# The Netherlands



**Dutch Patient Associations** 

# Israel



**Israeli Patient Associations** 

# A comparative research on the role and influence of Patient Associations in the Netherlands and Israel during the National Health Insurance System Reform

Diola Bijlhout **July 2008** dbijlhout@telfort.nl

# A comparative research on the role and influence of Patient Associations in the Netherlands and Israel during the Health Insurance System Reform

**Master Thesis** 

Diola Bijlhout

Master Thesis Supervisor

Dr. K.J. Grit

Co- Evaluators

Dr. M. Bekker

Drs. H. van de Bovenkamp

Institute of Health Policy and Management (iBMG)
Erasmus University Rotterdam
The Netherlands
July 2008

**PREFACE** 

In order to obtain the Masters degree in Health Economics, Policy & Law at the Erasmus

University in Rotterdam I performed this Master Thesis.

My interest for health policy became triggered, when I as a Hepl Master student learned that

health policy research was rather young and pioneering within health science. For me it

became a challenge to perform a research of health policy. The combination of the challenge,

my background in the health field and my interest for international health systems, resulted in

this qualitative research. Looking back I can conclude that it has been an enrichment of

knowledge and skills, I had never experienced before. My ultimate goal to present an

international Master Thesis has become true, looking at the result.

The research to my opinion has provided clear conclusions and recommendations. I truly hope

they will be of use for policy-makers and patient associations in order to learn, and that the

role of patient associations in the health field becomes secured within countries health

systems.

At this moment I want to thank a number of people without whom it would be troublesome to

have written this Thesis. First in the Netherlands, I want to thank Kor Grit for his ever useful

instructions and feedback. Especially at the moments I feared a deadlock. Furthermore, I want

to thank David Dror for his assistance into the Israeli health field. In Israel I want to thank

Dov Chernichovsky for his benevolence to assist me with the research and for his instructions

and feedback during my visit in Israel. I want to continue expressing thanks to all respondents

of the interviews, for their time and interest in the research.

I furthermore want to thank all friends in Israel and the Netherlands for their support.

Especially, the Rolvink family and dr. Agaath Bijl. Furthermore, I want to thank my favourite

aunt and cousin, Joan and Riona for their endless support. At this moment I want to thank my

dear mother Carmen for her everlasting support which inspired me all the way, and at this

moment I am grateful.

Diola Bijlhout

Rotterdam, July 2008

i

#### **SUMMARY**

#### **Prelude**

In 2006 a major health insurance system reform took place in the Netherlands and the health insurance law –ZvW- was implemented. In 1995 already a major health insurance system reform had taken place in Israel and the national health insurance law –NHI- was implemented. The implemented law in both countries was the end product of the health policy-making process. During this process numerous health actors (political and social political) interact with one another. The implemented regulations constitute health policies which affects nation's patients. For this apparent reason patients and their associations within democracies participate during health policy-making.

#### Aim

The aim of this thesis is to provide a scientific study about the determining factors which influence two key features of interest group behaviour. The key features are indicated as; the role and extent of influence of patient associations. In addition the aim of this thesis is to provide information from which patient associations and policy-makers in both countries can learn.

# **Research question**

The central question of this thesis is: "What has been the role and extent of influence of patient associations in the countries of Israel and the Netherlands during the National Health Insurance reform, and how can patient associations effectively enlarge their role and influence in health policy-making?"

The principal theory i.e. Scharpf's actor-centered institutionalism is utilized in order to: answer the central question, analyze the health insurance political environment, analyze the policy-making process and to establish comparison between the Netherlands and Israel. Scharpf distinguishes four factors which create the analyzing criteria: 1<sup>st</sup>. Institutions 2<sup>nd</sup>. Actors 3<sup>rd</sup>. Actor constellations and 4<sup>th</sup>. Modes of interaction. According to Scharpf, (health insurance) policies are the outcome of structured interactions. Secondly, the model of Arnstein's ladder of participation is utilized to classify the degree of participation of patient associations during the health insurance reform.

