<td>100 (376)</td>
<td>100 (703)</td>
<td>100 (332)</td>
</tr>
</tbody>
</table>

Age seems to affect the responses of the respondents. There was a larger proportion of respondents above 50 years of age than below 50 years that felt that both organisations showed ‘good abilities’ in affecting the diabetics situation in society. In comparison with respondents with higher education, there were a larger number of respondents who had not completed any higher education in both organisations who used the response category ‘good abilities’. This result may imply that younger persons and those with higher education are more sceptical than older persons and those with less education. In the City only every third respondent under the age of 50 used the response alternative ‘good abilities’, concerning the local branch, compared to almost every second of those older than 50. Only every fifth respondent with higher education gave the category ‘don’t know’, which can be compared with every third of those with less education. In both organisations the percentage for this alternative was over 30 per cent, which is fairly high. Concerning the North branch, a higher proportion of the respondents who had been members of more than two other organisations gave the response category ‘good abilities’ as compared with those who were not a member of an organisation or were members of one organisation.

In general, the respondents believe that the SDA has better abilities in affecting the diabetics’ situation in society. Despite different motives for joining the organisation, the respondents in the North and in the City are quite similar in their judgement of the local and national organisation’s ability to affect their situation as diabetics.

Most of the comments on this question concerned dissatisfaction with politicians:

Politicians and employees are restrained by the economic budget and thus the responsibility has been completely affected by this problem.

As long as the economy is more important to the government than people, there’s nothing we can do.

The politicians don’t know what diabetes means. They should be more informed about our problems.

dissatisfaction with the health services:

All the cost savings within the health services make the queues long.

or dissatisfaction with the local organisation:

I don’t feel as if they are [health services] there for our daughter, but are primarily for older people with mainly type 2 diabetes.

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206 The two response alternatives are combined in Table 7.5.
207 There is no direct translation of the Swedish word lagom into English. However, the word is usually translated into ‘just enough’ or ‘about right’. Here I have translated it to ‘appropriate’.
208 The two response alternatives are combined in Table 7.5.
209 33-40% of the elderly compared with 14-21% of the younger respondents.
210 30-33% of those with lower education compared with 20-27% of those with higher education.
211 43% of those with several memberships and 31% of those with no or one other membership. In the second case both of the groups were around 37-39%.
The local organisation has not enough focused on supporting and demanding intensified research. There’re too many coffee parties and too much administration.

For both the local organisation and the SDA, there were also a few positive comments regarding their good abilities:

The ability to influence is very good, as the diabetics still don’t have to pay for their insulin and their diabetes aids. A lot of it depends on the skilled and dedicated persons in various instances who speak up and fight on all the referrals.

If the local organisation and the association use their abilities to influence and create public opinion and lobbying, the possibilities to influence are good.

**The local branch’s influence on the Swedish Diabetic Association**

There is little difference between the respondents’ responses in the North and the City branches. Of those respondents with a view on this matter, they were nearly equally divided on the influence of local branches on the central organisation (SDA). The next most common response is ‘neither big nor small’, with about one fourth of the respondents selecting this alternative. Another fourth of the respondents think that the local organisation’s ability to influence the national association is ‘big or very big’. Again, of those respondents who have an opinion, the majority are positive. Very few of the respondents think that the ability of the central organisation is small.

**Table 7.6** Level of the local branch’s ability to influence the Diabetic Association as assessed by the respondents (per cent within each branch)

<table>
<thead>
<tr>
<th>Local branch’s ability to influence the SDA</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very big / Big 212</td>
<td>26.0</td>
<td>26.4</td>
<td>26.2</td>
</tr>
<tr>
<td>Neither big nor small</td>
<td>29.3</td>
<td>24.6</td>
<td>26.9</td>
</tr>
<tr>
<td>Small / Very small 213</td>
<td>4.2</td>
<td>3.6</td>
<td>3.9</td>
</tr>
<tr>
<td>Don’t know</td>
<td>40.5</td>
<td>45.4</td>
<td>43.0</td>
</tr>
<tr>
<td>Total (N)</td>
<td>100 (338)</td>
<td>100 (390)</td>
<td>100 (728)</td>
</tr>
</tbody>
</table>

However, more than 40 per cent of the respondents do not know whether the local organisation has the ability to influence the national Diabetic Association. In both organisations a higher proportion of women than men answered ‘don’t know’. Moreover, in both organisations the proportion of those younger than 50 is higher than those older than 50 for the ‘don’t know’ alternative. In the City the respondents with lower education are more positive when responding to the category ‘big ability’. In the North education did not make a difference in response to the ‘big ability’ alternative.

Most of the respondents’ responses to this question were positive and referred to good abilities. In the City there were, however, some respondents expressed dissatisfaction with the local organisation:

There’s too much trouble within the board.

It depends on if you’ve got skilled and interested people who have the time to work with long-term goals, unlike what we’ve had. Therefore, it can really vary.

or the importance of the individuals in the board and their relations:

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212 The two response alternatives are combined in Table 7.6.
213 The two response alternatives are combined in Table 7.6.
214 49-51% of the women compared with 32-39% of the men.
215 50-56% of the younger compared with 36-37% of the older respondents.
216 26% of those with lower education compared with 17% of those with higher education.
It depends largely on who’s leading the work and what their personal relations are with the management of the association.

In the North there were respondents indicating their difficulty in finding active people to represent the local organisation:

It’s difficult to get people committed, especially the youth.

Finally, two respondents in the City branch noted a gap between the local organisation and the association:

I believe there’s a substantial gap between the organisation and the association. Sometimes it feels as if they don’t belong to the same organisation.

During earlier years, the organisation has always had representation in the management of the SDA and thereby had the ability to influence. Nowadays, there seems to be a strained relation between the different actors.

The members’ influence in local branches

Approximately 30 per cent of the respondents in the North thought the individual’s ability to influence the local organisation is good. This figure can be compared with only a 20 per cent figure in the City. One explanation of this finding could be the size of the organisation. As the organisation in the North is much smaller (only a third of the number of members as the City branch), it may be easier to influence the organisation. Further, to judge from the respondents’ responses to various questions, there has been little complaint about the board and/or management of the Northern branch, which is not the case in the City branch.

Table 7.7 Level of the individual’s ability to influence the local organisation as assessed by the respondents (per cent within each branch)

<table>
<thead>
<tr>
<th>Individual’s ability to influence the local branch</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very good / Good(^{217})</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28.8</td>
<td>20.1</td>
<td></td>
<td>24.0</td>
</tr>
<tr>
<td>Neither good nor poor</td>
<td>26.4</td>
<td>26.2</td>
<td>26.4</td>
</tr>
<tr>
<td>Poor / Very poor(^{218})</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.0</td>
<td>6.5</td>
<td></td>
<td>7.2</td>
</tr>
<tr>
<td>Don’t know</td>
<td>36.8</td>
<td>47.2</td>
<td>42.4</td>
</tr>
<tr>
<td>Total (N)</td>
<td>100 (337)</td>
<td>100 (389)</td>
<td>100 (726)</td>
</tr>
</tbody>
</table>

Several differences were found between the responses from the North and the City respondents. In the North almost two fifths of the respondents responded ‘don’t know’, whereas almost 50 per cent gave this response in the City. As table 7.7 shows, most of the respondents do not know whether the individual’s ability to influence the local organisation is good or poor. A higher proportion of the younger respondents in both organisations selected the ‘don’t know’ alternative.\(^{219}\) The second most common response alternative was ‘neither good nor poor’.

Most of the comments made on this question were positive about one’s abilities to influence the local organisation. In the North, however, there were several comments on the problems of long geographical distance, as this presents problems for the members to travel to the different meeting places.

I live too far away from the town. I don’t drive. I’m half-deaf, half-blind and suffer from a lot of pain and poor balance.

\(^{217}\) The two response alternatives are combined in the table.

\(^{218}\) The two response alternatives are combined in the table.

\(^{219}\) 47-57% of the younger respondents compared to 32-40% of the older respondents.
I live in another region and there’re no activities here, but I can’t go 190 kilometres east to attend meetings, etc.

The problem is really that because of the long travel distances, you loose the ability to influence.

I live too far away, so I’ve never been to a meeting.

A few respondents in the North pointed out that they thought it was too complicated and the process was too slow in gaining sympathy / enthusiasm for one’s ideas.

I always have my right to make a statement. I also have the right to present a proposal, but the procedure is long and the motivation should be strong.

Again, several comments from the respondents in the City expressed dissatisfaction with the local organisation or the board of the organisation.

Today I don’t know, but when I tried a couple of years ago. The board wasn’t interested in listening.

I hope that our new board has more keen and sensitive ears than the earlier ones.

Examples of members trying to influence the local branch

One in ten respondents in both organisations tried to influence the local branch. In both organisations a higher number of respondents with higher education made an attempt to influence the local branch. In both organisations there was also a larger number of the type 1 diabetics that attempted to influence the branch. Almost twice as many respondents who are members of more than two other organisations tried to act upon the local branch as compared with those who are not members of other organisations or just one organisation. Roughly, the data indicate that members who are trying to influence the organisation’s work are well-educated, have diabetes type 1 and are members of several other organisations.

Examples were given of suggestions from 40 members, which had been carried out by the branch by respondents who had tried to influence it. The most common suggestion in the North considered different courses to take. In the City it varied as several of the respondents had put down a general comment on having worked in for the board (and thereby I assume had their various suggestions approved). The second most common approved suggestion in both organisations concerned social activities, such as excursions, trips and thematic nights, but also camps and activities for children and the youth. The rest of the suggestions ranged widely: to start a working group or a youth group, initiate meetings and debates with health care staff and physicians, influence the supermarket’s and grocery’s supply and school meals, arrange physical activities or sport activities for its members, arrange research trips, suggest financial planning for the organisation and reimbursements informing the police about ‘hypsos’ and how people with diabetes behave when they have a ‘hypo’ and having written bills to the SDA and the County Council.

Most important and influential actors

Concerning opinions about who has the most influence on the work of the local organisation, the respondents were asked to choose among the relevant alternatives, allowing several alternatives to be used.

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220 Note: N=727. N for (N)=340 and N for (C)=387.
221 There was no difference between the two branches.
222 15-23% compared with 5-7%.
223 12-13% compared with 4-5%.
224 13-14% compared with 5-6%.
225 Too much insulin or drug treatment occasionally makes blood glucose level become too low (hypoglycaemia). It is not uncommon for people with diabetes to experience a ‘hypo’. When experiencing a hypo, the diabetic may pass out and/or lose consciousness.
226 The 744 respondents, giving an average of 1.12 alternatives per person, used 833 response alternatives.
Table 7.8 Actors of influence on the local organisation’s work as assessed by the respondents (per cent within each branch)

<table>
<thead>
<tr>
<th>Most influence on local branch’s work</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>The board</td>
<td>29.7</td>
<td>27.3</td>
<td>28.4</td>
</tr>
<tr>
<td>Different working groups</td>
<td>6.6</td>
<td>10.9</td>
<td>8.9</td>
</tr>
<tr>
<td>The members as a group</td>
<td>10.7</td>
<td>7.3</td>
<td>8.9</td>
</tr>
<tr>
<td>Certain members</td>
<td>8.4</td>
<td>9.1</td>
<td>8.7</td>
</tr>
<tr>
<td>The local authority / other authority</td>
<td>1.2</td>
<td>0.3</td>
<td>0.7</td>
</tr>
<tr>
<td>Don’t know</td>
<td>53.3</td>
<td>59.1</td>
<td>56.5</td>
</tr>
</tbody>
</table>

Of the respondents who have an opinion on this matter, most (more than every fourth respondent) think that the board has the most influence. There was only a minor difference between the organisations. In the North the next most common response was the members as a group, whereas in the City it was different working groups. This finding is probably best explained by the existence of many more working groups in the City. Approximately 10 per cent of the respondents used the categories working groups, members as a group or certain members. Almost no respondents believe that the local authority or other authorities have a major influence on the local organisation’s work. However, a majority of the respondents responded that they do not know who is most influential in the local organisation’s work.

Regardless of organisation, there is a higher proportion of respondents who are members in two or more other organisations that believe that the working groups are the actors with the most influence. Among the respondents with several memberships, there is also a higher proportion of those who believe that members, as a group, are influential. There is nothing in particular that characterises the small group of respondents who believe that the local authority has most influence. A higher number of respondents that chose the ‘don’t know’ category are not members in any organisation, regardless of branch.

One of the problems pointed out by the respondents in the North was the large geographical distances. Transportation in remote areas is a problem and thus makes participation and involvement difficult.

Because of the location of the organisation, I can’t have an opinion on influence. It’s 23 miles to get there.

Several respondents mentioned difficulties of getting members committed and active:

It’s hard to get the members to take on assignments in organisations. If you’ve paid your member fee, most people feel that they’ve done their share.

The most frequent comment was that respondents who work actively or are active members are also influential:

The people that have worked a long time in the organisation [have influence]. It’s probably quite a limited group, which may not reach out to the members.

Those who work actively or are very interested (of course!) [have influence]. We, who aren’t directly influencing the organisation don’t really have anything to add and therefore we’re hardly relevant as influential persons.

A few members in the City branch expressed dissatisfaction with the board / the local organisation:

---

227 9-15% compared to 5-8%.
228 10-16% of those with several memberships. This compares to 5-6% of with those who are not members in any other organisation or in just one organisation.
229 63-64% compared with 42-52%. Moreover, a higher proportion of those younger than 50 (62-65%) has answered ‘don’t know’ compared with those older than 50 (49-55%).
230 A Swedish mile = 10 kilometres.
Unfortunately, during the past years, the board has lost a lot of its strength and power because of internal conflicts.

According to hearsay, there’s a ‘fight’ within the organisation because of strong wills. I think it’s good with different activities, but I hate to choose sides and reject everything that the ‘other’ group does. Such behaviour is far below the Neanderthal level.

A few members in both organisations also mentioned that “chosen” groups had an influence in the local organisation:

If you belong to the chosen groups, i.e. the right problem area, then it’s OK, but otherwise it’s not. Groups that aren’t represented are those gainfully employed with children and families with teenagers.

I think there’re too many territories, a few names circulate in many contexts and it’s hard to change how things have always been done. It feels as if we’re not always working for all the members, but concentrate on some, namely those who’re already active.

Such comments are probably an expression of the conflicts that prevail within the organisations.

Membership Participation

According to the national statistics on organisational life in Sweden, 44 per cent were active members in any type of voluntary association in 2000. This was the result of a decrease of 7.5 per cent since 1992 (Statistics Sweden, 2001, p. 25). We will now turn to membership activity by first considering reading the journal and members’ opinion about it, then member activity in their respective branch organisation, those who want to increase their membership activity and holding an elective or honorary office in the local branch before considering member satisfaction with their membership.

Reading the membership magazine

Nearly 80 per cent of the members read the membership magazine Diabetes regularly while the remaining 20 per cent read it sometimes. Very few respondents do not read it at all. One of the first questions can explain the high percentage of readers of the magazine (Table 7.4), where two thirds of the respondents answered that they had joined the organisation in order to get information and knowledge. Reading the membership magazine would thus be the most important activity in fulfilling this objective.

Women, to a higher extent than men, always read the membership magazine in both branches. 231 In both organisations there is a slightly higher proportion of those older than 50 years who always read the magazine, compared to those younger than 50 years, but those are on the other hand to a higher extent reading it often. Respondents who do not read the magazine at all are almost all younger than 50 years of age.

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231 84-87% of the women compared with 72-76% of the men.
Graph 7.4 Frequency of reading the membership magazine as assessed by the respondents (per cent within each branch)

![Proportion of respondents reading the membership magazine](image)

Note: N=736. N for (N)=344 and N for (C)=392.

Opinions about the membership magazine

More than 75 per cent of the members in both branches are interested or very interested in the content of the membership magazine. This interest explains why so many of them always read the magazine. Almost nobody thinks the contents are uninteresting and, contrary to many of the other questions, very few have responded that they do not have an opinion on this question. Only every fifth respondent remained neutral, reporting that the contents were fairly interesting.

Table 7.9 Level of interest regarding the content of the magazine as assessed by the respondents (per cent within each organisation)

<table>
<thead>
<tr>
<th>Opinions about the membership magazine</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>DIABETES</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very interesting</td>
<td>25.9</td>
<td>28.5</td>
<td>27.2</td>
</tr>
<tr>
<td>Interesting</td>
<td>51.2</td>
<td>51.1</td>
<td>51.1</td>
</tr>
<tr>
<td>Fairly interesting</td>
<td>22.6</td>
<td>19.4</td>
<td>20.9</td>
</tr>
<tr>
<td>Uninteresting</td>
<td>0.3</td>
<td>1.0</td>
<td>0.8</td>
</tr>
<tr>
<td>Total (N)</td>
<td>100 (340)</td>
<td>100 (376)</td>
<td>100 (716)</td>
</tr>
</tbody>
</table>

The findings in the two branches differ from each other. Concerning the response alternative ‘very interesting’, in the City twice as many of the older respondents, in comparison with the younger ones, used this alternative. However, in the North a lower number of the older respondents used the alternative ‘very interesting’. Furthermore, in the City a higher proportion of the older respondents gave the response ‘interesting’.

The respondents’ responses regarding the content in the DIABETES magazine were positive and mainly concerned four areas: a wish for more information on research, more information on technical aids (e.g. blood glucose self-monitoring aids and new insulin pumps), more information on diabetes and pregnancy and more to read for the children or young people.

There’s not so much written for the youth: mostly just for the elderly.

---

232 35% compared with 18%.
233 23% compared with 31%.
234 58% compared with 36%.
I’d like to read more on what it’s like to live with diabetes when growing up and in working life, especially for those with type 1 diabetes. I believe this topic is usually neglected.

As Felix is a kindergarten child with type 1 diabetes, we, as his parents, would like more written on this type of diabetes and his age and the problems/situations we encounter.

Obviously, the respondents’ comments concern what the individual would like to see more of in the membership magazine. There were, however, almost no comments on more information or articles for the elderly or on type 2 diabetes, indicating that this age group’s needs and wishes are satisfied, at least regarding the contents in the membership magazine. In the analysis I will further develop my thoughts on the possible reasons for this and what it means. (For a detailed list of the comments, see Appendix 7.)

**Membership Participation**

With respect to membership participation, we can note the following. A third or more of the members in both branches are active to some degree in the local organisations’ activities. Yet very few members consider themselves very active. Nearly one third of the respondents participate sometimes, whereas nearly two thirds are passive. In the Northern branch there is a higher proportion of the members older than 50 years who ‘often’ and ‘sometimes’ participate in the organisation’s activities. The majority of the younger respondents stated that they did not participate. In the City no difference was observed between the two age groups. Further, in the North twice as many of the respondents with type 2 diabetes (as opposed to respondents with type 1 diabetes) gave the alternative ‘participating sometimes’, whereas only 50 per cent of the older respondents stated that they did not participate. In the City no difference was observed between the two age groups. Further, in the North twice as many of the respondents with type 2 diabetes (as opposed to respondents with type 1 diabetes) gave the alternative ‘participating sometimes’. This finding indicates that the older respondents are more inclined to participate sometimes in arranged activities than the younger respondents.

**Graph 7.5** Level of participation in the branch’s activities as assessed by the respondents (per cent within each organisation)

The respondents listed a number of examples of the activities they had participated in during the past year. These ranged from lectures, courses, member meetings, happenings, excursions, trips, parties and sports for children and other youth activities. Two respondents in the North also pointed out that it was hard to participate in any activities because of the geographical distances involved (for a detailed list on these examples, see Appendix 7).

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235 6% compared with 1% of those younger than 50.
236 43% compared with 25% of those younger than 50.
237 74%.
238 46% compared with 24%.
Increasing members’ activity

As seen in Graph 7.6, almost half of all the respondents answered that they do not wish to be more active, they are satisfied as it is. However, every fifth respondent wishes to become a more active member.

**Graph 7.6** Wishing to be more active in the organisation as assessed by the respondents (per cent within each branch)

<table>
<thead>
<tr>
<th>Proportion of members who would like to be more active</th>
<th>North</th>
<th>City</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>46%</td>
<td>49%</td>
</tr>
<tr>
<td>Yes</td>
<td>21%</td>
<td>20%</td>
</tr>
<tr>
<td>Cannot</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>Don’t know</td>
<td>32%</td>
<td>31%</td>
</tr>
</tbody>
</table>

Note: N=727. N for (N)=336 and N for (C)= 391.

In both organisations a higher proportion of younger respondents wished to be more active. Approximately, every third respondent does not know whether he or she wishes to be more active.

**Holding an office**

Seven per cent of the respondents held elected or honorary functions within their branch. A slightly higher proportion of those with higher education held elected or honorary functions within the organisation in both the North and City branches. In addition, membership in more than two other organisations had an impact in both branches. A higher proportion of those who are members in more than two other organisations had had elected or honorary functions as compared with those who are not members in other organisations or are a member in only in organisation. Appendix 7 shows details regarding the distribution of those functions.

**Satisfaction with their branch organisation**

Member satisfaction with the performance of the branch organisation

About 40 per cent of the respondents have answered positively regarding branch performance by choosing the alternatives ‘yes, to a high degree’ and ‘yes, to a certain degree’. The positive responses clearly outnumber the negative ones, which were very few. A higher proportion of the respondents in the North than in the City gave the alternative ‘about right’. Nearly 40 per cent of the respondents said they do not

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239 24-31% of those younger than 50 years as compared with 16% of those older than 50.

240 13% compared with 4-5%.

241 In the North 3.7% of those who are not members in other organisations as compared with 10.1% of those who are members in several organisations. In the City, 3.9% and 9.8%, respectively.
know whether they are satisfied with the local organisation’s performance, with more respondents in the City than in the North feeling this way.

In general, the older respondents are more satisfied than the younger respondents in both organisations. A notable higher proportion of those younger than 50 years in both organisations gave the ‘don’t know’ alternative. In the North a difference was also found between respondents who are members in several other organisations and those who are not.

Table 7.10 Level of member satisfaction with the branches’ performance as assessed by the respondents (per cent within each branch)

<table>
<thead>
<tr>
<th>Level of satisfaction</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes, high degree</td>
<td>14.0</td>
<td>15.4</td>
<td>14.7</td>
</tr>
<tr>
<td>Yes, somewhat</td>
<td>26.8</td>
<td>22.9</td>
<td>24.7</td>
</tr>
<tr>
<td>About right</td>
<td>20.7</td>
<td>14.7</td>
<td>17.5</td>
</tr>
<tr>
<td>No, not particularly / No, not all</td>
<td>5.0</td>
<td>4.4</td>
<td>4.6</td>
</tr>
<tr>
<td>Don’t know</td>
<td>33.5</td>
<td>42.6</td>
<td>38.5</td>
</tr>
<tr>
<td><strong>Total (N)</strong></td>
<td>100 (343)</td>
<td>100 (389)</td>
<td>100 (732)</td>
</tr>
</tbody>
</table>

One respondent commented on the satisfaction varying with the prerequisites of the board:

It can vary greatly from year to year. Disagreements and strong wills can ruin several years of hard work. People dying and moving can drain a board, considering what you can ask from disabled people who work full-time and often have a family and other hobbies as well.

Satisfaction with their membership

All the respondents gave their opinion regarding their satisfaction with their membership. In contrast to their satisfaction with the organisation’s performance in general, 60 per cent of the members are either very satisfied or quite satisfied with their membership in the branch and SDA, 40 per cent are unsure and less than 2 per cent are dissatisfied. Nevertheless, nearly 20 per cent of the respondents have used the ‘neither satisfied nor dissatisfied’ alternative, which may indicate that they are either indifferent to their membership or that they are only interested in the membership magazine.

Table 7.11 Level of satisfaction with membership as assessed by the respondents (per cent within each branch)

<table>
<thead>
<tr>
<th>Level of satisfaction</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very / Quite satisfied</td>
<td>58.6</td>
<td>60.1</td>
<td>59.4</td>
</tr>
<tr>
<td>Neither satisfied nor dissatisfied</td>
<td>39.3</td>
<td>38.3</td>
<td>38.8</td>
</tr>
<tr>
<td>Quite / Very dissatisfied</td>
<td>2.1</td>
<td>1.6</td>
<td>1.8</td>
</tr>
<tr>
<td><strong>Total (N)</strong></td>
<td>100 (331)</td>
<td>100 (381)</td>
<td>100 (712)</td>
</tr>
</tbody>
</table>

The answer “don’t know” and missing data are not shown in the table.

A higher proportion of respondents over 50 years of age are very satisfied with their membership compared with those younger than 50 years, irrespective of organisation. This finding further indicates that

242 64-67% of the older respondents used one of the three positive answer alternatives, which can be compared with only 39-50% of the younger.
243 43-54% compared with 29-34%. The same tendency is found for type 1 diabetics as compared with the type 2 diabetics.
244 69% of those with several memberships are positive compared with 55% of those who are not members in any other organisation or just one organisation. In the City both groups are between 52-53%.
245 There is no direct translation of the Swedish word lagom into English. However, it is usually translated into ‘just enough’ or ‘about right’.
246 The two response alternatives are combined in Table 7.10.
247 The two response alternatives are combined in Table 7.11.
248 The two response alternatives are combined in Table 7.11.
249 23% compared with 13-16%.
the older respondents are more satisfied regarding their wants and needs as compared with the younger respondents.

Of the 49 comments dealing with this question, the majority were positive. Below are a few examples of the respondents’ comments:

For me it’s good with info. And through all the meetings and get-togethers I’ve been to, I’ve met other diabetics.

The diabetes care team and the association were working hard to keep the insulin and aids free of charge. This hard work has largely been rewarded to the benefit of the patients. They’ve worked hard for their position.

I’m convinced that the organisation does good work. For instance, there’s a whole range of activities offered. I just haven’t taken part in these activities.

Yet, there were also comments bringing attention to problems associated with the organisation. From members in the North branch there were, for example, comments regarding disadvantages with geographical distance.

I wish that we who live in the countryside would get more information; for example, perhaps we could have meetings in another town [closer to the respondent].

Other issues members from both organisations perceived to be problematic were the lack of focus on children, both in activities and the organisation in general, and having too few young members in the organisation.

There’re mainly pensioners at the annual meeting.

As most diabetes organisations there are substantial difficulties in attracting younger people in becoming members.

Again, there were a few comments from the City branch that expressed dissatisfaction both in general and with the board.

The member influx at the local organisation has been bad. More PR for the organisation is needed. There’ve been too many changes in the board.

On some occasions, the board has been or tried to be too arbitrary.

A now former chairman called me and we decided on a time to meet. He then got sick and didn’t show up without letting me know (ok, these things can happen). But this was repeated on several occasions. Of course, you get irritated! You work and make efforts and give of your time but it’s just ignored. You don’t want to make the effort any longer for free.

Suggestions for improving the situation for diabetics

Respondents gave 257 responses to the question: ‘In what way can the organisation improve the diabetics’ situation’. The answers were coded into 13 categories and three groups.

Many of the suggestions listed in Table 7.12 concern influencing politicians, which also was one of the most common reasons for joining the organisation. Many of the respondents also wanted the organisation to inform the public of the disease and how it affects the lives of people with diabetes. Influencing the health services was also a popular wish, as was informing the members on news within medicine and research on diabetes through special educational meetings. These requests are indeed explained by the major reason to join the organisation, which is to obtain information and knowledge (see Table 7.4). In general, there were a few more suggestions from the respondents in the City regarding influencing politicians, the health services and, more generally, making their voice heard with respect to these matters.
Table 7.12 Suggestions given by respondents on how the organisation could improve the situation for people with diabetes (per cent within each branch)

<table>
<thead>
<tr>
<th>Groups</th>
<th>How the branch can improve the diabetics’ situation</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information</td>
<td>Inform the public (schools, health care, society.)</td>
<td>20.8</td>
<td>18.5</td>
<td>19.5</td>
</tr>
<tr>
<td></td>
<td>Arrange lectures and inform members about medical news, etc.</td>
<td>7.5</td>
<td>7.9</td>
<td>7.8</td>
</tr>
<tr>
<td></td>
<td>Put money into research</td>
<td>8.5</td>
<td>6.0</td>
<td>7.0</td>
</tr>
<tr>
<td></td>
<td>Give courses (e.g. on diet.)</td>
<td>5.7</td>
<td>3.3</td>
<td>4.3</td>
</tr>
<tr>
<td></td>
<td>Recommend/warn about physicians, dieticians, etc.</td>
<td>-</td>
<td>1.9</td>
<td>1.2</td>
</tr>
<tr>
<td></td>
<td>More info via mail to the members (less active)</td>
<td>0.9</td>
<td>0.7</td>
<td>0.8</td>
</tr>
<tr>
<td>Social events</td>
<td>Arrange camps and concentrate on children and the youth</td>
<td>1.9</td>
<td>1.9</td>
<td>1.9</td>
</tr>
<tr>
<td></td>
<td>Arrange social get-togethers (parties, dance, sports, etc.)</td>
<td>2.8</td>
<td>6.0</td>
<td>4.7</td>
</tr>
<tr>
<td></td>
<td>More activities in the countryside</td>
<td>3.8</td>
<td>0.7</td>
<td>1.9</td>
</tr>
<tr>
<td>Influence / Political</td>
<td>Influence politicians</td>
<td>28.3</td>
<td>32.5</td>
<td>30.7</td>
</tr>
<tr>
<td></td>
<td>Influence the health services</td>
<td>14.2</td>
<td>12.6</td>
<td>13.2</td>
</tr>
<tr>
<td></td>
<td>By making their voice heard in the debate</td>
<td>2.8</td>
<td>7.3</td>
<td>5.4</td>
</tr>
<tr>
<td></td>
<td>Offer the members financial discounts (e.g. at gyms, sports, chiropody, dieticians)</td>
<td>2.8</td>
<td>0.7</td>
<td>1.6</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>(N)</td>
<td></td>
<td>(106)</td>
<td>(151)</td>
<td>(257)</td>
</tr>
</tbody>
</table>

If not, what then? Alternatives to the SDA?

Respondents were asked to consider what it would mean if no association existed for diabetics. With regard to this inquiry, there was very high agreement among the respondents.

What if there were no diabetes association? Would there be a change of status?

On the question ‘Do you believe the status of diabetics in society would be affected if the local branch organisation/association did not exist’, the overwhelming majority of the respondents thought it would be affected negatively (Table 7.13).

Table 7.13 Level of change of the status of diabetics if the local branch / the SDA did not exist as assessed by the respondents (per cent within each organisation)

<table>
<thead>
<tr>
<th>Change if the branch / SDA did not exist</th>
<th>The North</th>
<th>City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very negatively &amp; negatively</td>
<td>81.9</td>
<td>81.2</td>
<td>81.5</td>
</tr>
<tr>
<td>No change</td>
<td>3.6</td>
<td>1.8</td>
<td>2.6</td>
</tr>
<tr>
<td>Positively &amp; very positively</td>
<td>0.3</td>
<td>0.6</td>
<td>0.4</td>
</tr>
<tr>
<td>Don’t know</td>
<td>14.2</td>
<td>16.4</td>
<td>15.5</td>
</tr>
<tr>
<td>Total (N)</td>
<td>100 (338)</td>
<td>100 (387)</td>
<td>100 (725)</td>
</tr>
</tbody>
</table>
A great majority of the respondents feel that the status of people with diabetes in society would be affected ‘very negatively or negatively’ if the association did not exist. Only 15 per cent answered that they don’t know how the status of diabetics would be affected if there were no association.

Very few respondents (less than three per cent) felt there would be no change or that it would be affected in a positive way. Thus, it seems that most of the respondents recognise a value of the existence of the organisation and/or the association. One respondent pointed out the notable achievement of the SDA in influencing politicians to make insulin free of charge and its crucial impact in justifying the existence of the organisation:

I believe that the scale of a balance, which determines whether free insulin will remain free or not, would tip over to the disadvantage of the diabetics, where diabetics would have to pay the insulin themselves. It’s all those who fight and affect the status and situation of the diabetics that have given us diabetes care that’s still good in the country. We should treasure and protect our good situation.

Suggestions for improving the local branch

When asking for suggestions on changes / improvements concerning the branch’s work, the majority of the suggestions concerned the following four issues: arranging more courses and lectures and to educate the members, arranging activities that are more social:

Arrange a night a month with a simple lecture on diet, health care, physical exercise, etc., combined with cooking food together.

There’s a need for a more attractive selection of courses in order to increase the number of members, to find good ways to reach and include more immigrants in the organisation and to increase the work directed outwards.

Further, providing separate information for persons with diabetes type 1 and type 2, and finally, to give more support to parents, children and the youth:

There’s a lot being done for adults with diabetes (type 2); however, more should be done for the type 1 diabetics (these are increasing in numbers).

Offer activities suitable for all get-togethers for children, walking tours in the mountains, skiing weekends, horse riding, etc.

Arrange more activities for families with small children.

A website and more activities for teenagers (12-18) are needed.

Focus on the youth who must face many years with diabetes in the future. Fight concealment of the disease. Make sure that non-diabetics learn about the disease and how someone with diabetes can be helped. Visit schools and inform the students and teachers.

These suggestions corresponds with why the respondents joined the SDA (see Appendix 7 for a more detailed list of the suggestions). Not only was I interested in a situation without the SDA but also what alternatives might exist, which brings us to the next question. Other than the diabetes organisation, where can people with diabetes go to seek information and support?

Alternatives to the SDA?

Nearly 75 per cent of the respondents reported that there is no other place to turn to for the kind of service, information and support that the Diabetes organisation offers. A fourth of the respondents thought there were other places to receive help, including those within the health services (e.g. the diabetes care team at the hospital, the diabetes specialist nurse, the hospital, the health centre or primary care centre and (diabetes) physicians. Appendix 7 presents a detailed list of the suggestions given by the respondents.
Graph 7.7 Whether there exist other sources of support for people with diabetes as assessed by the respondents (per cent within each branch)

<table>
<thead>
<tr>
<th></th>
<th>North</th>
<th>City</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Yes</strong></td>
<td>66%</td>
<td>69%</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>28%</td>
<td>21%</td>
</tr>
<tr>
<td><strong>Don't know</strong></td>
<td>6%</td>
<td>10%</td>
</tr>
</tbody>
</table>

In this question, in comparison with all other questions, there was a large proportion of missing data (91). Note: N=653. N for (N)=304 and N for (C)=349.

In the North branch a higher proportion of the respondents over 50 years felt that there are no other sources of support for people with diabetes other than the diabetes organisation. This may be explained by the fact that young people with (mainly) type 1 diabetes are better taken care of by the health services, and they therefore see the health services as an alternative provider of the service, information and support that they can get from their diabetes organisation. Because the older people with diabetes (mainly type 2 diabetes) are not as taken care of by the health services, they do not see them as a viable alternative, at least not to the same extent as the younger people. There was also a higher proportion of respondents with higher education in both branches feeling that an alternative source of help existed other than the diabetes organisation.

Passive member and don’t know?

It would be reasonable to assume that the respondents responding that they are passive and never participate in the activities of the respective branches would be less informed and therefore chose the “don’t know” alternative more frequently. This was worth examining because we want to know if the passive members know what they think about the questions in the survey. In comparison with the active respondents, there is a higher percentage of passive respondents that gave the alternative “don’t know” to all the questions.

Almost 40 per cent of the passive respondents stated that they don’t know what the local branches or the SDA’s ability is when it comes to affecting the diabetics’ situation in society.

Concerning the local branch’s ability to influence the SDA, nearly half of the passive respondents don’t know and more than half of these respondents don’t know about the individual member’s ability to influence the local branch. Many passive respondents (60 per cent) do not know who the most influential actors are in the local branch. Moreover, half of the passive respondents don’t know whether they are satisfied or dissatisfied with the local branch’s work. 18 per cent of the passive respondents do not know if the diabetics’ position in society would change if the SDA did not exist. Surprisingly, a third of the passive respondents don’t know whether they would like to become active.

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250 70% compared with 60%.
251 25-34% of the younger compared with 18-25% of the older respondents.
252 27-37% of the respondents with higher education compared with 18-25% of the respondents with lower education.
253 64% of the respondents.
Comments on the survey

In the last question of the survey the respondents were asked if there was anything they would like to discuss further or if they had any opinions about the questionnaire. This question generated 29 comments that covered issues such as wanting more information on medical research, more activities and support to children and their families;

As a mother, I think it’s very important for children with diabetes to go to their camps, Christmas parties, etc., to make friends with other children in the same situation, who also take injections and so on. My daughter now has two new friends at a camp and a pen friend via the diabetes magazine. All this has been very important to her.

Furthermore, wishes for more information to the public about the disease, more social activities and activities closer to where the members live were expressed. The issue of how to gain more members and make the organisation stronger and influence politicians was also raised.

How are we going to get many new members who are taking undeserved advantage of the organisation’s work? This is apparently the case for most organisations of this kind.

There’s no group as vulnerable as families with children with diabetes. They need both financial and medical support. Nobody can help them with all their concerns, but indeed help make it easier for the person sick and his or her family so they can live as normal a life as possible. This is where the diabetes association and the local organisations have a big task.

Again, it’s very important that we diabetics not only get organised but also participate actively in meetings and get-togethers and really fight for our cause. We need to show that we’re strong together and we’re just as good in society as non-diabetics. The diabetes diet, for example, is ideal for all types of people. A diabetic who takes good care of his or her diet and exercises regularly is healthier than the average Swede.

Comments also concerned the feelings on the membership:

The reason why I have resigned from the organisation on several occasions is because I haven’t felt that it was there for me. I don’t feel that now either, but since I’m now working with different assignments and believe in changes, the membership nevertheless feels worthwhile.

One respondent expressed the dilemma of the diabetes movement:

The Diabetes organisation’s dilemma is to work internally with keep-fit measures254, while it at the same time work externally with politicians and the health services, as we must keep the appearance of diabetics as disabled people who can’t manage without subsidies from the society. As a result, we have hard managed and often completely uninteresting political hobby-groups.

Most comments once again stressed what they wanted from the organisation or shared some life experiences of the respondents. No one had any comments on the actual survey or the questions posed there.

Summary

This chapter presented the results of the Swedish Diabetes Association Study, a survey study in two strong local branches in two regions in Sweden. In this survey members’ preferences and opinions on a number of issues have been studied. A clear picture emerges from the results regarding the different social profiles of the studied branches in terms of regional differences in the social backgrounds of the respondents. Despite these differences, the respondents’ responses and attitudes were surprisingly similar between the two regions. This study examined the individual member’s opinion on several issues regarding membership, participation in the both the branches’ work and its activities, the interest in and ability

254 (‘Keep-fit measures’ (friskvård) usually refers to some form of physical training, but also training in healthy lifestyles, stress handling, diet and other health related issues could be included.)
to influence the branches, the views of both the local branches’ and the SDA’s ability to affect the diabetics’ situation in society, and so on. A general finding was that the respondents felt that the SDA was more important and had more influence than the local branches.

The results from the questionnaire showed two clear profiles of the North and the City branches. This was particularly clear concerning the reasons for joining the Diabetes Association. They were, however, similar in that an overwhelming majority of the members in both areas stated that the single most important reason for them to have joined the organisation was to acquire information and knowledge. This adds importance to the membership journal, which provides just that (i.e. information and knowledge). Other reasons differed in importance in accordance with the social profiles of the branches. Nonetheless, they connect again in the least chosen alternatives of reasons, i.e. dissatisfaction. The respondents of the two branches gave those reasons almost no importance at all.

Most members think that the SDA is important in having an affect on the diabetics’ situation. Still, uncertainty existed regarding the local branches’ influence on the SDA as well as on the members’ influence in the local branch and on identifying the most important and influential actors. This probably indicates a high level of passive members, which is what most of the members feel themselves. Nevertheless, almost all members read the membership magazine regularly and find the contents interesting. There was a higher level of member participation in the activities of the North branch compared with the City branch. At the same time, a fifth of the respondents wished to become more active though very few hold an office. A majority of the members are satisfied with their membership, but fewer with their branch’s performance. Most of the members think that the diabetics’ status in society would be negatively affected if the SDA did not exist, and see no given alternative to the SDA. Many of the comments expressed in this survey concerned the impact that geographical distance plays, the need for more information, activities and support for type 1 diabetics and their parents, the need to recruit younger members and the dissatisfaction with the board in the City organisation in particular.
8 Summarising and analysing the life of two branches of a patient organisation

I now intend to return to several theoretical points in this analysis in order to emphasise their importance for the main themes of this study. They concern selective incentives, joining, active membership, board members, member satisfaction, member influence, lobbying, co-production, co-operation with other patient organisations, empowerment and patient empowerment. Although the analysis in this chapter is structured after the research questions that were presented in Chapter 1, many of the sections naturally bring up issues that sometimes relate to more than one question. I have then chosen to let the discussion flow where it is, as I believe it would be the most natural and easiest way for the reader to follow the reasoning. I will start with the first research question that was formulated in Chapter 1 concerning membership engagement.

Membership Engagement

The first research question concerns the reasons for joining a patient organisation, what type of persons that become members in a patient organisation and why some of them choose to become active members? What characteristics do the members have and are there any geographic differences between the two local branches? Let us begin by discussing what incentives the organisations are offering their members.

Selective incentives: membership magazine, activities and support

Olson’s by-product theory argues that large pressure group organisations must derive their influence as a by-product of some non-political functions, that is by offering potential members a selective incentive that provides a reason for people to join the organisation (Olson, 1965 & 1971). He pointed out that the only way in which collective action groups can recruit and keep a large membership is by offering selective incentives along with public goods (ibid). As noted earlier, an obvious selective incentive offered to the members is the membership magazine Diabetes. The survey responses clearly indicate that it is very important to the members. The main reason for joining the organisation was to get more information and knowledge. A majority of the respondents were interested in the contents of the membership magazine. The comments in the survey on what the members wished to see more of in Diabetes concerned topics for the younger members, for parents, or for those with diabetes type 1. However, it seems that the needs and wishes of the type 2 diabetics are satisfied in this aspect. People with type 2 diabetes, as opposed to people with type 1 diabetes, can generally keep their disease under control by diet, physical activity and perhaps also by pills. It is also more common that type 2 diabetics are active in the local branch and this is also a way gain information and knowledge. The patient with diabetes needs more information than most other patient categories because the results of treatment to a large extent depends on the way of life of the patient – diet, physical activity and psychological stresses.

Another incentive for membership is the opportunity to meet other persons with similar interests. Both branches offered a number of activities for both types of diabetics. However, the majority of members did not report that social activities were the most important reason for joining the organisation. Yet, in the North, every second member claims that he or she joined because of social activities and in the City every third member. This means that the social reasons for joining were quite high. As for active mem-

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255 After having checked with the local public libraries in both areas, this magazine is available at the library in the City, but not in the North. However, they have it at the local library of the hospital in the North.
bership, 40 per cent of the members in the North take part in one or several activities, whereas about 33
percent of the City members participate. The branch association’s activities also comprise an important
selective incentive.

In addition, support from the branch organisation in terms of accompanying members to the meetings
with the health services could also be seen as a selective incentive, at least for some members. Yet, an-
other incentive is provided for those who wish to support work aiming at changing the social, economic
or political setting in which they and their members live. Both branches offered their members social and
educational activities aiming for empowerment. However, focus was more on the type 2 diabetics than
on type 1 diabetics. Finally, there is also an opportunity for those wishing to support medical research.
Given the substantial amount of funds that the SDA devotes each year to research, the potential is high to
reach members for whom this is important.

Joining

As shown in Chapter 7, there were regional differences in age, gender and type of diabetes between the
two branches. It was therefore only natural to expect some differences in the reasons for joining the local
diabetes branch. The most important reason given was the same in both branches, where an overwhel-
ming majority of members gave acquiring information and knowledge as their main reason for joining. The
educational incentives for membership (Parry et al., 1992) were clearly present as all members wished to
get more information and knowledge. In both branches it was mainly those older than 50 years that gave
this as a reason. This observation is in accordance with the findings from the qualitative data that showed
that the younger (primarily type 1 diabetics) could satisfy their need for information and knowledge else-
where, mainly through the health services. The information and knowledge the branch offered their
members could be obtained either through the membership magazine or through participation in the
branch’s lectures, courses or other educational activities. Such selective incentives were filling their
function in recruiting members to the organisations. Another aspect is that the branch fills an important
function in collecting the acquired knowledge on diabetes and life in general. There is no one else who
offers that service.