Arnstein distinguishes eight levels of citizen's participation: 1st. Manipulation 2nd. Therapy

3<sup>rd</sup>. Informing 4<sup>th</sup>. Consultation 5<sup>th</sup>. Placation 6<sup>th</sup>. Partnership 7<sup>th</sup>. Delegated power and 8<sup>th</sup>. Citizen control. In addition several study results are utilized to portray the role and strategies of interest groups during policy-making.

### The research method

The research method of this thesis follows a case-study approach, due to the observation of two empirical cases. The study contains a qualitative research in order to explore and investigate the range of opinions and representation of the issue. Three data collection methods were utilized. First, literature was reviewed. Second, face-to-face interviews were performed to gather data in order to examine the policy environment. The respondents in both countries were: patient associations representatives, an expert on the health insurance reform and in the Netherlands also a deputy of the Ministry of Health. In total 7 respondents were interviewed. The final method of data collection concerned the analysis and examination of documents.

# **Analysis**

The analysis provided country specific data, explanations and answers to the research question. Simultaneously the empirical findings were compared and reviewed alongside the theoretical framework. The analysis was performed and based on the four factors of Scharpf's Actor-centered institutionalism: 1<sup>st</sup>. Institutions 2<sup>nd</sup>. Actors 3<sup>rd</sup>. Actor constellations and 4<sup>th</sup>. Modes of interaction.

#### **Findings**

In the Netherlands patient associations were a legitimized actor. This implied the insider status and contained privileges during the policy-making process of the ZvW law. The established Patient Umbrella Organisation (NPCF) acted as a delegate during the policy-making process. Through recent years the NPCF has acquired a strong position and professionalism. Due to the political institutional system of Dutch corporatism (also known as Polder model), the NPCF interacted with all health actors during the construction of the ZvW law. They exerted influence in order to present and defend their interests, and preferences, by insider strategies. The NPCF attended numerous policy-tables, were in close interaction with the Ministry of Health, umbrella organisations of insurers and health care providers and the media.

Contrary to the Netherlands, patient associations in Israel were not a legitimized actor. This implies the outsider status during the policy-making process of the NHI law. Patient associations did not have delegates present at policy-tables and were not in close contact with policy actors. However, during the policy-making process patients experienced a development. Patients were allowed at a particular policy-table to express their voice in order to be heard. However, this reflects a rather pioneering method of patient participation. Due to the political institutional system of pluralism, some patient associations employed indirect strategies to influence the policy-making process from the outside. Some were successful. Furthermore, patient associations were not joined into a patient umbrella organisation. The latter as a result of; different opinions, ideas, institutions, interests and preferences, and social difficulties among the different patient associations. However at this moment, thirteen years later things have changed.

# **Conclusion and recommendations**

The role and influence of patient associations during the policy-making process, is influenced by the political and governmental institutions of the individual country. Yet an important factor of influence on the role and influence has been the time period of the 1990's, in both countries. Patients during that time were confronted with radical developments, such as a health system reform. This time period proved to be a window of opportunity to enlarge your role and influence as patient associations during national health policy-making.

Furthermore, patients associations make use of certain strategies to achieve their aims and goals during policy-making. Between countries these strategies can differ. The strategies patient associations apply are also influenced by the political and governmental institution. Evidently however, patient associations underestimate their own action repertoire since they regard themselves as young political actors and more often are impressed about the position of other health actors. Nonetheless, both countries reveal patient associations to some extend, are able to get around the rules of the political game to let their "voice" be heard.

#### The recommendations are summarized as follow:

Patient association's role may enhance when there is a collective body which incorporates professionalism and strategic leadership. However, challenges remain due to country's specific contexts.

- Patient associations may enhance the extent of their influence when the strategies they opt, pursue to influence both the formal and informal channels during the policy-making process. Patient associations should remain alert; the strategies applied might involve some constraints, due to country's institutions. Therefore, patient associations must realize to apply certain actions which are not part of the rules, if possible and necessary. Caution is required; the latter is an attempt to exert influence but requires not to damage the role patient associations have.
- Policy-makers need to consider if country's political system creates sufficient room for patient associations to have a role during policy-making. Patient participation after all, is on the global and regional agenda.