Other answers for joining were reflected in the social profiles of the two areas. For the Northern
members, who are older and more isolated than the City members, social and political reasons were also
important. Influencing politicians and health care personnel at the county council is also more important
in a remote area where there were problems with finding and hiring physicians. The problems and dissat-
sisfaction of only having relay doctors was emphasised several times by the active members of the branch
organisation and the health care personnel during my stay in the North. There was a strong need for a
diabetes organisation to influence the county council and improve the working conditions for potential
‘ordinary’ physicians to be employed. It is thus not surprising that the Northern members gave higher
importance to political reasons than the City members. However, taken together about the same number
-about 33 per cent) of respondents in both branches said they joined the diabetes organisations because of
political reasons. Nearly twice as many respondents who are also members in several other organisa-
tions than those who are only members of one or no other organisation answered this question in a posi-
tive manner. This may indicate that people to whom it is important to influence others (such as politi-
cians) join several organisations, as political interests and resources are cumulative (cf. Almond and Pow-
ell, 1966; Verba and Almond, 1963; and Verba, Nie and Kim, 1978.) More older members (about 30 per
cent) than the younger members (17 per cent) stated that they joined the organisation in order to influence
politics. For the younger City members, the medical reasons are more important for joining. This finding
could partly be explained by the high number of members with type 1 diabetes in the City, many of whom
had been registered as a member by a parent. Another aspect is that while the patient in the North has
only one medical service to rely upon for both general help and in acute situations, the patient in the City
has several options in the general and acute situation. This does not make it easier for the City patient
even though there are more options. Approximately every fourth respondent in both branches gave “other
medical reason” for joining or following the recommendation of the health services to do so. 257

256 Carlsson’s study of cancer patients (2005, p. 30). showed that the motive for supporting patient associations possibility to
have an impact and influence was more important for remaining a member than for becoming one.
257 Members with less education did this to a higher extent.
In the North the second most given reason for joining was social, i.e., to meet other diabetics; in the City this reason came in seventh place. It comes as no surprise that social reasons are more important in the remote areas in the North where nearly a third of the respondents joined because they wanted to meet other diabetics and share their experiences. Many fewer did so in the City, where the supply of various activities is larger than in the North. Contrary to the theoretical assumption that those with a higher level of education participate to a higher extent (cf. Verba, Nie and Kim, 1978; Petersson, Westholm and Blomberg, 1989), it seemed most of the Northern respondents who joined to meet other diabetics had an education below the gymnasium level. Every fifth respondent in both areas joined the organisation because they wanted to participate in the organisation’s activities. In the North it was mainly respondents with type 2 diabetes who joined the organisation because of its activities. Again, this might be explained by the fact that persons with type 1 diabetes are better taken care of by the health services and therefore do not feel the need for participating in the organisation’s activities.

Nevertheless, a fourth of the respondents claimed that they joined the organisation in order to influence politicians and the health services, but not because they were dissatisfied with the present situation. The reasons for joining are thus not negative, but positive, where the members simply wish to have a greater influence over those actors and decisions that affect their daily life. For a person with a chronic disease, a possible consequence of dissatisfaction with the health services or even with society could be to join an interest organisation and this way influence the actors or issues one is dissatisfied with. However, almost nobody joined for this reason. Dissatisfaction with the health services was also found to be unimportant by Carlsson in explaining why people with cancer join a patient organisation (2005, p. 33). Finally, for a few respondents, joining the organisation was a way of taking responsibility and accepting that they have diabetes as well as supporting research on diabetes.

It should also be noted that of the small group of support members a clear majority in both areas are women. Almost all support members were also family members. Very few work within the health services and almost no men become support members. Perhaps this could be explained by women’s traditional caring role. If so, it would be more natural for a grandmother to join the diabetes organisation as a supportive member than the grandfather if her grandchild is diagnosed with diabetes.

Patient empowerment is largely developed together with the individual’s increased level of knowledge. Therefore, in noting that most members have joined the organisation to gain knowledge and that those who participate in the branches’ activities will do so as well, these members are one step closer to empowerment. On an individual level, the members are indirectly empowered by reading the membership magazine, attending courses, etc. Having information and gaining knowledge of the disease and related areas is empowering. In turn, empowerment gives a reason to join and to become an active participant.

### Long-term recruitment perspectives

In other policy sectors than health, consumer groups are commonly seen as less well organised and less easy to organise, than producer groups, because they are fragmented geographically and socially. For patient organisations, not only are most diseases scattered across areas, between occupations and sexes, but also usually with no clear relationship to social status or wealth. Furthermore, patient organisations are likely transient or temporary bodies to a greater extent than other consumer groups, as patients may get better, get worse or die. Perhaps it is a general problem for different patient organisations that many of the board members leave the board because of the status of their disease, i.e. the health of these people deteriorate over time. If so, the problem is in the nature of the organisation: you can never count on people with a chronic disease to stay healthy and well. In both organisations, several board members could not be interviewed because they were too ill at the time the interviews were being conducted.

This fact may also have negative consequences for the recruitment of young people. In both organisations I found that there was a fear for this scenario; i.e., that those who are the least disabled/sick, and thus most valuable to the organisation, do not want to join because they do not want to be labelled as disabled. As one active member expressed: “I’ve never before felt so handicapped in my life as when I became active in the organisation”. This may be one of the reasons for why many young people with diabetes do not want to join the diabetes organisation. Perhaps they prefer to be like all other ‘normal’ people their age, which excludes being a member of a patient organisation. The same reasoning applies to

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258 Roughly one of ten in the North and one of twenty in the City.
healthy diabetics who do not feel any need for membership in the organisation: “that’s for those who are sick!”

There is a general tendency of a decrease of members in organisations, especially among the young. In 1998, the Swedish Parliamentary Commission on Democracy stated that young people’s trust in traditional democratic forms was waning and that the number of active members in idea driven organisations have decreased dramatically during the past two decades (SOU 1998:101, p. 8). Moreover, Klöfver noted in 1995 that there were many factors indicating the diminishing importance of popular movement, as the number of members was drastically sinking and the level of activity decreasing (Klöfver, 1995, p. 38). It seems that active members are getting older and older, especially when considering the younger generations where the level of activity is low. Younger persons in Sweden, in general, are not as inclined to join organisations as the generations before them (Statistics Sweden, 2003, pp. 23-73). However, both branches in the present study were putting more of their resources and efforts into type 2 diabetics rather than type 1 diabetics, although there is a higher percentage of type 1 diabetics who are members. Their argument was that people with type 1 diabetes (mostly children and young people) were already taken care of by society and supported by the medical services. Given this perception or attitude, it is not so strange that young people do not join organisations. It is only natural that young people with diabetes do not want to identify with those who are old and sick. In the choice of two ends of the scale, it is more likely for someone who is young and sick to repress it. Combining an organisation both for elderly and young people is hard enough. Finding activities of mutual interest for both age groups may be difficult to achieve.

From the survey results, the lack of the young generation became obvious, which is viewed as a serious problem by many of the organisations’ members. It would therefore be wise of the local branches to mobilise members not currently active but who stressed that they would like to become more active within the organisation. About 20 per cent of the inactive members reported that they would like to be more active. Further, many of these persons wishing to become more active were younger people.

Active membership

A third or more of the members in both branches are, to a greater or lesser degree, active in the local branches’ activities. Only a few members consider themselves very active, however. The elderly are generally more inclined to participate in arranged activities than young adults and children. Noteworthy is that 20 percent of the respondents would like to become a more active member. The majority of those members wanting to become more active were younger people. Here is a potential asset of the branch organisations. In this study, all board members but one had diabetes themselves. The empirical data showed what also was brought up in the literature (Olson, 1965 & 1971), namely that a common reason for becoming active is social pressure. Other persons have persuaded them to become active. A problem for the organisations was to find the right people for the boards, i.e. persons who are active, take initiatives, and so on. The experience of these branches suggested that these desirable individuals did not have time to participate actively. The importance of time for active participation has been emphasised by Verba et al., (1995 a & b). Yet another reason found in this study for becoming an active member, or rather for accepting a place on the board, concerned status. The board posts were perceived as prestigious by some members and providing high status. Some respondents explained that many people within the Disability movement never had a retirement post in the business world or any other board posts or positions of trust. Becoming a board member in the local diabetes branch may be the only way for these persons to acquire status. From this perspective, status is connected to empowerment in that the achievement of status for some individuals will increase their self-esteem, and consequently, enhance their empowerment.

The intellectual and motivational resources that were discussed earlier (Martinussen, 1973) also were found in this study as prerequisites for participating actively in the branch organisation. For example, the chairwoman became an active member in order to get the best possible care for her son with diabetes. This was an example of instrumental incentive (Parry, Moyser and Day, 1992) as her main interest was to influence the health care in the region and the decision making that concern it.

259 85% of all people with diabetes have type 2 diabetes.
Why do so few people join a patient organization and even fewer become active in it? According to Verba et al. (1995b, p. 271f), there are three possible answers to this question: because they do not want to, because they cannot, or because nobody asked. The answer “They do not want to” emphasises the absence of psychological engagement, including minimal concern with public issues, a sense that activity makes no difference, a lack of interest in politics and no consciousness of membership in a group with shared political interests. The answer “They cannot” focuses on a lack of necessary resources such as civic skills (the communicative and organisational skills that facilitate effective participation) or time to participate in activities. The answer “Nobody asked” implies isolation from the recruitment networks through which people are mobilised to join interest organisations (ibid).

Yet, none of the above motives can explain why so few of the diabetics in Sweden have become members. Several indications were brought up in this study, such as not wanting to acknowledge having the disease or not wanting to identify with it. It is also possible that people with diabetes already are members of other patient organisations as it is not uncommon that diabetics get several other diseases as well. Another relevant explanation could be that many unorganised people with diabetes are contented free riders. The results of the SDA’s work and lobbying efforts are public goods and can thus be enjoyed by all people with diabetes regardless of holding a membership or not. The selective incentives offered by the diabetes organisation may not exceed the value these unorganised diabetics already achieved as free riders.

Board Members – intensely dedicated or status-seekers

As shown elsewhere, strong leadership in patient organisations is important, in order to reach health care professionals and counterbalance ‘the voice of medicine’. This was judged to be necessary, as the patient organisations expressed that health care professionals saw them as a threat to their own profession and did not feel that patient expertise was always welcome (Carlsson, 2005, p. 29).

One notable similarity between the two diabetes branches is that they have been run by enthusiastic women in their younger middle ages. At least in one organisation it was obvious that the leader had a natural charismatic leadership (e.g. Conger and Kanungo, 1998; Valle, 2001; Storey, 2004; Yukl, 2006). Both women were also just leaving their positions within the organisation for the same reasons, at the time of my stay. Both felt they “had given too much of themselves” and felt burnt out. One of these women leaders was a nice illustration of Hirschman’s shifting involvements (1985). In this organisation, the leader felt disappointed by the results of her work as well as the work of the organisation, noting that she had been doing too much of it on her own without any appreciation from others. Because of the disappointment and dissatisfaction she was experiencing, she turned to the private sector.

The other leader had diabetes herself and her health had recently deteriorated, which also could explain her reason for leaving. In the Northern branch it was clear that the major part of the organisation as well as some external groups (e.g. the management group for the diabetes registration) did not look forward to a new leader after the resignation of the chairwoman. It could also be that because she has been so dedicated and enthusiastic, she had become very much appreciated, but also disliked as she ‘should not believe that she is better than anyone else’ (the notorious Swedish Jantelagen). Such a person is very im-

260 Charismatic leaders challenge the status quo and empower their followers to perform beyond normal expectations (Towler, 2001). The components of empowering behaviours of charismatic leadership are a demonstration of optimism and determination, self-confidence and risk-taking and an expression of confidence in followers (Towler, 2001, p. 6ff). Local leadership has been found to be an important domain of community/collective empowerment (Laverack, 2004 and 2005). Charisma is an attribute and a manifestation of the belief among followers that the leaders possess or exhibits charismatic qualities. It is not something endowed by divine forces as once was believed (Weber, 1947). Charismatic leaders are characterised by a strong personal power of attraction and rhetoric competence (Maltén, 2000; Sandberg and Fogelberg Eriksson, 2000) and they have been found to have the ability to positively empower and transform their followers and achieve many positive organisational changes (Valle, 2001). Followers must hold a particularly strong emotional reaction to, identification with, and belief in an individual, in order to attribute charisma to that person (Conger and Kanungo, 1987). They influence and play an active role in determining the beneficial and deleterious consequences of charismatic leadership (Howell and Shamir, 2005). Research also shows that leaders can be trained to act more charismatic (e.g. Howell and Frost, 1989; Towler, 2001). Charismatic leadership is one of the four traditions which expressive leadership originates from (Salzer-Mörling, 2003, p. 52f), closely connected to the transformative and visionary leadership (e.g. Barrett, 1998; House, 2001). Recently a study showed that leadership attributes associated with charismatic/transformational leadership are universally endorsed as contributing to outstanding leadership (Holmberg & Åkerblom, 2006, p. 314). While focusing on the leader as a person and on different leadership styles, research on charismatic leadership has been criticised for only studying the notions of the practices, rather than the managers’ actual practices (Ellström and Kock, 2003). However, recent examples of studies on practices of managers exist (e.g. Moqvist, 2005).
important in such organisations. (Generally, the Jantelagen may be more rooted in the north, but this study showed the same findings in the City, which indicates the prestige involved.)

In the North branch other board members and active members tried to persuade their leader not to resign by using social pressure as described by Olson (1971, p. 60f). Although this is often effective since most people value social status, it did not succeed in her case. The appointment of board members in the City branch was problematic because the board members constantly defected and then rejoined together with brand new board members. To judge from some of the comments in the member survey, the change of board and its conflicts had an impact on the participation of some members in the City branch’s activities and work.

Both branches are in some respects a kind of specialized pensioner’s organisation, where several of the board members are retired because of either age or sickness. Furthermore, the office staff are always unemployed persons gaining work experience. In such organisations people meet that are from different levels in society and with different educational backgrounds. The two things they have in common are (1) they have the same illness, or have a child with the illness or work with people with this condition and (2) they have joined the organisation (for various reasons). In at least one organisation, the social differences between the active members (board members) also had an impact as seen in Chapter 6. The member survey showed that of those who were or had been an elected representative of the organisation, the majority were older than 50 years, were members in several other organisations and where more than half had some university studies. Thus, in both areas a higher proportion of those with higher education held executive functions within the organisations. This finding agrees with the general theoretical standpoint that socio-economic status correlates with political participation (Verba and Nie, 1972; Olsen, 1982; Nagel, 1987; Verba and Schlozman, 1995 b). During the interviews and observations, some of the active members showed signs of having an inferiority complex (e.g. not being able to question somebody with a higher education). This implies that well-educated board members can dominate without being questioned by board members with a lower education.

As shown by Verba et al. (1995b, p. 273f), such capacities as civic skills, as well as the resources of time and money, are important individual prerequisites for active participation. In this study the leaders and some of the board members possessed civic skills in that they had high communicative skills and were comfortable organising and taking part in meetings. Psychological qualities (such as confidence in one’s ability) are very important for active participation. As Pateman (1970, p. 45f) noted, such confidence is a psychological benefit acquired through participation and growing with it. A sense of political competence is achieved through participation. As for the resource of time, many of the active members are pensioners or on a disability pension and thus have time to devote to the branch. This was not the case for the two chairwomen, however, as one of them worked full-time and the other was a full-time university student, with several young children at home.261 Both thought they had a tough workload in their respective organisations, spending several hours each day, and even had to work from home (e.g., taking phone calls). Active participation is thus not only explained by motivational factors (e.g., lobbying) but also by the individual’s skills, available time and money.

In the North branch there was empathy for the board. Despite the dissatisfaction experienced by some members, there was also an obvious gratefulness among a few active members regarding the work done by the board, as well as a wish to gloss over what could otherwise be seen as a failure. (For example, the low participation level at the annual meeting is justified: “elderly board members can be satisfied with the attendance”.)

### Membership Influence

The second research question concerns members’ satisfaction and their influence, whether they want influence, and what the individual members think about their own influence in their local organisation and their membership.

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261 The impact of having young children (and other life circumstances) on female leadership is discussed in, for example, Kellerman & Rhode (2001) and Billing (2003).
Member satisfaction

The respondents of the two branches are satisfied with their respective branch organisation’s performance as well as with their own membership in the branch and SDA. In general, the elderly are more satisfied than the younger. An overwhelming majority believe that the diabetics’ status in society would be negatively affected if the SDA did not exist. Members feel that there is no other place for them to turn to for the kind of service, information and support that the Diabetes organisation offers.

The feelings and expressions of dissatisfaction that emerged during my stay with these organisations mainly concerned organisational problems and conflicts inside the organisation, as well as more general issues regarding the outside world (e.g., authorities, politicians and other patient organisations). There were never any remarks questioning or downplaying the very existence of the branch or SDA or their work.262

Despite quite different motives for joining the organisation, the respondents in the North and in the City are similar in their judgement of the local and national organisation’s ability to affect their situation as diabetics. However, this concerned only the organisations’ influence. What about influence at the individual member level?

Member influence

From the member survey, half of the respondents had no an opinion on who has the most influence on the local branch’s work. Of those with an opinion, most think, as might be expected, that the board has the greatest influence. In the North, the next most frequently answer was the members as a group, whereas in the City it was different working groups. However, this reflects their different structure.

In both organisations, it was clear that only the active members had influence, meaning that only members who came to the meetings or took initiatives had any impact on the organisation’s projects or activities. In the City organisation there were many more active members than in the North organisation. Most of the City members were actively taking part in a working group or in a study circle, or both. Because of the different needs of the members, the division into groups was natural.

In the City organisation there was a special group, the health consumer group, which focused on influencing the local health care actors and politicians. It had no counterpart in the North. Internally, however, few members seemed interested in being active. In both organisations the activity level of the participants at meetings and study circles was rather low. It was also the impression of the active members and the board in both organisations that the majority of their members wished to remain passive. This view was supported by the results of the member survey, which showed that a clear majority in both organisations did not wish to participate in the branches’ activities and did not want to be more active, i.e. they are happy to remain in their passive role. However, one fifth did express a desire to play a more active role. They comprise an untapped reserve, as seen below.

As for the individual’s ability to influence the local branch, the respondents in the North branch are more positive than the respondents in the City branch. This may reflect the size of the organisation. As the organisation in the North is much smaller, it may be easier for the members in a smaller organisation to gain influence. Furthermore, according to the comments in the survey, there were fewer complaints about the board and/or management of the North branch, as compared with the City branch. However, nearly 10 per cent of the respondents in both branches have answered that they have tried to influence the local branch. This type of member is generally well-educated, a member of several other organisations and has diabetes type 1.

Travelling distances

Although one of the branches was situated centrally in a big city, there were problems in both organisations regarding distance to travel to the organisations though the problem was more serious in the North branch because of the greater distance to travel. On the other hand, it could also be argued that there may

262 It is possible that such views exist among the un-organised diabetics. However, it is hard to believe this considering the organisation’s importance in the successful lobbying regarding keeping the insulin free of charge for all people with diabetes.
be a greater need for an organisation in the North as the supply of other services is not as abundant or as widespread as in a big city. In the North organisation the travelling time and the distances always had to be taken into account when planning activities. This factor may help to explain the rather low rate of participation in the branch’s various activities. Even in the City, the travelling time was given as the major reason for why a board member resigned.

The threat of losing a driver’s license can be stressful for persons living in remote areas. The issue of keeping the driver’s license was very important to persons living in those areas. Because they were living in a rural area, many of the members of the diabetes branch in the North were dependent on having a car and a driver’s license. Therefore, the driving licence issue was on the agenda of the Northern branch.

**Strong Organisations**

The third research question deals with the local branch organisations, their characteristics and their work. However, some of the topics in this part touch upon the fourth question on patient empowerment as well. For example, the co-operation with the medical services (and with other patient organisations) can both be viewed as work carried out by the local branches and as action aiming for patient empowerment.

**Lobbying**

Both branch organisations engaged in co-production with the health services and in lobbying the health services, politicians or other authorities. In the City organisation, the structure of the branch was formed in such a way as to promote lobbying activity and other advocacy as a legitimate and essential aspect of the larger work of the non-profit organisation. Special sub-groups had been formed in order to work for more power and influence, such as the health consumer group. These small groups of the organisation play a crucial role (Olson, 1971, p. 53). No such groups existed in the North, but the efforts seemed just as developed and successful. The major difference between the branches was that so much was concentrated to one single person in the North branch. The disadvantage is obvious in the sense that everything stands and falls with the leader. In the end, it would also be hard to keep such an active leader as he or she would most likely be unwilling to take on a tough workload with little or no compensation over a long period. The lack of compensation is obviously a problem. The financing of the organisations, or rather the lack of it, is constantly seen as a problem, especially in the North, where this ultimately has led to a high number of resignations. In the long run it is also disheartening to always be plagued by a lack funds, or as one board member phrased it, “with a pistol to one’s head.” For successful results in the long term an organisation that builds on several sub-groups and with several individuals is a better option. Regardless, it is interesting to note that the Northern organisation has been such a successful and influential branch, which is mainly because of the hard work of one person. Just as Olson (1965) concluded, that even if the existence of a large pressure group gets its strength as a by-product of non-political functions, it is clear that regardless of the raison d’être the branches fill a political function at the local level, especially in the North and especially in co-operation and co-production with the county council. Here the lobbying efforts largely depend on the individual leader.

**Conflicts**

I was surprised to discover so many conflicts within these two organisations. Conflicts are a part of the reality of organisations. These conflicts occur within the organisations and concern their relationships to their surroundings (e.g., Abrahamsson and Andersen, 1998; Maltén, 2000, p. 226ff). Conflict arises whenever interests collide (e.g. De Bono, 1986). In an organisational context the natural reaction to conflict is usually to look upon it as a dysfunctional force that can be attributed to some regrettable set of circumstances or causes which under circumstances that are more favourable would disappear (Morgan, 1997, p. 167f). However, this view has been criticised by Morgan (1997), who states that conflicts are always present in organisations and that such conflicts can be fruitful. These constructive conflicts can
help build a valuable new reality as opposed to destructive conflicts that waste emotional energy, money and time (Parker and Stone, 2003, pp. 107-115). Conflicts can be interpersonal, personal or between rival coalitions or groups. It can be covert or explicit and open for all to see. It can be built into attitudes, roles, stereotypes and organisational structures or surface because of a scarcity of resources. However, it originates in some perceived or real divergence of interests. The reasons for conflicts vary and could involve differentiation of tasks, scarcity of resources, disputes over roles, personal and/or perceptual differences, misunderstandings and differences in orientations to time, information breakdown, structure and interpersonal relations (Bowditch and Buono, 1997, p. 180f; Parker and Stone, 2003, p. 108f). The diversity of the group also contributes to conflict as it spawns differing values, goals, commitments, perceptions and demands on resources (Donnellon and Kolb, 1994; Wall and Callister, 1995).

A hierarchical organisation system in businesses promotes conflict in that it is both a system of cooperation (e.g. subdivision of tasks) and at the same time a career ladder that people are motivated to climb. Since there are more jobs at the bottom than at the top, there are likely to be more losers than winners in a career race (Morgan, 1997, p. 168). This reasoning clearly applies to the situation in the two local diabetes organisations as well. Because for some members the few positions on the board are associated with high status, it becomes important for them to obtain and to hold on to a position. Still, overall, it is hard to get board members, and it is especially difficult to get the right board members. Perhaps this can partly explain the conflicts within and between the active member groups.

In both organisations it seems that the branch is of great importance to the few people who participate or work actively in the branch. This affects how they look upon themselves, their identity and status, within not only the organisation but also within society in general. On the one hand, it could be reasoned that this could either speak against the fact that many of them quit. On the other hand, it could explain this same phenomenon; with so much invested (prestige, pride and disappointment), the conflict issues become personal and therefore leave. Perhaps it is as one of the respondents suggested: for some people, being a board member in the organisation becomes an important retirement post, especially for those who did not get one in society earlier, due to being unemployed or having a disability pension. As was discussed earlier, such motives are important as most people value personal prestige, social status and self-esteem, as well as the fellowship of their associates and friends (Olson, 1965 & 1971, p. 60f). However, different individuals try to satisfy different motivations by active participation (Udén, 1993; Clary et al., 1996, p. 486f). Moreover, many active members also create conflicts. For example, although the fact that two of the active members have never gotten along may seem trivial, it can be a powerful force in organisational life.

After my first study of a diabetes branch in a mid-sized town in the north, I thought that perhaps all the internal conflicts had to do with the size of the town. Because this is a mid-sized town, I could assume that most people knew each other or knew of each other. When I realised that some of the board members met privately, I also realised that all the conflicts could have to do with other things and not necessarily have anything to do with the organisation itself. Perhaps several of the board members and active members were active in other organisations, and they brought the conflicts from there with them. Alternatively, perhaps they had a history in the group from earlier relations that could affect current relations. If so, this proves the importance of social incentives. People who are friends or belong to the same social group tend to work better together to achieve a common goal (Olson, 1965 & 1971). In this organisation it was obvious that those who looked upon each other with respect, worked better for the interests of the branch. There were, however, also conflicting opinions on what those interests were.

In the second study of the branch organisation in a big city the same findings were obtained. This would thus question my earlier mid-sized/small town hypothesis. Regardless of the size of the town, it seems the same type of conflicts and problems prevail. Is this a typical phenomenon of patient organisations? Is there something special in local diabetes branches that promotes conflicts?

In both these organisations, there were conflicts and disagreements within the boards. In the City organisation it also covered some of the working groups. Here the conflicts have a long history and have led to the board being changed several times. Actions and decisions in the present may be formed by grudges, conflicts or differences that others believe were settled or long forgotten. Such underlying conflicts can be extremely difficult to identify and to break down (Morgan, 1997, p. 170). In this organisation there were different opinions on a few issues regarding the aims of the local branch and what the important issues for them were. Perhaps this is the reason for or the consequence of all the arguments, intrigues and conflicts that were not solved. Alternatively, internal communication did not work well or there was a lack of a unanimous management policy. These conflicts can be very time consuming for the
office staff as well as for the board. According to the literature, group performance depends on the extent to which the individual members are capable of communicating in an open and honest manner, perceive themselves to be part of the team and willing to change and take initiatives on behalf of the team (Bassin, 1996). In the two branches none of these qualities seemed to be present to a high degree. It is rather interesting that both these organisations, which are ‘strong’ and influential, are so full of conflicts. Why is that? Do other local branches have this problem or is this only characteristic of these two branches? Could it be that the persons there are ‘cranks’, i.e. people who have joined the organisation because of their dissatisfaction, but then all they do is complain about others? I visited the organisation in the City at the same time as they were preparing their annual meeting. Thus, it was a hectic time for this organisation. This helped me to understand the importance of the nomination and election process to many of the people within the organisation.

Voluntary organisations are probably special in the sense that they are marked by idealism and have a different definition of what the good life is. Conflicts may arise because of these reasons in addition to the reasons associated with status and positions. To judge from the member survey, however, the branch organisations do not primarily recruit cranks or persons with few other social activities or purposes in life. Less than six per cent have joined the organisations because of their dissatisfaction, either with the status and influence of diabetics or with the care of diabetics.

Yet, despite the conflicts of those respondents who know what they think of the local branch’s ability to influence the SDA, the majority of members are positive. However, in the City branch there were a few comments expressing dissatisfaction with the board of the local branch. Comments referring to the importance of the individuals in the board and on their personal relations to the management of the SDA were also made. A similar observation was found in the qualitative study of the board members.

Co-operation with the medical services – the question of co-production

In both organisations there was good co-operation between the diabetes branch and the medical services. There was a difference between the projects in the small town in the north and the big city. In the City it was not the board of the local branch that was collaborating with the health services (although they had their say). Rather, such issues were delegated to the health care consumer group within the branch, which both arranged and participated at different meetings with various health care staff and representatives. In the Northern organisation a few board members of the local branch or the chairwoman of the regional organisation was active in collaborating with the local or regional medical services. There are logical reasons for this arrangement. The City branch is three times as large as the Northern branch and thus the tasks are delegated outside the board to a larger extent there. In the north, perhaps because of the small size of the town and the smaller population, the collaborative efforts could be generally run less formally than in the city. In the north, because of the shortage of physicians, it was easier for physicians to profile themselves if they so wished. For example, in the Northern organisation there was a doctor who was very well known in the ‘diabetic population’ and who very often was committed to projects or activities arranged by the local branch, sometimes even initiating activities himself. In the city area the shortage of physicians was a minor problem.

Ostrom’s (2002) uses of the term co-production emphasises the potential relationships existing between the ‘clients’ and the producers of a service. Physicians or other health care personnel cannot produce good health for their patients without the active engagement in the latter’s treatment. Here the diabetes branch can play an important role to facilitate, encourage and support the co-production between the health services and the members of the diabetes organisation. Co-production is thus the synergy between what the patient does and what the health services do. In two of Ostrom’s four conditions of co-production (as described in Chapter 4), the diabetes branch can play a part (2002, p. 363f). This concerns the third condition where a credible commitment between the two parties must be established. Here the branch can offer help by producing clear contracts between the patient and the health services and by informing its members about the contracts. It also concerns the fourth condition that deals with the use of incentives that aim at encouraging inputs from both parts. Here the branch can provide opportunities for people from the health services and from the branch to get to know each other. Examples of this were seen in both organisations of this study. For example, the local branches arranged several get-togethers or more formal meetings arranged for members and health service personnel. They also helped each other when representatives from the health services participated in various activities arranged by the diabetes
branch and vice versa. When representatives from the branch accompany a member to an appointment with the health services or when the branch informs the health services about feelings of inferiority, this is a positive step towards patient empowerment.

The relation between the patient and the health services personnel, specifically the physician, is very important in this respect. In a report on the patient-doctor relationship by the Swedish Council on Technology Assessment in Health Care it was found that the tone, nature and focus of the encounter between patient and doctor play a decisive role in how their relationship develops. The physician’s relation to the patient has three dimensions: medical knowledge and experience, the patients’ psychosocial condition and the physician’s competence in the encounter with the patients and their families (SBU, 1999). Co-production here would very much be about making the meeting between patient and physician equal. The branch organisations have found two ways of working towards this goal. One way is to influence and teach the health services about the patient’s needs and the other is to educate the individual member to become an empowered and active user of the health services or a co-producer perhaps. If so, is it appropriate to think if it is the same thing that causes people to become active that also makes them capable of being a co-producer?

The prerequisites for a more developed co-production exist, but even more would be demanded of the local diabetes branch. In order to get the most out of the co-production, the branches and the health services must show more interest in working together. Throughout this analysis, it has become clear that empowerment and co-production go hand in hand. By achieving true co-production, empowerment can be achieved for all involved. Individual empowerment, however, can be attained without any co-productive actions, but collective empowerment demands more. Individual empowerment alone is necessary but not sufficient for collective empowerment. Co-production is also needed.

Co-operation with other patient organisations

At my first visit to the local diabetes branch in the north, I became aware that it shared premises. Not only did the local diabetes branch and the regional diabetes organisation share offices, they also shared working and leisure areas for the staff of a number of other patient or disability organisations. Obviously, they had all the requirements needed for co-operation with their neighbours on the same floor. This closeness certainly could create opportunities for successful mutual work in planning, etc. However, there seemed to be very little collaboration between the local patient organisations in both places. Concerning the premises in the City branch, it was more natural as it was the only patient organisation in the neighbourhood. I therefore expected more co-operation, especially as people with diabetes often have complications and thus tend to suffer from other diseases as well. Therefore, I thought it would be natural for the diabetes organisation to collaborate with these organisations regarding seeking influence politically or at the local health services and in arranging activities. Instead, it seemed that a power struggle emerged among different actors. Either the board of the diabetes branch looked upon the other patient organisations as competitors who might ‘steal their members’, or the diabetes organisation was looked upon as a competitor by the other patient organisations who might ‘steal their members’. The result of this power struggle was that few joint efforts and activities were undertaken.

One significant finding in Wood’s study of British and American patient organisations, was the lack of coalitions or alliances between associations representing related medical conditions (2000, p. 109ff). There should, however, be a potential for coalitions, since patient organisations share common ambitions and goals, e.g. demands for higher levels of public spending on medical research, speedier access to the latest drugs and improved specialised facilities for the treatments of various conditions (ibid, p. 176). In the USA, patient organisations seemed to value their individual autonomy above collaboration, whereas in the UK the few alliances that were found were weak shoestring coalitions who completely depended on their individual members for action. The competition between patient organisations is not only external as in the search for funds, support and sponsors, but also internal within the confines of a particular medical condition. Therefore examples can be found of two (or more) associations covering the same disease, as both compete to ‘represent’ people with that specific condition. Perhaps the two different groups within the City branch representing their female members, the Women’s section and the Girl’s section, are examples of such competition.

Public action is usually perceived as being full of idealism, dedicated to a cause and perhaps with some traces of sacrifice for the common good. Individuals recognise this as an alternative to the disappoint-
ments and selfishness of action in the private sphere. This stands in contrast to the fact, “political activity often involves one in a very different set of activities: the making of strange alliances, the concealment of one’s real objectives, and the betrayal of yesterday’s friends – all of this of course for the sake of the ‘goal’” (Hirschman, 1985, p. 100). The lack of co-operation and distrust between the various patient organisations are examples of this disappointment.

It could be a problem for possible collaborative projects that empowerment may mean different things to the participants. For some, empowerment can only be represented in direct action (Couto, 1998), while for others, broadened participation in itself represents empowerment. Some think that the distribution of information is an empowering activity, but others see empowerment as an extended process including developing a collective sense of purpose and overcoming a sense of powerlessness over time (Crowson, 2003).

Whether there is any co-operation or co-production between the patient organisations clearly depends on the individual person. In the Northern branch, co-operation was mainly initiated by the chairwoman of the regional organisation. Nevertheless, expressions of fear among other board members were made: “What will happen when she is not around?” The individual person was also important when it came to the branch’s network contacts. In the Northern branch, a great deal of the contacts was related to an individual in the board, and it seems closer at hand to say that it is more a matter of personal contacts than the branch’s contact. The individual’s importance was also expressed from the health services when the resignation of the chairwoman was discussed at a meeting between the health services and the diabetes organisation. The health care representatives expressed sadness but also scepticism towards the new and unknown representative for the diabetes organisation. In the City branch the importance of the individual leader was not as apparent as it was in the Northern branch. This is because the City branch had members that are more active and special groups devoted to specific issues.

Strong organisations?

My thoughts and ideas as a researcher have changed throughout the data collection process. I knew that the Diabetes movement in general was viewed as being the ‘strongest’ of all patient groups in Sweden, at least among the health profession, and I was going to study the two ‘strongest’ local branches. I was therefore curious about the members’ commitment. In my mind I pictured all these people of various ages participating with passion and enthusiasm at meetings. Going to my first encounter with a patient organisation, I was wondering about what type of influence they had and what influence they felt they had, which did not necessarily mean the same thing. I imagined that the people working for the organisation were full of strength, dedicated and with a strong will to fight for the organisation’s members. In short, I believed these were persons who constantly would question and motivate others to work for its causes.

When I left the first organisation after 10 days, these images had changed dramatically. My experience from the North branch was that most active members, including the board members, were pensioners and elderly persons who did not seem very active. The chairwoman of the regional organisation, who was also very much involved with the local organisation, at times so much it was hard separating the two, seemed to play the leading role.263 She was indeed hard working, initiating several joint projects as well as a number of internal projects. Therefore, she was also highly admired by some of the other board members who, in interviews with me, expressed fear for the organisation’s existence after her resignation. At the same time, some board members disliked her. They felt she did too much on her own. This could be interpreted to mean some board members were jealous, but this is only conjecture. The consequence, however, was that after many years she decided to resign from the board. My questions about what influence they had and how they felt about it had also changed. Now, I was wondering whether they wanted any influence at all. Perhaps they were happy with arranging their activities and meetings. It seemed that many of the board members were content, being an organisation mostly for pensioners, which arranged some social activities for their members (also mostly pensioners). It might be that this branch was

263 It was impossible to distinguish the regional and the local organisation from each other in the North branch. The formal separation between the two organisations was so recent and the division of work and issues were still unclear at the time of my visit. Furthermore, there seemed to be close co-operation between the two organisations. My impression was that the organisations still overlapped, especially as they shared the same premises and office staff.
deemed to be strong because of the well-known physician who was committed to it, especially because this is a region where there is a high shortage of doctors and because the chairwoman of the regional organisation was intensely dedicated.\textsuperscript{264} It seemed that the branch functioned more as a social meeting point than as a strong voice for their members locally. However, it also seemed that the chairwoman of the regional organisation dealt with the issues of influence (with the health professions, politicians, etc.).

One of Olson’s important explanations for collective action is that people become members of organisations because of economic, social or psychological reasons. The same is true for the functions the organisations have in society. This branch organisation clearly filled a social function for many of the members. In the member survey 40 per cent of the respondents answered that they had joined the diabetes organisation for social reasons. The social reasons ranked higher in the North than in the City and there was a higher degree of member participation in the North. The fact that this was a local branch in a mid-size town up north was also significant in that most active members knew each other and belonged to the same social life in this town, which put pressure on other members of the group to join or participate in the branch’s activities. According to Olson’s by-product theory, many lobby organisations obtain their support mainly because they perform some function in addition to lobbying (Olson, 1965 & 1971, pp. 132-167). In this organisation, the activities arranged by the local branch and the social contacts that are provided through membership were important reasons for joining the organisation. This was more important for the older and more isolated members of the rural areas in the north than for the younger members in a major urban area. The organisation also had other functions, such as providing information and knowledge, which were more important to most of the members I met than the issue of gaining influence.

With this in mind, I went to visit the local diabetes branch in the city, discovering that the situation was somewhat different there. More people in the City branch were involved. Further, the organisation was bigger, was divided into several working groups and had a higher activity level than the North branch. However, the City branch had 1000 more members than the North branch. Naturally, there were a few more committed and active members in the City branch. The active members and the board members were aged 30 years and over. Thus, the members were much younger in the City branch. However, the majority of the members were pensioners here as well. Because of the wider age range in the City branch, the provision of activities was larger and more differentiated as compared with the North branch. Some of the active members were very interested in making the organisation’s voice heard and fighting for their rights. In the City branch it seemed that people wanted to have some influence on society. In the member survey, however, it was found that in the North branch that more members had joined for political reasons or to gain influence than in the City.

**Resources**

Perhaps it is not only a question of whether they want to be ‘strong’ but also whether they know how to be ‘strong’. With limited resources, this can be hard to answer. As we have seen in Chapters 5 and 6, the SDA has much more resources at the national level as compared with the local branches. In 2005, the SDA had 12 employees, the North branch had none, while the City branch had two half-time employees. The revenue of these organisations also differed greatly, with the SDA bringing in 17.7 MSEK, the North branch almost 200000 SEK and the City branch 350 000 SEK. From these figures, it is obvious that the local branches have limited funds. Both local branches, however, managed to achieve a positive financial result (11000 SEK and 7000 SEK in the City and in the North, respectively) in 2005. The SDA’s net result the same year was 5 MSEK. Their work, however, is more focused on issues of influence and lobbying.

It is not surprising that the branch organisations’ activities are so limited and their influence is so constrained given the meagre resources available to them. If more local activities are going to be engaged then they will have to gain more control over their own member dues. Considering the different levels of resources, it is not surprising that the members of the North and the City branches recognise that the SDA is more important and has more influence than the local branch organisations. Being a meta-

\textsuperscript{264} Here I would use the Swedish word *eldsjäl*, which refers to an enthusiast, which is defined as an ardent and enthusiastic supporter of some activity or cause. An *eldsjäl* is an altruist (as opposed to an egoist), but an altruist is not necessarily an *eldsjäl*. The Swedish word contains an aspect of activity, i.e. the *eldsjäl* is not only dedicated to a cause but also works actively and enthusiastically for it.
organisation\textsuperscript{265} (Ahrne and Brunsson, 2001), this would lie in the SDA’s nature. Accordingly, it is not surprising that the respondents think that the SDA has better abilities than the local branches in affecting the diabetics’ situation in society. Younger persons and those with higher education are more sceptical than those with a lower education and who are older. Another reason as to why the SDA gains influence is because it is a nationwide organisation with many local branches and a large number of members. Their funds are also impressive considering that they spend 14 million SEK (in 2005) on scientific research on diabetes and the care of patients with diabetes. Taken together, this gives a symbolic weight in debates and in lobbying. In accordance with Ahrne’s (1994) reasoning, the combined resources of the SDA give weight and emphasis to its standpoints. The raison d’être of the diabetes organisation was clearly expressed in the interviews with active members from both branches. A quote from Chapter 6 exemplifies how important the organisation is in seeing to the diabetics’ interests on the issue of keeping insulin free of charge: “as soon as there’s any sign of this being threatened, one has to be active.” Organisation from this perspective therefore means latent readiness for action and therefore influence. The resources, especially those mobilised and produced by the SDA at the national level, are of vital importance for their continued work.

Patient Empowerment

The final pages of this chapter focus on the fourth research question which concerns patient empowerment and its relation to membership, activity and influence.

When applying the active membership figure (as described in Chapter 4), with its prerequisites and effects on the findings from this study, it is clear that both types of prerequisites played a part in deciding the level of participation of the active members in the two local branches. This was found in the interviews with active members who expressed their reasons for being active. However, it should be noted that persons may not always be aware of their resources or the incentives that trigger them. The level of activity varies from person to person which also has an important effect on the outcome. It can move on a scale from participating seldom in an activity of the branch to being the leader of the branch with the responsibility of motivating others to participate. Naturally, both prerequisites and effects will differ between the individuals at different points on this scale.

\textsuperscript{265} Members of a meta-organisation are not individuals, but other organisations. By establishing a new formal organisation, it is easier for the members to co-operate, as well as to create a distinctive image of themselves as opposed to the surrounding world and to act to influence others. Meta-organisations are commonly established to formulate and pursue their members’ position.
Examples of both social and educational effects were found in this study as well as effects of empowerment. Being a highly subjective concept, it is unclear to what extent empowerment was achieved by the members.

The box representing all the effects of having participated actively was called self-development in Chapter 4. Although this would still be correct, I believe that after this study a better term would be *healthy lifestyle*. This represents what the participants hopefully have gained and maintain even if they no longer are active members. Thus, in a patient organisation, self-development becomes a healthier lifestyle.

Becoming an active member of a social movement may have good effects on an individual level as well. This means that a person has to enter the public and take a stand for his or her convictions. Through active membership, feelings of shame can turn into feelings of pride (Starrin, 1997). Consequently, what was earlier a stigma (e.g., being a diabetic) is now something of a more positive character, i.e. the individual no longer feels shame about his or her condition. This improved self-esteem is also a form of empowerment.

**The way to…-project - empowering the participants**

Empowerment can be looked upon from two perspectives. Empowerment can be power distributed from above or it can be power distributed from below. As seen in Chapter 4, there are several mechanisms affecting empowerment in patient organisations. From the beginning, the empowerment program “the way to…” was a form of co-production with the SDA. On the initiative of the chairwoman of the regional organisation in the North, the SDA in Stockholm trained and educated participants from the Northern region to become study circle leaders. When other regions only brought patients with diabetes there, this chairwoman also brought diabetes nurses with her in order that there was co-operation with the health services. In the North, the diabetes branch and the county council first identified the region’s health centres. They then planned and organised the study circles in the region, both for people with diabetes and for people with other physical impairments.

During this project, diabetes physicians and nurses within the region were informed and the local branch further trained the study circle leaders, who either were diabetics themselves or employed within the medical services. Thereafter, the ABF ran the study circles. In addition, the study material was produced in the form of co-operation between an educational company, the ABF, the SDA and two other patient associations.

‘The way to-project’ aimed to empower the members participating in the study circles. The goal of these study circles was to strengthen and empower patients in their contacts with the health services and others who they depend on (e.g. staff at the municipality). At the local branch and the regional organis-
tion in the North, this project was one of the most important activities that the organisation could offer their members. During my stay there, this project was constantly being referred to and it was obvious that the board members were very proud of this activity. One positive consequence for the local branch was the recruiting of new members, which had stagnated during recent years. This project was able to reverse this negative trend.

In the City ‘the way to-project’ was also run through the ABF. Here, however, the project did not get the same attention or focus as it had in the North. It was one of many activities, but not necessarily one of the most important ones. Rather, focus was put on the various working groups. ‘The way to-circle’ in 2000 was also arranged in Persian for the immigrant members who speak Persian.266

Although most empowerment programs show unclear results, the diabetes organisation in the North made a serious effort at addressing the psychosocial areas that usually are neglected, such as the social, emotional and cognitive aspects of living with a disease. Earlier research has shown this to be an important area (Arnold et. al, 1995, pp. 308-312). Patient empowerment or education programs traditionally focus on physical factors (e.g. glucose management in the case of diabetes), although good knowledge about the disease and psychosocial skills are needed in making informed choices about daily care (Anderson et al., 1995, p. 943f). ‘The way to-project’ mainly focused on the psychosocial skills.

One of West’s (1989, p. 109f) principles of empowerment was that the group must be able to generalise the interests of its members and that any differences among members must be reconciled within broader political objectives. Externally, the diabetes organisations in this study have achieved this intention, but internally there are still major differences between the members with the two different types of diabetes. As seen in this study, on the local level this is hard to achieve. Instead, the result is that more resources and efforts are put into one category, which consequently is more inclined to increase at the expense of the other type. That is not to say that differentiation cannot work; rather, it merely means that there are problems associated with differences among an organisation’s members. What is needed is perhaps is simply more financial and personnel resources, as well as commitment from those who are active and in charge of the different groups.

‘The way to-project’ is an excellent example of how empowerment and co-production work together. This is most likely one reason for the positive results, such as a higher level of knowledge in health care issues and a higher level of active participation in meetings with the health services, both for the participants and the circle leaders. Furthermore, a result was that either the circle leaders or the participants commonly contacted their local health services in order to collaborate in developing the quality of the health care.

A central theme in ‘the way to-project’ was the focus on consumer identity. The North and the City organisations were putting a great deal of emphasis on their members being health care consumers rather than being just patients. They were working actively in an endeavour to motivate their members to identify with the idea of being consumers rather than passive patients, despite there being active members who were against this change in identity. The vast majority of the members, however, were positive to the change, mostly it seemed because of ‘the rights that come with being a consumer’.

Patients, consumers and health care consumers are different concepts. Traditional paternalism refers to the fact that patients are required to trust the health professionals who are considered to know what is best for the patients. Consumerism, on the other hand, tends to go to the other extreme. Health care consumerism is becoming increasingly popular in patient organisations and in society in general. Patients as consumers are far from being passive consumers of pre-packed health care (Keaney, 1999), rather they do not take the trustworthiness of professionals for granted. Patients in this context are responsible for acquiring the best buy for their own health care. Language plays a significant role regarding the differences between the words ‘consumer’ and ‘patient’ and the underlying assumptions of these labels. Different words mean different things to us and are based on different assumptions, which, of course, affect our understanding of the terms. Moreover, as Czarniawska-Joerges and Joerges point out, language has a tremendous impact on any situation, and those controlling the use of terms are those with substantial power (Czarniawska-Joerges and Joerges, 1990; Czarniawska-Joerges, 1988). The language we use matters in the sense that it is the most important tool we are disposal in having an impact on our surroundings, including communication with other people. Consumer legislation and consumption processes may not appear to have any direct connection to the field of health care. Nevertheless, this language has force-

266 So were a few other circles. This was because of one of the active members, who himself came from Iran, decided to translate study material and initiate activities for people with diabetes who only speak Persian.
fully been introduced in health care and its use is continuously increasing. For a discussion on the implication of the concepts mentioned above, see Werkö (2000).

Now it is time to determine whether the switch from ‘patient’ to ‘health care consumer’ equals empowerment. Is just switching labels insufficient in producing real change between the patients and the health care professional? Although changing from ‘patient’ to ‘health care consumer’ is necessary for both the health services and the people with diabetes in raising the diabetic patient to a participant that is on a more equal level with the health care professional regarding care, it is not sufficient for empowerment, greater influence and power. Another alternative – co-production – is necessary as it transcends the simple black and white alternative of patient/consumer labels.

Empowerment and identity

Membership in a patient organisation has earlier been identified as important for the individual’s self-perception and identity, although not expressed in these terms (see Carlsson, 2005, p. 35f). The member’s process was then described as going from being a victim ‘having cancer’ to survivor, and from survivor to advocate. One strategy used by the local diabetes branches and the SDA in their quest for empowerment has been to try to change the view of people with diabetes from being patients to health care consumers. These people include not only their own members but also other people, particularly those within the health services. Through active participation in ‘the way to-projects’ people can adopt this new terminology and thus gain a new collective identity (Gamson, 1992, p. 55). The people’s sense of who they are connects to a shared definition in an effort at social change (ibid). Although most of the respondents were positive to this change in terminology, there was some resistance in both organisations. The main criticism against this change was that consumers choose to consume, but there is no one who has chosen to acquire diabetes or to consume medical services. These active members felt that they did not have a choice regarding whether to consume health care or not because in their case they had no choice in the matter. The symbolic importance of changing terminology should nevertheless not be underestimated. In several interviews with active members in the two branches of this study, the use of the term health care consumer was highly appreciated and indeed strengthening the individuals identity and promoting a positive view of themselves as members of the community.

In this study identity has proven to be an important explanatory factor to account for why it is difficult to recruit young people to patient organisations (the reason being that they prefer not to see themselves as patients). For many, being a member in a patient organisation, especially an active member, implies an identity of a person who is sick. In this way membership can lead to the opposite of empowerment.

How then can identity emerge through membership in a patient organisation? Only people acknowledging their disease have obviously joined a patient organisation (apart perhaps from small children who have been signed in as members by their parents). Thus, they have already identified themselves as belonging to the group of people who have diabetes. This identification is probably further enhanced for the passive members when considering that most of them frequently read their membership magazine. For the active members, the identification process will be even stronger. When participating in the branch’s activities or in its work, most members will further develop and adhere to their mutual feelings of belonging and the group identity that is being formed. If, however, the discrepancies among the active members are too large (e.g., major differences in age among the participants), a mutual identification process will be harder to achieve.

Understanding the growth of empowerment through membership

Empowerment can thus be seen as a reason for and a consequence of membership. Further, this is more likely to be the case for active membership. It is reasonable to assume that for people seeking empowerment, one way could be to join an organisation or participate in the actual organisation of such a group. For people not actively seeking empowerment, it may still come about as an unintended consequence of the membership. Whether empowerment as such is something the organisation wants largely depends on the circumstances at each local organisation and its environment.

Moreover, patient empowerment can be expressed as patients’ active involvement in the decision-making process of their treatment, as well as their will to be actively involved. The concept of empow-
Empowerment is self-perpetuating in that patients tend to empower other patients through the sharing of knowledge and personal experiences (Melin, 1996, p. 9). Hence, both informal networks and formal ones (such as patient organisations) play a significant role in empowering patients. Another example is the diversity of websites as patient networks: for example, the wellnessweb (www.wellweb.com) or CHESS (Gustafson et al., 1999). Several studies have shown how the Internet can play an important role in empowering patients (e.g. Fox et al., 2005; Broom, 2005). As was shown in Chapter 6, both branches in this study contributed to empowering their members in a number of ways, particularly in their various educational activities. By engaging in such activities, the participants have the possibility to gain insight and knowledge of diabetes, as well as how to live with the disease in the best and longest way possible. The same reasoning applies to the physical activities offered in the Northern branch, although not as directly. In addition, social motives and purely social activities can have impact on empowerment (such as improved self-esteem through socialising and sharing of experiences). However, this aspect of empowerment was not included in this study’s definition of empowerment. Such effects are mainly attributed to the educational activities. However, members of both branches have a variety of social activities that they can participate in on a regular basis. For members wishing to become active, there was a greater selection of activities to choose from in the City than in the North. There were also more member groups with various themes available in the City branch. Thematic nights and information meetings for members in general were offered to a greater extent in the City branch. This does not mean that it is harder for members in the North branch to become empowered, but that there is a wider selection of alternatives for those who wish to participate in the City.

One of the working groups in the City, the health consumer group, was actively working to change the views of people with diabetes within medical education and the health services. Much of the branch’s work on the local level aimed to help empowering their members by influencing the outside world, which is possible by changing the views on diabetics in society or in medical surroundings, or by collaboration and co-production with the health services and other organisations. The SDA has a key role in changing the views of people with diabetes and in achieving their lobbying goals. This also has a great effect for the empowerment process at the local level.

The Health Care Law states that patients have a right to be informed and to actively participate in decisions concerning their treatment and health. It is important to differentiate between two situations here: first, the individual patient’s right to express his or her own will in consultation with the doctor, and second, patient organisations’ right to participate in the planning of health services and the delivery of care. The individual patient’s right is affected by organised influence and membership promotes more knowledge, which can also influence the individual in his or her meeting with the health services.

Empowerment as a room

In order to understand the concept of empowerment better, the metaphor of a room may be useful. Imagine a room with many doors. Some of the doors can be opened from the inside and some from the outside. All the doors lead to the same area outside the room. Some doors are easy to open (all you need to do is to touch the doorknobs), whereas other doors are more difficult and it takes greater effort or jiggling with the door knobs in order to open these doors. Some doors are locked and require a key to be opened. The doors can be opened at any time and in any combination. Some doors can be closed at any time. Usually, some doors are opened and some are closed, but they can all be opened at the same time as well. They can also be opened to different degrees, i.e. some doors may only be slightly opened, whereas others are wide open. Thus, there are many possible visions of the room, with the look of the room varying from individual to individual.

The room symbolises empowerment and the doors symbolise the various ways we can become empowered. Doors that open from the inside concern feelings and the development of a special way of looking upon oneself (e.g., the individual’s self-esteem, self worth, trust in oneself or others and feelings of being able to act). Doors that open from the outside concern not only changed conditions and attitudes in society but also the individual’s knowledge and view that society’s structures can be modified and changed. Doors opening from the inside therefore refer to self-development while doors opening from the outside refer to external influences.

First of all we must find the doors. Some doors are easier to find than others and some doors we need help to find. Depending on the context, it may be enough to open only a few doors for the empowerment
to appear, although the fewer that are opened, the longer it takes. Doors can also be slightly opened (when just starting the process of improving one’s self-confidence and self-determination) or wide open (when fully embracing all opportunities to control the decisions affecting one’s life and realising one’s ability to make a difference in the world).

If a door is difficult to open, we find ways to make it easier to open (e.g., if the hinges are rusty, we use a lubricant). Membership in an organisation functions as a lubricant, where the more lubricant you use (i.e. the more active a member you are) the easier it gets to open the door. We know that participation on the broad increases the individual’s knowledge and leads to an improvement of his or her self-esteem. The more individuals participate, the more their skills improve. The very qualities needed for participation are developed through taking part in the common exercises and the experience of participation leaves the individual better psychologically equipped for further work in organisations. Doors can also be difficult to open from the outside (e.g., when participation is not possible or education not available and people’s level of receptiveness vary).

If the door is locked, we need a key to open it. The key in this context can be educational efforts. Education in combination with participation will likely lead to empowerment as this combination gives many of the prerequisites and can thus help in unlocking the door.

We must be careful because doors can also be closed. Empowerment is not constant, although it may appear to be so. If the self-esteem or the external conditions of society that the empowerment is built on should collapse, the doors will close and the process of opening them must start all over again.

In my view, there is such a room of empowerment in each individual and that there exist numerous ways available to open the doors to empowerment. The rooms to which all the doors are closed are not yet accessible. The rooms or their contents do not mean the same thing to all of us in the sense that each individual’s experience is different and highly subjective.
A current trend among Swedish voluntary organisations and in society in general concerns changing views in governance and audit and professionalisation (Wijkström and Einarsson, 2006, p. 41ff). From the perspective of voluntary organisations, we can witness numerous changes in their relations to companies in industry and trade and to the authorities. This regards both the content and the use of ideas and terminology from business life. There are several reasons to account for why professionalism is increasingly advocated. One reason is to oppose amateurish or unprofessional behaviour, the point being that things must be done in a better way or more efficiently (Wijkström and Einarsson, 2006, p. 42). Another is to focus on whether the work carried out is paid for (salaries to employees) or not (unpaid work by members). Professionalism is often discussed in terms of expert-knowledge and education. Consequently, a line is drawn between the work of those who are paid (the professionals) and those who are unpaid. A prerequisite for employing people, however, is to be able to pay the salaries. In this study there were quite different levels of financial resources in the diabetes organisation. Only at the top level (i.e. SDA) was there enough resources to hire staff. The local branches wanted to hire office employees but none of them could afford to hire on their own. Only when the state contributed with a wage subsidy covering (a part of) the costs for the employees with reduced working capacity, could they employ a secretary or two. Today, the local branch in the North has no employees and thus the branch’s work is run on a purely voluntary basis. The low remuneration to the board members carried negative consequences. For instance, the chairwoman resigned after many years of hard work because of the lack of compensation for her efforts. The City case had a similar experience. Not being able to offer any economic compensation makes it even more difficult to recruit people to the board, especially the right people.

At the national level there is a clear professionalisation in that their staff is paid and most of them are well educated or have some expertise knowledge (e.g., from the health services, the governmental ministries, departments or other authorities). This could be perceived negatively, partly by arguing that the organisational control stays with the employed staff at the expense of the members and their representatives, thereby causing a shift of power within the organisations. Those employed improve their competence to organise the work, but simultaneously risk loosing the other perspective on the work of many of the members (Ahrne et al., 2004, p. 51). Another argument is that professionalisation tends to standardise the work (Wijkström and Einarsson, 2006, p. 43f). However, I could not find any examples of dissatisfaction with the SDA or their employees. Almost all respondents were happy about the work of the SDA and felt that the SDA was more important and had more influence than the local branches. Accordingly, their work also had importance for empowerment.

This study has shown some common characteristics of local patient organisations. One is that intensely dedicated people lead the organisations and that only a few other board members or regular members are active.

The local diabetes branches often have an inner core of active members who carry out the main work of the branches. These members often possess organisational competence. Without this core group, there is virtually no organisation. In each organisation, an intensely dedicated individual acted as the driving force, more so in the North than in the City, initiating and performing the work. Many activities aimed at influencing local authorities, building networks and engaging in co-production with, for example, the health services depended on this one person more than the local branch organisation. It is obvious that for local branch organisations to be influential and pursue empowerment they must create prerequisites and opportunities for recruiting and keeping intensely dedicated persons at the leading positions, and allowing them to do their job. As these intensely dedicated persons also usually are driving forces, conflicts easily arise.

Conflict is traditionally viewed in our culture as being bad or dysfunctional. The opposite of conflict is harmony, which is viewed as good or functional. Yet, there can be dysfunctional consequences of never having conflict or suppressing conflict, just as there also can be dysfunctional consequences of
having too much conflict. In this study we have seen how organisations are influential and active despite having internal conflicts.

This study has showed that organisational structure and highly dedicated individuals are needed at the local level in order that a branch has influence. With so much depending on a dedicated individual, what is the branch organisation’s function? Apart from giving legitimacy and access, which the organisation does as an entity, the organisation runs various member activities, arranges contacts and functions as the social meeting point for its members. The organisation constitutes a necessary platform for the dedicated members. Without this platform, a dedicated patient or individual will not likely gain the attention of civil servants or politicians.

Of the two branches in this study, one was found to be more structured than the other branch. The success of the less organised branch may not originate in the lack of organisational structure. Perhaps it is rather the number of decision-makers in the area within the organisations that the branch wants to influence. The smaller Northern branch was much less structured than the larger City branch, but because of the smaller size of the town (which might result in relations that are more personal), there are also fewer decision-makers to influence as compared with the big city. Again, it is the impact of the most dedicated member(s) that counts. With only a few committed persons, the influence will be greater in a small town than in a big city.

From what we have seen, the active members of the patient organisations probably consist of two different types of member. The first group prefers social get-togethers, to have something to do, perhaps some meaning in life, status, prestige and a position in society. The other group wants to have influence. From the local branch’s perspective, in order to get a strong and influential organisation, it is important that social and status-seeking members do not stand in the way of intensely dedicated individuals. The creation of an organisation for people with a common interest will, after all, necessarily also include an improved social life with the possibility for informal discussions and exchange of views that get-togethers invite.

The structure of people’s motivations for passive and active membership involves multiple motives corresponding to psychological or social needs of the individual as well as for informational, medical and political reasons. The results of this study suggest that people mainly join a patient organisation in order to acquire information and knowledge about the disease and how best to live with it. When first stricken with an illness, it is unlikely that the first feeling is disappointment with the health services but rather the need for information. This may be true for many non-profit organisations. Patient organisations differ somewhat from other non-profits in that they are concerned with an issue that affects their members’ lives and quality of life. However, it is obvious that a majority of the members of the diabetes organisation have joined in order to acquire information. As noted previously in this thesis, being informed and gaining knowledge contributes to empowerment.

Passive membership in this study is a way of supporting the SDA and the local branches in their work. Further, it is a means of supporting medical research and keeping oneself informed about new aids, medical discoveries or other information regarding living with diabetes. This way of gaining knowledge is important for the empowerment process.

Active membership carries with it a number of important implications. By participating actively, individual members can have a social life, gain new insights and knowledge about their disease, the organisation and other issues, as well as contribute to improving the conditions of other diabetics in the community. For the few members who are elected on the board, they can gain status, prestige and respect in their new role.

The active membership of board members and other leaders in patient organisations usually involves long hours without pay. It also implies being available for members during their free time, including when they are in the privacy of their own home. In this study this situation resulted in two resignations from leaders who had been intensely dedicated to the organisation and its cause and on whom the organisation greatly depended. At the same time, because these individuals are highly desirable, other people within the organisations may run the risk of becoming highly dependent on these persons.

The members’ views and opinions of their branch organisation were found to differ with respect to their level of activity. On the other hand, all members see the existence of the organisation as important and want to support it in some way. Not surprisingly, most of the passive members are happy in this role.

267 For example, most members of the golfer’s association are probably members in order to play golf and not to influence the appearance of the golf course.
and satisfied with receiving the membership magazine. Yet, about 20 percent of the members (regardless of branch) were willing to increase their participation. A majority of these persons were young. The active members all shared the basic positive view of the organisation’s existence, but differed considerably in their opinions on how the branch was led or the way the branch carried out its various activities. This difference was a clear reflection of all the conflicts that prevailed within the organisations. For some active members, the branch organisation meant everything in their life. It was in the organisation that some persons found the true meaning of life. These people seemed lonely and wanted the attention and feeling of being needed that working for the organisation offered. Some of these members also wanted the status that came with being a board member of the local branch. Very few others were intensely dedicated in working for the cause and to changing the conditions of people with diabetes.

Instead of providing services themselves (as the large Swedish state-provided health care system has left little room for organisations outside the state), patient organisations have focused on acting as pressure groups and lobbied different levels of government to provide services. The SDA has offered its members a number of selective benefits by publishing journals needed by its members, and by making its activities educational as well as social. These benefits provide incentives for joining the organisation. The SDA obtains a large membership because it provides non-collective benefits. It would not have the non-collective benefits to sell if it were only a lobbying organisation. Therefore, the impressive political power of the SDA and the local groups that compose it are a by-product of the non-political activities of organised diabetics. Nevertheless, without this organisation members felt that they would lack influence.

In this study, the aggressive pressure or lobbying organisation is found at the national level, i.e. the SDA. At the local level, the branch organisation largely functions as a social meeting point, though in both organisations some lobbying is done.

Both branches offered their members participation in an empowerment project known as ‘the way-to-project’. The project started out as a pilot project in the Northern region and became a national collaboration project between three patient associations with the goal of empowering the members who participated in the study circles. Other activities of the branches’ also concerned empowerment, although not as direct as in ‘the way-to-project’.

To gain empowerment it is necessary to have a platform from which you can exercise empowerment. Production of information and advice to members in the patient organisation may contribute to creating such a platform (e.g., through the co-production with the health services). Co-production serves a dual role: as a means of recruiting new members and as a platform for empowerment.

Although it is increasingly being recognised that patients should be co-producers of their own care, it is still widely assumed that the medical services own the patient data and do something ‘to’ the customers, rather than ‘with’ them. Instead of being on the producing end, the patient is then still on the receiving end. In order to become co-producers, patients need to be involved in the design of their care and have a stake in the outcomes. For co-production and empowerment to occur, power must be shared more equally between the health care providers and the patients. This would require more engagement from patients and more letting go from health professionals. Here patient organisations can play an important part.

In order to achieve any real empowerment and influence, it seems that it is not enough with empowerment only, at least not on the collective level. In order for real empowerment and influence there must be co-production. Co-production means there has to be at least two parties that work together in producing something that is usually of benefit to both parties. Both parties can perhaps achieve individual empowerment on their own within their respective spheres of work, but it is only when they work together that true collective empowerment can be realised. Individual empowerment refers to the individual’s own goals or process, or a combination of these that intend to increase the social, psychological, political or economic strength of the person in question. The same reasoning applies to collective empowerment, with the only difference being that it is the strength of the group rather than the strength of the individual. The distinctions are equally important.

This study shows that many prerequisites for a more developed co-production already exist, but the local branches could do more. The branches and the counterpart, i.e. the health services or some other authorities, must develop a greater interest in working together. Problems need to be addressed in enhancing the co-operation between the actors and finding ways of more effectively motivating patients, their representatives and public officials to work together to achieve trust, empowerment and co-production. One aspect of co-production is that the patient organisation oversees what is done and what is not done in the health services. The matching between public health services and the voluntary organisations was
exemplified in this study by the local branches adjusting their educational efforts and activities, particularly to patients with type 2 diabetes as the type 1 diabetics were already under the care of the health services.

True co-production also means empowerment. Co-production should not been seen as an alternative to empowerment in that these concepts presuppose one another. Indirect empowerment can be achieved through participation and gaining knowledge, but direct collective empowerment needs co-production. This study therefore supports the inclusion of co-production in empowerment theory, as suggested earlier in different contexts by Pelikan and Trummer (2002), Crowson (2003), Harris (2003) and King (2005).

Regardless of their social background, the members of the two organisations gave similar responses to the questions in the survey, which was not expected. This finding suggests we now have a clear picture of what members of a ‘strong’ local patient organisation think about their membership, their ability to influence and their branch organisation and the SDA. The goal of most of the members is not to have an influence on the care of patients with diabetes; rather, they join in order to acquire information in a socially positive surrounding. A membership in the diabetes organisation fills several functions for a small part of the diabetes population in Sweden. As we have seen in this work, it fills educational, psychological, political and social functions, the latter being more important in the North than in the City regarding the elderly population.

Although dissatisfaction268 in this study did not prove to be important in explaining reasons for membership, Hirschman’s rebound effect is still helpful in emphasising that happiness arises not only from the expected results of the chosen action (here the active membership) but also from theendeavour itself. This is because the benefits from the actual process of attaining the wanted outcomes and the results of this action are inseparable. Although it may not be considered the very best in achieving happiness, theendeavour is seen as at least being second best. Perhaps it was not apparent from the results of the surveys, but there were hints of this effect from active members who seemed to be more interested in the work itself than in the outcomes. These active members felt they were making an important contribution for the good of the organisation, regardless of whether the outcomes would be successful or not. These efforts then obviously “carry their own rewards” (Hirschman 1985, p. 86). There are two other aspects of the inseparability of the two concepts striving and attaining. The fulfilment of individual development (that is caused by taking pleasure in the actual effort and self-development) and the result of radical cognitive change (when realising that by joining an organisation with like-minded people, one can improve the social conditions). In this study there were a few examples of active members who expressed such views, though 25 per cent of the respondents in the survey claimed that they joined the organisation for political reasons in order to change their situation through influencing politicians or the health services.

From the analyses of this study, empirical support is provided to account for the reasons for membership and the functions the organisations fill. With this approach and the present results, we have several answers to the initial questions why people join and participate in patient organisations, whether they want to have an influence on the organisation and how the organisations work. This knowledge should be used to increase the number of people joining the organisation. The present number (only ten per cent of the diabetic population are members) is very low. Attracting more members may increase the patient empowerment canalised through the diabetes organisations.

In conclusion, from the work of the patient organisation, people with diabetes have gained substantial financial benefits as compared with other patient groups. Organising a strong patient lobby organisation obviously can have payoffs: in this case free medication and aids for all diabetics have been achieved. The threat that the government may change the present laws concerning free medicine in a sense forces the organisation to keep on the alert and of a latent readiness to take action when necessary. The SDA’s potential to mobilise and its numerous resources are important in this work.

Implications for further research

How do the implications of my research affect its quality? As discussed earlier in Chapter 2, this study is not meant to be used for strict generalisations. However, I want to claim that the studied groups are examples of larger groups of active or passive members. (The groups of respondents were all members of

268 With the health services or with the general situation for people with diabetes in the society.
one of these two local diabetes branches, but in other regards they were heterogeneous, for example re-
garding level of education, age and membership in other organisations.) It is reasonable to assume that
these members’ experiences provide a good example of what membership in a patient organisation entails
for people with chronic diseases and how it relates to empowerment. Scientific generalisations from case
studies cannot only be done through statistical sampling (Gummesson, 1991, p. 78f). It is to a certain
degree up to the user of these research results to decide how general they are (Kvale, 1997, p. 210f).
What are the similarities and what are the differences between different populations? How can the result
be applied on another population than the one studied? It is thus important that the researcher provides
enough information for an analytical generalisation to be made. It has been my ambition in this thesis to
do so.

It has been important to find evidence of my interpretations directly in the empirical data. For example
whether the conclusions are confirmed and supported or if they are ”only” interesting theoretical reflec-
tions without direct proof in the empirical findings. I propose that this study’s results have general values
that reach beyond the studied groups of members. It concerns the phenomenon of living with a chronic
disease and being a member of an active patient organisation. This can be applied on other members of
other active patient organisations for people with chronic diseases.

This dissertation had several possible endings. What has been presented here is but one possible ave-
nue, but there were others I could have chosen instead. I passed several alternative paths that were interest-
ning and that might lead in the same direction. One of those paths was the non-membership path. Ninety
per cent of the people with diabetes have not joined a diabetes organisation. How do these diabet-
ics feel about the diabetes organisation? Do they know about the organisation? If they do know about the
organisation, what precisely do they know? What are their reasons for not being members and what ef-
fect do their reasons have on the identity of the non-members? Possible explanations have been discussed
in this thesis (such as not wanting to be identified as being sick or being satisfied and already feeling well
taken care of by the health services), but we do not know whether any of these explanations are accurate.
Not only are the opinions of the non-organised diabetics worthy of knowing, but also who they are? For
example, are the members of the local branches lonely people without their own “backup” in terms of
family, friends, associates or other contacts. Are non-members persons with family and friends? Very
little is known about the unorganised group and very little can be said. How do we study them? They
have no statutes, no resources, no offices, no annual meetings, no journal and no member register. How
do we contact them?

I also decided not to study the weaker local or national organisations. Therefore, it is unclear whether
the present results from ‘strong’ organisations could be generalised to these weaker organisations. It
would seem worthwhile to carry out the same type of study on weak patient organisations (suggested as
‘weak’ from the health services) to determine differences and similarities between weak and strong or-
ganisations (e.g., to see whether conflicts prevail to the same extent in both types of organisation). There
are problems, however, with this approach in that ‘weak’ groups probably have no lobby, take no action
and are not likely to exert any form of pressure. Those persons who are weakest and need it the most,
usually have little or no ability to exercise power of influence. In this study we have seen how organisa-
tions are influential and active despite many internal conflicts. However, it is hard to determine what is
the source and what is the consequence. Whether it is the conflicts that make them strong or whether
there are conflicts because of their strength. Alternatively, perhaps there is no connection at all. This
study has amply demonstrated that most of the successful work of the local branches depends on the dedi-
cated leaders who are motivated by non-financial gain. Most conflicts were caused by a combination of
insufficient organisation, support and teamwork. Dedicated driving forces further aggravate conflicts.
It seems to be in the nature of voluntary interest organisations to be affected by inner conflicts and
self-assertion, whether it is consumer organisations, political parties, unions, physical activities clubs or
residential organisations. The fact that the members within organisations do not always agree does not
mean that the organisations are meaningless. On the contrary, it suggests that these types of organisations
are needed more than ever and these organisations need strong and independent leaders.

It would also be interesting to see whether the results from studying patient organisations apply to
other types of voluntary organisation, (e.g., political parties, unions, sobriety organisations, diet or physi-
cal activity clubs and consumer organisations).

Had I known beforehand that the present results would largely focus on the importance of the intensely
dedicated driving forces, I probably would have studied what it is that motivates and impels dedicated
people. What types of people become dedicated driving forces? Do they have any common characteristics?

Having studied what it takes to participate, I wonder if it is the same reason that causes people to become active that also makes them capable of being a co-producer. Prerequisites and effects of co-production or the qualities and skills necessary for individuals to become co-producers, would be another interesting research approach.

A consequence of applying my own definition of empowerment in the study is that activities that were excluded may be included in the concept with a different perspective. From this aspect, it would be interesting to learn if, in what way and to what extent activities that were excluded in my definition (e.g., social activities) would contribute to patient empowerment.

Other avenues lead to other ways of studying patient empowerment. In this thesis I felt that the best way to study patient empowerment, given the nature of the field (the Swedish health services and local involvement in health care planning as described earlier), was to focus on local patient organisations (because they are closest to the members) and the empowerment that possibly could be achieved through them. This, however, meant excluding other ways of investigating patient empowerment, such as focusing on individual empowerment by studying individual patients or people with diabetes.

To conclude, this study proposes several areas for future research. Let me finish this section with the words of some researchers that I find enlightening:

An actor at the national level said that community participation for health development in Sweden today is weak and lacks enthusiasm. [...] We have no equivalent of tree-lovers as regards health – not like the people who love forests and the environment. There is no real public participation... There is no Greenpeace in public health. It would be very exciting to have an eager participation and people who would almost fight for this concept.

(Brännström et al., 1994, p. 323)

So what is new?

It is now time to discuss in what way this dissertation has contributed to our understanding of the role of patient organisations in empowering patients, and to determine if the study has contributed to developing the fields of business administration, organizational theory, organisation studies, voluntary organisation discourse, participation theory and empowerment theory.

What lessons can be drawn from this study at a more general level? Most importantly, I think it has demonstrated that the combination of a qualitative and quantitative approach to the study of patient empowerment through patient organisations can be rewarding. The cases of local branches of the diabetes organisation have illustrated how both active and passive members look upon their branch organisation and their membership and in what way the organisation is important for empowerment. The methodological contribution is thus the combination of qualitative and quantitative data. The triangulation of using interviews, participant observations and a questionnaire was important in narrowing down patient empowerment through patient organisations. It was also necessary to get two perspectives here: one from the active members and one from the members in general, including the passive members. The unique empirical data are therefore a major contribution to the literature concerning business administration, organizational theory, organisation studies, participation theory and notions of empowerment. This dataset of voluntary organisations, i.e. patients’ associations relating to particular medical conditions and diseases, has previously virtually been ignored by many scientific disciplines. To my knowledge, equivalent empirical data do not exist and there are no similar studies available.

Participation theory claims that the reasons people cannot participate in political life are that they lack some of the necessary resources such as time, money and civic skills (Verba, Schlozman & Brady, 1995 (b), p. 271ff). Two additional resources that people in this study lacked were transportation and good health. Not having a car or access to public transportation was found to prevent members from the activities arranged by the local branch. This was particularly true in the Northern organisation. Further, sick people were prevented from engaging actively in the organisation when their health status did not allow it. People with diabetes commonly suffer from a range of other diseases as well, and sometimes this was
a problem regarding participation. This factor will always be present in patient organisations, as people with a chronic disease are likely to have difficulty staying healthy and well.

Reasons for why people do not want to participate in political life are, according to participation theory, that they lack interest in politics and psychological engagement with politics (i.e. a feeling that activity makes no difference), as well as not being concerned with public issues or having consciousness of membership in a group with shared political interests (ibid). Another reason for not wanting to participate or wanting to be a passive member has to do with the concept of non-identification. As revealed from the findings of this study, both local branches had problems attracting and recruiting young members. One explanation offered for this problem was that young members did not want to identify with those who are old and sick. This may also be the case for older persons who are not members, i.e. that they do not want to think of themselves as sick, which they would have to if they joined the patient organisation.

The final reason given by participation theory for why people do not participate in political life is that they were not asked or allowed to participate. They are thus isolated from the recruitment networks through which people are mobilised into politics (ibid). Another reason is that they were not recommended to (by) the health services. When being diagnosed with diabetes, meetings are arranged for the individual with several professional groups in the hospital or the health centre. In most cases the individual depends on the health services for information and knowledge. If the health services recommend the patient to get in touch with the patient organisation, then at least the patient has been made aware of the existence of the organisation. Such a recommendation is likely to be taken seriously because it is from the health services. Another theoretical implication for membership concerns patient dissatisfaction. In this study it was not found to be an important factor in explaining why people join patient organisations. This finding does not support the participative theories presented earlier (e.g., Hirschman, 1985).

In addition to developing a conceptual framework for understanding the motivations of members of patient organisations and their quest for empowerment, as well as linking that framework to the existing literature on membership and empowerment, this study has presented a theoretical contribution in developing the concept of empowerment.

Empowerment was connected to identity and examples were given of the members’ contradicting opinions regarding the change of terminology from patient to health care consumer. Identity also proved to be important in explaining why especially young people with diabetes do not join the patient organisation, as membership for these people would lead to the opposite of empowerment. A quote from Chapter 6 nicely illustrates this point: “I’ve never before felt so handicapped in my life as when I became active in the organisation. Here I feel like I’m handicapped. I never looked at myself in that way before.” Feelings of shame also help explain why young people do not join the organisation. Another quote from Chapter 6 is illustrative: “I joined because of my mother. I didn’t want to join [the organisation]. I was 15 years old when I got diabetes. I was the only one in the family who had it. I was ashamed of my disease when I was young.” Active membership in a voluntary organisation offers the members a collective identity in connecting the individuals’ sense of who they are to a shared definition. In this study I have revealed that it is not easy to achieve a collective identity when the discrepancies among the members are too large, both in terms of age and interests.

I have shown how co-production also means empowerment and that co-production is necessary in achieving collective empowerment. Finally, it should be noted that the promise of empowerment and co-production occurs in a context in which the empirical literature is relatively sparse.

Possible implications of working with empowerment

Regardless of how empowerment is defined or treated, or whether empowerment is desirable, it is a fact that organisations worldwide work to empower people. Organisations continuously use this type of activity in an effort to strengthen individuals or groups. Individuals and groups continuously work in an active manner to be empowered. Therefore, my final question is to ask the following: What can organisations learn from the conclusions in this dissertation? Considering the conclusions drawn in this thesis, there could be several managerial implications to the way work ‘ought to be done’ with respect to empowerment. Nevertheless, instead of providing a list of ten keys to success, I am happy to conclude that this study contributes to a richer understanding of patient empowerment through patient organisations and has, I hope, shed some light on what it means and how it can be achieved. I was able to shed new light on empowerment theory in general and patient empowerment combined with co-production in particular.
Given the impact and scale of health care on people’s lives, it is logical to expect there to be a strong consumer movement. This expectation, however, seems to be at odds with reality. Although there are more than a hundred patient groups in Sweden, few are perceived as having influence over the medical care they receive and the medicine they consume. Patients are seen as largely unimportant and passive consumers of whatever the medical profession provide (Wood, 2000, p. 174). Perhaps this study can help change this view.

In a time when the role of patients is discussed more than ever before in Sweden, this study shows that there are many activities carried out by local patient organisations that intend to change the current situation. Patient organisations in this sense can be the answer to patients feeling helpless and powerless. These organisations, as we have seen, can help alleviate the feelings of helplessness that many patients experience and offer security in a time of powerlessness.

The commitment and the level of intensity of the local branches vary in pursuing empowerment for their members and organisation. This commitment and intensity were found to vary with the leaders of the organisation. One question remains, however: Will the likely juridical and practical changes in the individual meeting between the patient and the health services lead to empowerment? The evidence suggests that patient organisations are likely to play an active part in that process of change. Because, in answering the question posed in the title of this dissertation, patients are not as patient as they once were.

Throughout the work on this thesis, I have become inspired by diverging theories on participation and empowerment. I have constructed a room with many doors, but slipped in and out of the room on my way somewhere, and every time I was challenged by new and exciting actors or ideas. However, in the end I always returned to the room. This room and the doors leading to it are in need of further exploration, as is the everlasting discussion on what empowerment is, where in fact it resides, how it can be achieved, what characteristics it possesses and whether it is possible to codify or manage it. The room is still largely unexplored, and there are many doors and questions to explore as well, calling for teams of explorers to find their way there. Does the room or access to it change over time? If so, how and why do changes occur and how does the room with its doors relate to other efforts of organising and managing influence?
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APPENDICES

Appendix 1: Questionnaire to members in two local diabetes organisations.

MEDLEMSKAP I DIABETESFÖRENINGAR (Membership in Diabetesorganisations)
MEDLEMSENKÄT (Members’ questionnaire)

1. Är Du?  (Are you?)
 □ medlem (member)    □ stödmedlem (support member)
 □ vet ej (don’t know)
 □ man (male)         □ kvinna (female)

Grund för medlemskap:  (Reasons for membership)
 □ Typ 1 diabetiker  (Type 1 diabetic)
 □ Typ 2 diabetiker  (Type 2 diabetic)
 □ Ej diabetiker, har anhörig som är diabetiker (Not diabetic: have a family member who is diabetic)
 □ Ej diabetiker, arbetar i vården med diabetiker (Not diabetic: work within health care with diabetics)
 □ Annan, nämligen (Other, namely)

……………………………………………………………………………………

2. Hur gammal är Du?  (How old are you?)
(1-10 years, etc.)
 □ 1-10 år    □ 11-20 år    □ 21-30 år
 □ 31-40 år    □ 41-50 år    □ 51-60 år
 □ 61-70 år    □ 71-80 år    □ 81 år -

3. Om Du är vuxen, vilken utbildning har Du?  Om Du har flera examen, kryssa i den högsta nivån.  (If you are an adult, what education do you have?  If you have several degrees, please indicate the highest degree.)
 □ Grundskola/Folkskola  (Primary and secondary school)
 □ Yrkesskola  (Vocational school)
 □ Annan yrkesutbildning  (Other professional education)
 □ Gymnasieskola  (Sixth Form College)
 □ Universitet/Högskola  (University/Higher education)
 □ Studerande  (Student)
 □ Annat, nämligen (other, namely)…………………………………………………

4. Hur länge har Du varit medlem i föreningen?  (How long have you been a member in the organisation?)
 ………….år.  (in years)

5. Vilken var de viktigaste anledningarna till att Du gick med i diabetesföreningen?  Kryssa för de alternativ som passar bäst.  Du kan kryssa i flera alternativ.  (What were the most important reasons for joining the Diabetes Association?  Please tick the alternatives that fit the best.  You can check off several alternatives.)

(I was diagnosed with diabetes.)
 □ Jag blev diagnosticerad med diabetes
(I have diabetes type 1 and my parents enrolled me as a member.)
 □ Jag har typ 1 diabetes och mina föräldrar skrev in mig som medlem
(I was recommended by someone in the health service to join the organisation.)
 □ Jag blev rekommenderad av någon i sjukvården att gå med i föreningen
(I wanted to get information and knowledge about diabetes and the situation of diabetics.)
 □ Jag ville få information och kunskap om diabetes och diabetikers situation
(I wanted to meet other diabetics and share our experiences.)
 □ Jag ville träffa andra diabetiker och få gemenskap med dem
(I wanted to take part in the activities that the organisation arrange.)
 □ Jag ville få ta del av de aktiviteter som föreningen anordnar
(Through my membership, I wanted to influence politicians and the health care sector.)
 □ Jag vill genom mitt medlemskap påverka politiker och sjukvården
(I was dissatisfied with the status and influence of diabetics.)
 □ Jag var missnöjd med diabetikernas ställning
(I was dissatisfied with the care of diabetics.)

☐ Jag var missnöjd med diabetikernas vård
☐ Annan, nämligen (Other, namely)………………………………………………..
Kommentar: (Comments)………………………………………………………………
…………………………………………………………………………………………
…………………………………………………………………………………………

6. Vad anser Du om a) Din lokalförening och b) förbundets möjlighet att påverka diabetikernas situation i samhället? (What do you think about (a) your local branch organisation and (b) the association’s ability to affect the diabetics’ situation in society?)

(a) lokalföreningen (the local branch organisation)
☐ Mycket goda (Very good)
☐ Goda (Good)
☐ Lagom (About right)\(^{269}\)
☐ Dåliga (Poor)
☐ Mycket dåliga (Very poor)
☐ Vet ej (Don’t know)

(b) förbundets (the association’s)
☐ Mycket goda (Very good)
☐ Goda (Good)
☐ Lagom (About right)
☐ Dåliga (Poor)
☐ Mycket dåliga (Very poor)
☐ Vet ej (Don’t know)

Kommentar: (Comments:)
…………………………………………………………………………………………
…………………………………………………………………………………………

7. Vad anser Du om Din förening’s möjligheter att påverka Diabetesförbundet? (What do you think about your organisation’s ability to influence the Diabetic Association?)

☐ Mycket stora (Very big)
☐ Stora (Big)
☐ Varken stora eller små (Neither big nor small)
☐ Små (Small)
☐ Mycket små (Very small)
☐ Vet ej (Don’t know)

Kommentar: (Comments:)
…………………………………………………………………………………………
…………………………………………………………………………………………

8. Vad anser Du som enskild medlem om Dina möjligheter att påverka Din förening? (What do you think of your ability as a member to influence your organisation?)

☐ Mycket goda (Very good)
☐ Goda (Good)
☐ Varken goda eller dåliga (Neither good nor poor)
☐ Dåliga (Poor)
☐ Mycket dåliga (Very poor)
☐ Vet ej (Don’t know)

Kommentar: (Comments:)
…………………………………………………………………………………………
…………………………………………………………………………………………

9. Har Du någon gång försökt påverka föreningen? (Have you ever tried to influence the organisation?)

☐ Ja (Yes) ☐ Nej (No)

Om ja, kan Du ge exempel på något/några förslag från Dig eller andra medlemmar, som föreningen har genomfört? (If yes, can you give examples of suggestions from you or other members that the organisation has carried out?)

\(^{269}\) There is no direct translation of the Swedish word “lagom” into English; however, it is usually translated into ‘just enough’ or ‘about right’.
10. Har Du haft eller har Du något förtroendeuppdrag inom föreningen?  (Have you had or do you have any executive functions within the organisation?)

□ Ja  (Yes)  □ Nej  (No)

Om ja, vilket?  (If yes, what are these functions?) ………………………………………………………………………………………

11. Deltar Du i föreningens aktiviteter?  (Do you participate in the organisation’s activities?)

□ Ja, ofta  (Yes, often)  □ Ja, ibland  (Yes, sometimes)
□ Nej, inte alls  (No, not at all)

Om ja, vilka aktiviteter har du deltagit i det senaste året?  Nämn gärna flera.  (If yes, in what activities have you participated in during the past year?  Please mention more than one if you wish.) ………………………………………………………………………………………

12. Skulle Du vilja vara mer aktiv?  (Would you like to be more active?)

□ Ja  (Yes)  □ Nej  (No)  □ Vet ej  (Don’t know)

13. Läser Du medlemstidningen DIABETES?  (Do you read the membership magazine DIABETES?)

□ Ja, alltid  (Yes, always)  □ Ja, ibland  (Yes, sometimes)
□ Nej, inte alls  (No, not at all)

Om ja, vad anser Du om tidningens innehåll?  (If yes, what do you think about the magazine’s contents?)

□ Mycket intressant  (Very interesting)  □ Intressant  (Interesting)  □ Ganska intressant  (Fairly interesting)  □ Ointressant  (Uninteresting)  □ Vet ej  (Don’t know)

Kommentar:  (Comments:)
……………………………………………………………………………………
……………………………………………………………………………………
……………………………………………………………………………………

14. Vilken/vilka har mest inflytande på Din förenings verksamhet, som du ser det?  Kryssa för de mest relevanta alternativen.  Kommentera gärna Ditt svar.  (In your view, who has the most influence on your organisation’s work?  Tick the most relevant alternatives.  Please comment on your answer.)

□ Styrelsen  (The Board)  □ Vissa medlemmar  (Certain members)  □ Olika arbetsgruper  (Different working groups)  □ Medlemmarna som grupp betraktade  (The members as a group)  □ Kommunen/annan myndighet  (The local authority/other authority)  □ Vet ej  (Don’t know)

Kommentar:  (Comments:)
……………………………………………………………………………………
……………………………………………………………………………………

15. Tycker Du att Din förenings arbete är tillfredsställande för medlemmarna?  Kryssa för ett alternativ.  (Do you think that your organisation’s performance on behalf of its members is satisfactory?  Please indicate only one alternative.)

□ Styrelsen  (The Board)
□ Vissa medlemmar  (Certain members)
□ Olika arbetsgruper  (Different working groups)
□ Medlemmarna som grupp betraktade  (The members as a group)
□ Kommunen/annan myndighet  (The local authority/other authority)
□ Vet ej  (Don’t know)
16. Är Du nöjd med medlemskapet hittills? Kommentera gärna. (Are you satisfied with the membership so far? Please comment.)

☐ Mycket nöjd (Very satisfied)
☐ Ganska nöjd (Quite satisfied)
☐ Varken nöjd eller missnöjd (Neither satisfied nor dissatisfied)
☐ Ganska missnöjd (Quite dissatisfied)
☐ Mycket missnöjd (Very dissatisfied)
Kommentar: (Comments:)

………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………

17. På vilket sätt kan föreningen förbättra diabetikernas situation? (In what way can the organisation improve the diabetics' situation?)

………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………

18. Har Du några förslag till förändringar/förbättringar beträffande föreningens arbete? (Do you have any suggestions for changes/improvements concerning the organisation’s work?)

………………………………………………………………………………………
………………………………………………………………………………………
………………………………………………………………………………………

19. Om föreningen/förbundet inte fanns, hur skulle diabetikernas ställning i samhället förändras? (If the local organisation/the association did not exist, do you feel the status of diabetics in society would be affected?)

☐ Mycket negativt (Very negatively)
☐ Negativt (Negatively)
☐ Inte förändras alls (No change)
☐ Positivt (Positively)
☐ Mycket positivt (Very positively)
☐ Vet ej (Don’t know)

20. Finns det någon annanstans dit diabetiker kan vända sig för att få den service, information och gemenskap som diabetesföreningen kan erbjuda? (Is there any other source to which diabetics can turn to in order to get the service, information and communal support that the Diabetes organisation can offer?)

☐ Ja (Yes)  ☐ Nej (No)

Om ja, i så fall var? (If yes, where?)

………………………………………………………………………………………

21. Har Du varit medlem i andra föreningar? (Have you been a member in other organisations?)

☐ Ja (Yes)  ☐ Nej (No)

Om ja, i så fall vilka? (If yes, in what type of organisation?)
Om ja, har Du *varit aktiv* i någon av dem? (If yes, have you *been active* in any of these organisations?)

☐ Ja (Yes) ☐ Nej (No)

22. Är Du nu *medlem* i andra föreningar? (*Are you now a member* in other organisations?)

☐ Ja (Yes) ☐ Nej (No)

Om ja, i så fall vilka? (If yes, in what type of organisations?)

☐ Facket (The Union) ☐ Nykterhetsförening (Sobriety organisation) ☐ Konsumentförening (Consumer organisation) ☐ Kost-eller motionsförening (Diet club or physical activities club) ☐ Politiskt parti (Political party) ☐ Kulturförening (Cultural organisation) ☐ Hus/Bostadsförening (Residential organisation) ☐ Pensionärsförening (Pensioners organisation) ☐ Annan patientförening, nämligen (Other patient organisation, namely)…………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………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Hej!

Jag heter Sophie Werkö och är doktorand på företagsekonomiska institutionen vid Stockholms Universitet och vid Södertörns Högskola. Jag forskar om patientinflytande i vården inom och via patientorganisationer och jag studerar två lokala diabetesföreningar, varav din är den ena.

Denna enkät till medlemmarna i de föreningar som jag har studerat, utgör en viktig del i min studie. Det är därför min förhoppning att ni kommer att ta er tid att besvara denna enkät och skicka in den i det bifogade svarskuvertet.

Enkäterna är anonyma, men de måste kodas under insamlingsprocessen för att veta vilka som har svarat. Kodningen kan dock inte under några villkor härledas till den enskilde individen.

Er diabetesförening kommer givetvis få ta del av mina resultat, vilka förhoppningsvis kan vara till hjälp i det framtida arbetet.

Frågor gällande studien kan ställas till min handledare, Professor Victor Pestoff (adress: Södertörns Högskola, Box 4101, 141 04 Huddinge. Tfn: 08-585 880 59. Fax: 08-585 883 40. E-mail:)

Vänliga hälsningar,

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Appendix 3: Copy of the original letter from the two branch organisations to their members.

Till alla medlemmar i X:s lokalförening


Hälsningar styrelsen

Genom (underskrift)

Ordförande
Hej!

För två veckor sedan skickade jag en enkät till Dig om ditt medlemskap i en diabetesförening. Jag har tyvärr inte fått in tillräckligt många svar ännu och vill därför en extra gång be om Din hjälp. Eftersom Du tillhör dem som ännu inte har besvarat och skickat in enkäten, så vill jag nu be Dig att göra det. Ditt bidrag är viktigt, både för min avhandlingsstudie och för föreningens framtida arbete.

Denna enkät utgör en viktig del i min studie. Det är därför min förhoppning att Du kommer att ta Dig tid att besvara enkäten. Bifogat finns en ny enkät och ett portofritt svarskuvert.

Enkäterna är anonyma, men de måste kodas under insamlingsprocessen för att veta vilka som har svarat. Kodningen kan dock inte under några omständigheter härledas till den enskilde individen.

Innan den 14/7 skulle jag gärna vilja ha Ditt svar.

Jag hoppas på Din hjälp!

Med vänliga hälsningar,

Sophie Werkö
Södertörns University College
Box 4101
S-141 04 Huddinge
Ph: +46 (0)8 58 58 8032
Fax: +46 (0)8 58 58 8340

Frågor gällande studien kan ställas till min handledare, Professor Victor Pestoff (adress: Södertörns Högskola, Box 4101, 141 04 Huddinge. Tfn: 08-585 880 59. Fax: 08-585 883 40.)
Appendix 5: Description of the survey study and the response rates

The surveys were carried out during the spring and summer 2000 and included 1012 members of two local diabetes organisations in two towns in different regions.

There were structured, semi-structured and unstructured questions with or without response alternatives in the questionnaire. Many questions had a “don’t know” response alternative. In total there were 23 questions out of which three were unstructured and 20 were semi-structured with pre-coded answer categories, including open-ended sub-categories. Space was however left for comments in many of the structured questions and the respondents were encouraged to do so and to elaborate further on their answers in 9 cases (see the questionnaire in Appendix 1). At the end of the questionnaire, the respondents were also asked to comment more generally on something they thought might be missing in the questionnaires.

All the questionnaires were coded in SPSS for Windows and a code book was created. The data analysis was thus also performed with SPSS.

In the North, a total of 347 subjects filled in the questionnaire, representing a response rate of 74,6% and in the City, 397 subjects replied which gave a response rate of 76,5%, see table A.1. All data presented below stems from this study; Söderholm Werkö, The Swedish Diabetes Association Study, 2002.

<table>
<thead>
<tr>
<th>Selected</th>
<th>The North</th>
<th></th>
<th>City</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
</tr>
<tr>
<td>Selected</td>
<td>479</td>
<td>100,0</td>
<td>533</td>
<td>100,0</td>
</tr>
<tr>
<td>Included</td>
<td>465</td>
<td>100,0</td>
<td>519</td>
<td>100,0</td>
</tr>
<tr>
<td>No response</td>
<td>118</td>
<td>25,4</td>
<td>122</td>
<td>23,3</td>
</tr>
<tr>
<td>Total respondents</td>
<td>347</td>
<td>74,6</td>
<td>397</td>
<td>76,5</td>
</tr>
<tr>
<td>Omitted because:</td>
<td>-14</td>
<td></td>
<td>-14</td>
<td></td>
</tr>
<tr>
<td>Moved or no longer a member</td>
<td>3</td>
<td>7</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Too sick or demented</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Deceased</td>
<td>8</td>
<td></td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Table A.1: The survey selection for the questionnaire survey in 2000 (total number and per cent of the included subjects).
Appendix 6: Descriptives of respondents and non-respondents of the surveys and the Dropout analysis.

<table>
<thead>
<tr>
<th>Case Study No. 1 (North)</th>
<th></th>
<th>Case Study No. 2 (The City)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-respondents:</strong></td>
<td><strong>Respondents:</strong></td>
<td><strong>Non-respondents:</strong></td>
<td><strong>Respondents:</strong></td>
</tr>
<tr>
<td>External drop-outs: 120 subjects</td>
<td></td>
<td>External drop-outs: 123 subjects</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Males: 54 (45%)</td>
<td>Males: 168 (48.4%)</td>
<td>Males: 57 (46.3%)</td>
<td>Males: 180 (45.3%)</td>
</tr>
<tr>
<td>Females: 65 (54.2%)</td>
<td>Females: 179 (51.6%)</td>
<td>Females: 66 (53.7%)</td>
<td>Females: 216 (54.4%)</td>
</tr>
<tr>
<td>Non-persons: 1 (health centre) (0.8%)</td>
<td>Non-persons: -</td>
<td>Non-persons: -</td>
<td>Non-persons: -</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>Younger than 50 or 50: 33 (27.5%)</td>
<td>Younger than 50 or 50: 111 (32%)</td>
<td>Younger than 50 or 50: 61 (49.6%)</td>
<td>Younger than 50 or 50: 171 (43.1%)</td>
</tr>
<tr>
<td>Older than 50: 25 (20.8%)</td>
<td>Older than 50: 233 (67.1%)</td>
<td>Older than 50: 56 (45.5%)</td>
<td>Older than 50: 224 (56.4%)</td>
</tr>
<tr>
<td>Missing: 62 (51.7%)</td>
<td>Missing: 3 (0.9%)</td>
<td>Missing: 6 (4.9%)</td>
<td>Missing: 2 (0.5%)</td>
</tr>
<tr>
<td>Average age: 46</td>
<td>Average age: approx. 51</td>
<td>Average age: 46,8</td>
<td>Average age: approx. 46</td>
</tr>
<tr>
<td>Median: 42</td>
<td>Median: approx. 50-60</td>
<td>Median: 50</td>
<td>Median: approx. 50-60</td>
</tr>
<tr>
<td><strong>Type of membership</strong></td>
<td></td>
<td><strong>Type of membership</strong></td>
<td></td>
</tr>
<tr>
<td>Support members: -</td>
<td>Support members: 23 (6.6%)</td>
<td>Support members: 6 (4.9%)</td>
<td>Support members: 13 (3.3%)</td>
</tr>
<tr>
<td>Members: 68 (56.7%)</td>
<td>Members: 306 (88.2%)</td>
<td>Members: 117 (95.3%)</td>
<td>Members: 365 (91.9%)</td>
</tr>
<tr>
<td>Have left: -</td>
<td>Have left: 2 (0.6%)</td>
<td>Have left: -</td>
<td>Have left: -</td>
</tr>
<tr>
<td>Don’t know: -</td>
<td>Don’t know: 1 (0.3%)</td>
<td>Don’t know: -</td>
<td>Don’t know: 4 (1%)</td>
</tr>
<tr>
<td>Missing: 52 (43.3%)</td>
<td>Missing: 15 (4.3%)</td>
<td>Missing: 52 (43.3%)</td>
<td>Missing: 15 (3.8%)</td>
</tr>
<tr>
<td><strong>Type of Diabetes</strong></td>
<td></td>
<td><strong>Type of Diabetes</strong></td>
<td></td>
</tr>
<tr>
<td>Type 1: 47 (39.2%)</td>
<td>Type 1: 136 (39.2%)</td>
<td>Type 1: 79 (64.2%)</td>
<td>Type 1: 227 (57.2%)</td>
</tr>
<tr>
<td>Type 2: 12 (10%)</td>
<td>Type 2: 171 (49.3%)</td>
<td>Type 2: 28 (22.8%)</td>
<td>Type 2: 142 (35.8%)</td>
</tr>
<tr>
<td>Non-diabetics: 1 (0.8%)</td>
<td>Non-diabetics: 31 (8.9%)</td>
<td>Non-diabetics: -</td>
<td>Non-diabetics: 25 (6.3%)</td>
</tr>
<tr>
<td>Missing: 60 (50%)</td>
<td>Missing: 9 (2.6%)</td>
<td>Missing: 60 (50%)</td>
<td>Missing: 9 (2.6%)</td>
</tr>
<tr>
<td><strong>Length of membership</strong></td>
<td></td>
<td><strong>Length of membership</strong></td>
<td></td>
</tr>
<tr>
<td>Average length in years: 3.9</td>
<td>Average length in years: 10.4</td>
<td>Average length in years: 2.7</td>
<td>Average length in years: 13.1</td>
</tr>
<tr>
<td>Median: 4.5</td>
<td>Median: 8</td>
<td>Median: 5</td>
<td>Median: 9</td>
</tr>
<tr>
<td>Missing: 88 (73.3%)</td>
<td>Missing: -</td>
<td>Missing: 88 (73.3%)</td>
<td>Missing: -</td>
</tr>
</tbody>
</table>

The Dropout analysis (or the ‘non-participation’ analysis)

According to Trost (2001, pp. 118–119), a dropout analysis compares the data on the respondents with the data one has on either the whole population or the original sample. However, the dropout analysis is usually rather limited as one can only show the similarities or differences in the issues where information is available, either about both the
population, or the sample and the collected data. Even if there are no major differences in the distribution of gender, age and the other few variables that can be controlled, the difference in other variables can still be big. When I compared those who returned the questionnaire (respondents) with those who did not (non-responders) there were no significant differences in the background data of the respondents versus the non-responders. This regards the distribution of gender (approx. 50% of each gender in all categories in both cases), type of membership overwhelmingly ‘ordinary’ members, and not support members. As for age they differed somewhat. In the North, the majority of the respondents were older than 50 (67%) compared to a much lower rate for the non-respondents (21%). In the City however, there was no major difference in the age distribution of the respondents and the non-respondents. Both categories had between 40–50% of those older respectively younger than 50 years old. Concerning the type of Diabetes, the data between the case studies differed. In the organisation up North, a slight majority of the respondents had type 2 diabetes\textsuperscript{270}, whereas a majority of the non-respondents in the North organisation as well as a majority of both respondents and non-respondents in the City, had type 1 diabetes.\textsuperscript{271} This corresponds with data on the age difference, where respondents of the organisation up North are older which correlates with a higher degree of type 2 diabetes. Another major difference between responders and non-responders in both case studies is length of the membership. In both areas the length of the membership is notably shorter for the non-respondents compared to the respondents. (The average being 2.7–3.9 years and the median value 4.5–5 years for the non-respondents compared with the average value of 10.4–13.1 years and median value of 8–9 years for the respondents.) This indicates that one reason for not having returned the questionnaire could be a perception of not having been a member of the organisation long enough to provide an adequate or informed answer. For more detailed information on the non-respondents, see Appendix 6.

The main conclusion of the dropout (non-participation) analysis is that the group who have responded to the questionnaire mainly fits the structure of the whole sample, regarding the studied variables mentioned above, with a few exceptions. But the studied group has to a major extent been members for a longer period than those who did not participate in the study and can therefore provide more informed answers.

The internal missing data are not included in the tables and the analysis. The missing data on the questions are more or less equally distributed, with the exception of one question. It concerns the existence of sources to which people with diabetes can turn to, other than the Diabetes organisation. (See diagram 7.7.)

\textsuperscript{270} 49% and 39% respectively.
\textsuperscript{271} 57% and 64% respectively.
Appendix 7: Results from the questionnaire
Source: Söderholm Werkö, 2002, the Swedish Diabetes Association Study.

Type of activities for those with executive functions

Of those with executive functions, the answers covered the following alternatives:

<table>
<thead>
<tr>
<th>Executive functions</th>
<th>North</th>
<th>The City</th>
<th>Total (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participates in a working group</td>
<td>-</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Treasurer</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Board member</td>
<td>7</td>
<td>12</td>
<td>19</td>
</tr>
<tr>
<td>Board member in the regional organisation</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Chairman</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Representative in other disability forum (HCK)</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Representative in the SDA’s management</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Accountant</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Secretary</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Member of the selections committee at regional level</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Member of the selections committee</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Vice chairman</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Vice chairman in the regional organisation</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>27</td>
<td>35</td>
<td>62</td>
</tr>
</tbody>
</table>

Table 10.1: executive functions of the respondents.

The organisation’s activities

Examples of the activities the members had participated in during the last year were:

<table>
<thead>
<tr>
<th>Examples of activities last year</th>
<th>North</th>
<th>The City</th>
<th>Total (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lectures (physicians, patient representatives, chiropodists, dieticians etc.)</td>
<td>15</td>
<td>19</td>
<td>34</td>
</tr>
<tr>
<td>Study circles &amp; courses</td>
<td>20</td>
<td>14</td>
<td>34</td>
</tr>
<tr>
<td>Member meetings</td>
<td>14</td>
<td>16</td>
<td>30</td>
</tr>
<tr>
<td>The Diabetes day</td>
<td>7</td>
<td>10</td>
<td>17</td>
</tr>
<tr>
<td>Research trips (to Umeå), and active leisure trips (to Poland)</td>
<td>13</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Other trip, excursion</td>
<td>9</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>Annual general meeting</td>
<td>5</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>Children and youth activities (camps, the parents’ organisation, family weekends etc)</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Physical activities or sports</td>
<td>7</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Christmas party</td>
<td>-</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Too sick to participate, does not have time</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Cultural activities (art walks, wine tasting, culture day etc.)</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Too big distances (several Swedish miles)</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Working group</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Board member training/education (course)</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Shows new products / exhibitioners</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>107</td>
<td>97</td>
<td>204</td>
</tr>
</tbody>
</table>

Table 10.2: activities the respondents participated in the last year.
Opinions on the magazine

<table>
<thead>
<tr>
<th>Opinion on content of membership magazine</th>
<th>North</th>
<th>The City</th>
<th>Total (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In general positive, satisfied with the magazine</td>
<td>4</td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td>More for the youth, now too little for and about young people. Too adult magazine.</td>
<td>7</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>More on research (&amp; foreign aids)</td>
<td>4</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Too much about /to type 2, more about/to type 1 (children)</td>
<td>1</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>More on pregnancy and parenthood</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>More on products (insulin pumps)</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Too positive and “happy” magazine – “we are sick!”</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>A broader magazine: many topics</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Too negative magazine – “you get depressed”</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>More on diet (light-products, recipes etc.)</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Too much about children/parents – more to the adults!</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Does not add anything</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>More professional texts</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>28</td>
<td>36</td>
<td>64</td>
</tr>
</tbody>
</table>

Table 10.3: respondents’ opinions on the membership magazine.

Suggestions for changes or improvements of the organisation’s work

<table>
<thead>
<tr>
<th>Suggested changes / improvements of the org.’s work</th>
<th>North</th>
<th>The City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>More courses &amp; lectures, educate the members</td>
<td>3</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>More activities (social)</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>More support to parents/children/youth</td>
<td>5</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Increase the number of members</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Arrange groups for physical activities (walks etc.)</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Influence the food industry (increase the supply)</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Come pout to the countryside (the distances are too big)</td>
<td>2</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td>Inform the public</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>More information about the board’s work</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Influence the politicians (e.g. insulin free of charge!)</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Support research more</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Age – attract more young diabetics</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>25</td>
<td>16</td>
<td>41</td>
</tr>
</tbody>
</table>

Table 10.4: Suggestions from the respondents as to improvements and changes of the organisation’s work.

Other sources to turn to

Of the comments as to where that other source would be, 134 people commented. Their comments could be categorised into 13 different categories, as follows:

<table>
<thead>
<tr>
<th>Other sources to which people with diabetes can turn</th>
<th>North</th>
<th>The City</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes care team (at the hospital)</td>
<td>28</td>
<td>8</td>
<td>36</td>
</tr>
<tr>
<td>Diabetes specialist nurse</td>
<td>14</td>
<td>22</td>
<td>36</td>
</tr>
<tr>
<td>Hospital</td>
<td>14</td>
<td>22</td>
<td>36</td>
</tr>
<tr>
<td>Health centre (primary care centre)</td>
<td>13</td>
<td>4</td>
<td>17</td>
</tr>
<tr>
<td>(Diabetes-) physicians</td>
<td>6</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Internet (discussion groups)</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Children’s ward (at the hospital)</td>
<td>4</td>
<td>-</td>
<td>4</td>
</tr>
<tr>
<td>Dieticians</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Disability/Patient org.</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>EU through the health services</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Friends</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Almoner (Welfare Officer)</td>
<td>1</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Library</td>
<td>-</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL</td>
<td>85</td>
<td>68</td>
<td>153</td>
</tr>
</tbody>
</table>

Table 10.5: Respondents’ examples of other sources to turn to, than the Diabetes organisation, for people with diabetes.
Current and previous membership in other organisations

Current membership in other organisations
Number of respondents who also now are members in other organisations.

<table>
<thead>
<tr>
<th></th>
<th>North</th>
<th>The City</th>
<th>Total</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>26.2</td>
<td>30.5</td>
<td>28.4</td>
<td>205</td>
</tr>
<tr>
<td>Yes</td>
<td>73.8</td>
<td>69.5</td>
<td>71.6</td>
<td>516</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>721</td>
</tr>
</tbody>
</table>

Table 10.6: Whether the respondent is now a member of several other organisations (per cent within each organisation).

Previous membership in other organisations
Number of respondents who also have been members in other organisations.

<table>
<thead>
<tr>
<th></th>
<th>North</th>
<th>The City</th>
<th>Total</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>16.1</td>
<td>21.3</td>
<td>18.8</td>
<td>137</td>
</tr>
<tr>
<td>Yes</td>
<td>83.9</td>
<td>78.7</td>
<td>81.2</td>
<td>590</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>727</td>
</tr>
</tbody>
</table>

Table 10.7: Whether the respondent had been a member of several other organisations (per cent within each organisation).

Membership in other organisations, type of organisation

Of those who are now members of other organisations, this is how the respondents answered:

<table>
<thead>
<tr>
<th>Category of organisations the respondents are now members of.</th>
<th>North</th>
<th>The City</th>
<th>Total</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Trade Union</td>
<td>35.4</td>
<td>33.8</td>
<td>34.7</td>
<td>258</td>
</tr>
<tr>
<td>Residential organisation</td>
<td>18.2</td>
<td>19.4</td>
<td>18.8</td>
<td>140</td>
</tr>
<tr>
<td>Pensioners organisation</td>
<td>19.6</td>
<td>12.9</td>
<td>16.0</td>
<td>119</td>
</tr>
<tr>
<td>Consumer organisation</td>
<td>12.4</td>
<td>14.4</td>
<td>13.6</td>
<td>101</td>
</tr>
<tr>
<td>Diet or physical activities club</td>
<td>11.0</td>
<td>13.9</td>
<td>12.5</td>
<td>93</td>
</tr>
<tr>
<td>Political party</td>
<td>11.8</td>
<td>5.8</td>
<td>8.6</td>
<td>64</td>
</tr>
<tr>
<td>Cultural organisation</td>
<td>13.0</td>
<td>10.1</td>
<td>11.4</td>
<td>85</td>
</tr>
<tr>
<td>Other organisation</td>
<td>14.7</td>
<td>10.4</td>
<td>12.4</td>
<td>92</td>
</tr>
<tr>
<td>-economic/financial organisation</td>
<td>0.6</td>
<td>0.3</td>
<td>0.4</td>
<td>3</td>
</tr>
<tr>
<td>-vehicle organisation</td>
<td>1.7</td>
<td>1.5</td>
<td>1.6</td>
<td>12</td>
</tr>
<tr>
<td>-relief organisation</td>
<td>1.4</td>
<td>0.5</td>
<td>0.9</td>
<td>7</td>
</tr>
<tr>
<td>-religious organisation</td>
<td>0.9</td>
<td>1.5</td>
<td>1.2</td>
<td>9</td>
</tr>
<tr>
<td>-interest organisation</td>
<td>8.1</td>
<td>5.3</td>
<td>6.6</td>
<td>49</td>
</tr>
<tr>
<td>-other</td>
<td>2.0</td>
<td>1.3</td>
<td>1.6</td>
<td>12</td>
</tr>
<tr>
<td>Other patient organisation</td>
<td>7.8</td>
<td>7.6</td>
<td>7.7</td>
<td>57</td>
</tr>
<tr>
<td>-visually disabled</td>
<td>1.2</td>
<td>0.8</td>
<td>0.9</td>
<td>7</td>
</tr>
<tr>
<td>-vascular &amp; pulmonary diseases</td>
<td>0.6</td>
<td>0.5</td>
<td>0.5</td>
<td>4</td>
</tr>
<tr>
<td>-rheumatics</td>
<td>2.0</td>
<td>1.3</td>
<td>1.6</td>
<td>12</td>
</tr>
<tr>
<td>-allergy &amp; asthma</td>
<td>0.3</td>
<td>0.8</td>
<td>0.5</td>
<td>4</td>
</tr>
<tr>
<td>-brain damage and diseases</td>
<td>0.9</td>
<td>0.8</td>
<td>0.8</td>
<td>6</td>
</tr>
<tr>
<td>-disabled</td>
<td>1.4</td>
<td>1.5</td>
<td>1.5</td>
<td>11</td>
</tr>
<tr>
<td>-hearing impaired</td>
<td>0.6</td>
<td>0.3</td>
<td>0.4</td>
<td>3</td>
</tr>
<tr>
<td>-cancer disease</td>
<td>0.3</td>
<td>0.3</td>
<td>0.3</td>
<td>2</td>
</tr>
<tr>
<td>-kidney disease</td>
<td>0.6</td>
<td>0.5</td>
<td>0.5</td>
<td>4</td>
</tr>
<tr>
<td>-other diseases</td>
<td>0.6</td>
<td>0.5</td>
<td>0.5</td>
<td>4</td>
</tr>
<tr>
<td>Sobriety organisation</td>
<td>4.0</td>
<td>1.5</td>
<td>2.7</td>
<td>20</td>
</tr>
</tbody>
</table>

Table 10.8: Category of organisations the respondents are now members of (Per cent within each organisation). Note: N=743. Missing data=1.
Membership in other organisations, type of organisation

Of those having been members of other organisations, this is how the respondents had answered:

Category of organisations the respondents *have been* members of.

<table>
<thead>
<tr>
<th>Type of organisation</th>
<th>North</th>
<th>The City</th>
<th>Total</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>A Trade Union</td>
<td>59.4</td>
<td>51.8</td>
<td>55.4</td>
<td>412</td>
</tr>
<tr>
<td>Residential organisation</td>
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<td>27.3</td>
<td>28.2</td>
<td>210</td>
</tr>
<tr>
<td>Pensioners organisation</td>
<td>27.1</td>
<td>16.7</td>
<td>21.5</td>
<td>160</td>
</tr>
<tr>
<td>Consumer organisation</td>
<td>20.2</td>
<td>18.4</td>
<td>19.4</td>
<td>144</td>
</tr>
<tr>
<td>Diet or physical activities club</td>
<td>15.0</td>
<td>18.9</td>
<td>17.1</td>
<td>127</td>
</tr>
<tr>
<td>Political party</td>
<td>21.0</td>
<td>11.6</td>
<td>16.0</td>
<td>119</td>
</tr>
<tr>
<td>Cultural organisation</td>
<td>15.6</td>
<td>13.9</td>
<td>14.8</td>
<td>110</td>
</tr>
<tr>
<td>Other organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-economic/financial organisation</td>
<td>0.6</td>
<td>0.5</td>
<td>0.5</td>
<td>4</td>
</tr>
<tr>
<td>-vehicle organisation</td>
<td>3.2</td>
<td>1.0</td>
<td>2.0</td>
<td>15</td>
</tr>
<tr>
<td>-relief organisation</td>
<td>2.0</td>
<td>0.8</td>
<td>1.3</td>
<td>10</td>
</tr>
<tr>
<td>-religious organisation</td>
<td>0.6</td>
<td>0.8</td>
<td>0.7</td>
<td>5</td>
</tr>
<tr>
<td>-interest organisation</td>
<td>4.9</td>
<td>4.0</td>
<td>4.4</td>
<td>33</td>
</tr>
<tr>
<td>-other</td>
<td>0.3</td>
<td>1.5</td>
<td>0.9</td>
<td>7</td>
</tr>
<tr>
<td>Other patient organisation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-visually disabled</td>
<td>8.9</td>
<td>9.8</td>
<td>9.4</td>
<td>70</td>
</tr>
<tr>
<td>-vascular &amp; pulmonary diseases</td>
<td>1.2</td>
<td>1.5</td>
<td>1.3</td>
<td>10</td>
</tr>
<tr>
<td>-rheumatism</td>
<td>2.0</td>
<td>1.5</td>
<td>1.7</td>
<td>13</td>
</tr>
<tr>
<td>-allergy &amp; asthma</td>
<td>1.2</td>
<td>2.0</td>
<td>1.6</td>
<td>12</td>
</tr>
<tr>
<td>-brain damage and diseases</td>
<td>0.9</td>
<td>0.8</td>
<td>0.8</td>
<td>6</td>
</tr>
<tr>
<td>-disability</td>
<td>0.9</td>
<td>0.8</td>
<td>0.8</td>
<td>6</td>
</tr>
<tr>
<td>-hearing impaired</td>
<td>0.6</td>
<td>0.8</td>
<td>0.7</td>
<td>5</td>
</tr>
<tr>
<td>-cancer disease</td>
<td>0.3</td>
<td>0.5</td>
<td>0.4</td>
<td>3</td>
</tr>
<tr>
<td>-kidney disease</td>
<td>0.6</td>
<td>1.0</td>
<td>0.5</td>
<td>4</td>
</tr>
<tr>
<td>-other diseases</td>
<td>0.6</td>
<td>0.8</td>
<td>0.7</td>
<td>5</td>
</tr>
<tr>
<td>Sobriety organisation</td>
<td>12.4</td>
<td>2.8</td>
<td>7.3</td>
<td>54</td>
</tr>
</tbody>
</table>

Table 10.9: Category of organisations the respondents *have been* members of (Per cent within each organisation). Note: N=743. Missing data=1.
Appendix 8: List of interviews and observations

INTERVIEWS
Below is a list of people both in and out of the two local diabetes branches of this study that I have interviewed formally. In addition to these formal interviews, I have talked to several members and non-members on a more informal basis. These persons are not included in the list below.

Formal Interviews of Case Study No.1 – The local diabetes branch in the North
Member of the board, 2000-02-01
Office staff, 2000-02-01
Treasurer (also member of the board in the local diabetes organisations in a neighbouring town and treasurer in the local Asthma & Allergy organisation and the regional Diabetes organisation), 2000-02-02
Chairman, 2000-02-03

Others in Case Study No.1
Chairwoman of the regional Diabetes organisation, 2000-02-01, 2000-02-02, 2000-02-03 (non-diabetic)
Diabetes specialist nurse at the local hospital, 2000-02-02 (non-diabetic)

Formal Interviews of Case Study No.2 – The local diabetes branch in the City
Group leader of the women’s group, 2000-04-04
Member of the board, 2000-04-04
Member of the board (former secretary), 2000-04-10
Treasurer (also filling other administrative functions at the office), 2000-04-06, 2000-04-10
New member of the board (former chairwoman), 2000-04-06
Office staff, 2000-04-04
Member of the board, 2000-04-05
Office staff, 2000-04-06, 2000-04-10

Others in Case Study No.2
Diabetes specialist nurse, 2000-04-05 (non-diabetic)

Formal Observations of Case Study No.1
Meeting at the hospital, the steering committee for the national diabetes register in the County, 2000-01-31
Study Circle Meeting “The Way to…” (Vägen till) in a neighbouring county, 2000-02-05

Formal Observations of Case Study No.2
Board Meeting of the local Diabetes branch in the City, 2000-04-04
Study Circle Meeting ”Measuring techniques “ for type 2 diabetics, 2000-04-05
Study Circle Meeting ”Measuring techniques “ for type 1 diabetics, 2000-04-05
Annual meeting of the local Diabetes organisation, 2000-04-10
Appendix 9: Example of a typical circle meeting

A typical circle meeting within ‘The Way to…’-project

On the first Saturday in February, I was invited to attend a study circle meeting within the “Way to…project” in a little town, which is situated in one of the border of two regions. Two members of the board of the local branch and the chairwoman of the regional organisation were invited to speak. Most of us went there together in a small minibus. On our way out of the town, we also picked up the dietician. The drive there took us almost two hours.

Upon arrival to the premises, I checked the room. There were 27 participants in total at the meeting. The majority were overweight pensioners, but then again this meeting was especially for people with type 2 diabetes. Still, I could not help the feeling of misplacement. What would a teenager with diabetes ever do here? The only people younger than 40-50 in this room, were some of the invited speakers and me.

The meeting started more or less directly after we arrived. Firstly we were given some local information, e.g. to everybody’s joy, there were two study circles about to start in this region.

The chairwoman of the regional diabetes organisation spoke first, starting off with a joke about the different types of diabetics. Something about not only having type 1:s and 2:s, but also type 3:s who are family members of someone with diabetes and type 4:s who are health care personnel, ”those who live off your disease!” All these types are namely represented among the members of the local branch. She covered three different issues.

- Organisational and membership issues, such as membership, member fees and how the diabetes organisations are organised, covering the Association (SDA) with in total approx. 10% of all diabetics as members. The questions she got were however much more focused on local grounds, on what exists in places nearby, which are closer to this town than to the one they came from.
- The national diabetes register. At this point there were many comments made on the problems with the so called relay doctors, who at some places also are called ”The Dane of the week” (veckans dansk). Many of the participants were both unsatisfied and worried about the problems of getting a doctor to come here. A discussion was initiated by the participants, on the problem of getting doctors in the region. This problem had also been brought up in my interview with a diabetes nurse at the hospital, and had been emphasised several times by members of the branch during my stay there. Naturally this problem affects the need for a patient organisation in this area.
- The Care Program. The national guidelines are a general agreement with the National Board of Health and Welfare, for equal care throughout the country. But, at regional level they also make their own agreements with the county council, ‘the care program’.

She also presented future activities and finally she showed a film about the project ”The Way to…” in the region. On the film, VVV was presented. VVV stands for ‘We value the health care’ (Vi Värderar Vården) and is unique in the aspect that it is the first time in Sweden that a user organisation has formed and raised demands on evaluative material, but it is financed by the County Council.

The next speaker was the dietician who talked about eating healthy. During this session there were very many individual questions on ‘what specifically should I eat, considering I am also allergic to so and so’ etc. This session generated more questions from the participants, perhaps because the topic was easier to relate to. It was clear that the meeting obviously served a purpose of being a forum for pensioners to get together as well. At the coffee break people started chatting and I thought to myself that this was probably a social event for many of the participants.

Then the Disability Coordinator at the County Council in the region, who was responsible for ‘disabilities and services’ talked about her work. She is very much in touch with all the disability and patient organisations and works with guidance, information, conferences in the region, case handling, recreation grants (e.g. camps), funds for children and the youth (but there is not much money here), the interpreter central within the region, HSV in the region, user groups, interpreter committee, grant matters for disability and patient organisations and pensioners’ committees.

As a Disability Coordinator she has several co-operation partners, e.g. disability and patient organisations, the County Council, politicians, the Association of Local Authorities, the regional department, the County Administrative Board, the Disability Ombudsman, the National Board of Health and Welfare, the Federation of County Councils, the municipality and the pensioners’ organisations (PRO, SPF). Within the region there are 28 disability organisations. Within the HSV there are about 25 disability organisations in the region. (E.g. the DHR is not a member of the HSV.) At national level within the country there are between 30-40 disability organisations.

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272 Circle meeting at a local branch in the North, February 5th, 2000
273 Interview with N6
Then the Patient Ombudsman spoke about the Patient's Committee and about her work in the region. Patient representatives at County Councils have existed since 1980. There is a law on Patient's Committees (from January 1999.) In the region, there were 450 complaints during 1999. These refered to the following causes: physical treatment (Behandling) (262), treatment (Bemötande) (49), economical (14), informational (16), legal, juridical (20), care (24), organisational / routines (52) and other issues (13).

At this point some of the participants started discussing why politically made decisions are not obeyed? The discussion concerned why the patients cannot choose their own doctor within the County Council, although they by law are entitled to do this? One participant argued that the County Councils have decided that this cannot be and instead they allot patients to a doctor. Most participants were however passive and I could actually see that a few had fallen asleep!

Finally the word was given to the chairman of the local diabetes branch, who briefly presented the organisation. Most participants seemed however more interested in the following dinner which was to take place.

After the dinner there were 22 participants left. I then asked them how many of them who were members of any diabetes branch organisations? 11 of them were, which means that exactly 50% of the participants at this meeting already had joined a diabetes organisation.
Appendix 10: Examples of Empowerment Programs

Several authors have written about the topic of the patient’s point of view in for example psychotherapy, reflecting on attempts to describe clinical work from the patient’s point of view (Casement, 1990 & 1994), mental health policy, focusing on patient advocacy and patient empowerment (Rose and Black, 1985) and the psychiatric consumer movement in the USA with regards to empowerment (McLean, 1995). McLean conducted an ethnographic study of an alternative care program entirely run by consumers and ex-patients. This type of program has been developed out of the patients’ experiences of inadequacies in the mental health system. Here, “empowerment came to mean self-determination and control over their entire lives, not only their treatment” (McLean, 1995, p. 1053). Now they are producing their own self-help alternatives.

Arnold et al. (1995) evaluated a diabetes empowerment program called ‘a personal path to self-care’ at the Michigan Diabetes Research and Training Centre. The evaluation was carried out through observing the running group education program with five diverse groups of 18 people with diabetes in each group. Briefly, they found that diabetes care should include opportunities for people to address the emotional, social, behavioural, spiritual and psychological, as well as physical, challenges of living with their disease. In their article, they describe key ingredients for planning and implementing a successful patient empowerment program, which helps participants develop skills and self-awareness in goal-setting, problem solving, stress management, coping, social support and motivation (Arnold et al., 1995, pp. 308-309).

The same authors have later carried out another study, which aimed at determining whether participation in a patient empowerment program would result in improved psychosocial self-efficacy and attitudes toward diabetes, as well as reduction in blood glucose levels (Anderson et al., 1995, pp. 943-949). It was a randomised controlled group trial, with a total of 64 patients. A six-session (one session per week) empowerment education program was received by the control group, while the intervention group was on a waiting list. After the six weeks, it was now the turn of the control group to receive the same sessions. Six weeks after this program, follow-up data was given from both groups. The results showed improvements in self-efficacy for both groups and minor improvements in blood glucose level. The results were constantly higher for the psychosocial aspects of living with diabetes, i.e. mastering the daily problems of sickness.

A British group of researchers with a broad competence, studied the effect of letting patients with chronic inflammatory intestinal disease (Crohn’s disease or ulcerous colitis) either get the ordinary treatment or participate in the program which received extended information, met with a specialist on patient-oriented visits and made their own decisions. After the program, the result showed that the group from the empowerment program made less visits to the hospital, but unchanged number of visits in the primary care and that these patients felt a higher satisfaction than before (Kennedy et al., 2003 & Stewart et al., 1995).

A Swedish patient education program in Kalmar, called Nyckeln, aims at giving participants tools for living a better life with their disease and getting more knowledge on the disease and its treatments options. The evaluation of the program in 2004 showed that 60% of the participants had made changes on their own that had led to increased self-esteem and feeling in control of one’s life and disease. Compared to the normal population, the participants of the course had extremely low health related quality of life and they were major consumers of health care, prior to taking the course. After the course, the psychological dimension of health-related quality of life increased significantly and the consumption of health care decreased (Bengtsson & Morén Hybbinette, 2004).

Another empowerment technique has been developed by Balint (Luban-Plozza, 1995, pp. 257-263), the so called ‘Balint approach’. This method emphasises the interpersonal relations between the group members and their patients and the role of psychology in medical care. It stresses the need for communication and throws a light on the doctor-patient relationship. Psychosocial problems and family groups are also taken into account. The development of this method started when Balint realised that many patients are ill due to psychic rather than physical causes. Their problems are relationship problems. Another problem when trying to come to terms with the above, was that physicians generally lack time. But, according to Balint, the quantity of time available is not as important as the physician’s concentration and the quality and intensity of the relationship. Since the 1950s, Balint and co-workers have given seminars aiming at training general practitioners to hear, see and relate better during their contacts with patients (Luban-Plozza, 1995, p. 258).

The reactions and opinions of physicians and nurses regarding empowerment group education in diabetes were recently studied (Adolfsson et al., 2004). A conflict in roles was found to cause problems. The health care personnel knew their role in the traditional approach as experts, but not their role as facilitator in the empowerment approach. For this they themselves needed support, both from a supervisor connected to empowerment group education and from the family practice.

There are also examples of empowerment programs not aimed at patients, but at others in need, e.g. a project called “The way out” (Vägen ut) in Göteborg focused on empowerment for people with a background in drug abuse and
crime (Hedin, Herlitz & Kuosmanen, 2005). Through social worker’s cooperatives, where participation and own responsibility were key issues for the participants, the aim was to empower these individuals on their own terms. Empowerment was in this project seen as strengthening oneself in relation to, but not at the expense of other people and institutions. Workplace health promotion has also been evaluated in terms of empowerment processes (Arneson & Ekberg, 2005). The intervention aimed at promoting empowerment and health among the employees in three public sector organizations. The method of problem-based learning was found to be successful and powerful in enabling empowerment.

Arnold et al. (1995, pp. 308-312) argue that while traditional medical treatment models often ignores the emotional, spiritual, social and cognitive aspects of living with a disease, empowerment programs address these psychosocial areas. There is minimal research concerning the actual process of providing such programs to patients. Empowerment programs have the greatest showing effects, when applied to self-managed diseases like e.g. diabetes. The patient usually provides more than 95% of the daily care in this disease-situation (Anderson et al., 1995, p. 943).
Appendix 11: The Diabetic Registry

During the last decades it has been possible to register symptoms and signs centrally from patients with different disease entities. The electronic handling of data is developing rapidly and many professional and governmental bodies desire to gain a better picture of the diseases in the populations and how the patients are taken care of through a register of certain data from all, or as close as possible, patients. This has also happened with diabetes, which probably was one of the diseases where a central registration was contemplated early. It is therefore interesting that only ten percent of the total of the population with diabetes are followed in a central register.

As far as I know, the interest of recruiting patients for the register lies with the medical services and the Board of Health and Welfare, or perhaps with a nurse or physician who is interested of this type of follow-up, while the diabetes organisation mostly has to rely on their own recruiting efforts. A register of certain data from patients with a defined disease constitutes an important tool for professional organisations and governmental bodies to control how a certain disease population are taken care of and also how they live. This means that they have a possibility to judge both the way the different professions handle the patient population, and how well the patient is following the advice from the health care. Even though the thinking behind the creation of the register is benevolent with the aim of improving the life for the person registered as having a certain disease entity, it also means that the rulers of the land may have an insight in the most intimate life of every citizen. The pros and cons of registers must therefore be discussed thoroughly, however elsewhere. The empowerment of patients may have a more important role in the whole question of disease registration than in most other parts of the health services.

An example from New York City illustrates this. There the city administration wants to start a register of all patients with diabetes in the city. This has given rise to an engaged discussion between doctors, patients, the administration of the city and the American Diabetes Association. This discussion has focused on personal integrity and demonstrates the importance of having a well known association to represent the patient’s interests (Fairchild, 2006).