# TABLE OF CONTENTS

PREFACE	I
SUMMARY	II
1. INTRODUCTION	3
2. PROBLEM DEFINITION	5
2.1 ANALYSIS OF THE PROBLEM	5
2.2 THE RESEARCH QUESTION	
2.3 IMPORTANCE OF THE TOPIC	8
2.4 STUDY OBJECTIVE	
2.5 THE IMPORTANT TERMS DEFINED	8
3. THE RESEARCH METHOD	9
3.1 THE RESEARCH METHODOLOGY	9
3.2 DATA COLLECTION	9
3.3 DATA ANALYSIS	
3.4 TIMEFRAME	11
4. THEORETICAL FRAMEWORK	
4.1 Introduction	
4.2 ACTOR-CENTERED INSTITUTIONALISM	
4.3 ARNSTEIN'S TYPOLOGY ON EIGHT LEVELS OF CITIZEN PARTICIPATION	
4.4 INTEREST GROUPS: RELATION TO THE STATE	
4.5 TACTICS AND STRATEGIES OF INTEREST GROUPS	
5. THE CONTEXT	25
5.1 Introduction	
5.2 THE NETHERLANDS	
5.2.1 Demography and macro-economy	
5.2.2 Political and Institutional system	
5.2.3 Socio-economy 5.2.4 The Dutch culture	
5.2.5. The Dutch health system before the ZvW law 2006	
5.2.6 The Netherlands and patient associations	
5.3 THE STATE OF ISRAEL	
5.3.1 Demography and macro-economy	
5.3.2 Political and Institutional system	31
5.3.3 Socio-economy	
5.3.4 Israeli culture	
5.3.5. The Israeli health system before the NHI law 1995	
5.3.6 Israel and patient associations	
6. HEALTH REFORMS PRESENTED	
6.1 Introduction	
6.2 PROCESS OF THE DUTCH HEALTH INSURANCE REFORM	
6.2.1 The Dekker commission	
6.2.2 Reforming the Dutch health system	
6.2.3 The new Health Insurance Law, ZvW 2006	
6.3 PROCESS OF THE ISRAELI HEALTH SYSTEM	
6.3.2. Reforming the Israeli health system	
6.3.2 The new Health Insurance Law, NHI law 1995	
6.4. CROSS-COUNTRY COMPARISON OF THE NETHERLANDS AND ISRAEL	
7. CASE PRESENTED: DATA ANALYSIS	48
7.1 Interpolation	40
7.1 INTRODUCTION	
/ ■ 11707111U11U110000000000000000000000000	

<b>7.2.1</b> The Netho	erlands	48
7.2.2 Israel		50
7.3 ACTORS		53
<b>7.3.1</b> The Netho	erlands	53
	ELLATIONS	
	erlands	
	ERACTION	
	erlands	
8. DISCUSSION		76
8.1 Evolution of	F PATIENT ASSOCIATION'S ROLE AND INFLUENCE IN HEALTH POLICY-MAKING	· 76
	E OF ROLE AND INFLUENCE BY PATIENT ASSOCIATIONS	
9. CONCLUSIONS .		83
	N	
	\\	
	TIONS	
REVIEW		89
REFERENCES		90
SUPPLEMENTS		96
SUPPLEMENT 1	UN CHARTER ARTICLE 4 AND 29	97
SUPPLEMENT 2	IMPORTANT TERMS DEFINED	98
SUPPLEMENT 3	INVITATION LETTER	99
SUPPLEMENT 4	TOPIC LIST- PATIENT ASSOCIATIONS	100
SUPPLEMENT 5	TOPIC LIST- EXPERT HEALTH INSURANCE/ REFORMS	101
SUPPLEMENT 6	TOPIC LIST- MINISTRY OF HEALTH DEPUTY	102

#### 1. INTRODUCTION

The topic of this thesis centres on the prominence of participation by patient associations in health policy-making within democracies¹. An empirical case i.e. a major health insurance system reform shapes the analytical and retrospective comparative environment in this thesis. The democracies of interest are the Netherlands situated in Western Europe and the country of Israel, which is situated in Southwest Asia. Why focus on these two countries? The choice for the Netherlands was easily made because I am a Dutch citizen. However, this choice became more interesting, when the government decided to change the Dutch health insurance system drastically at the beginning of 2006. The choice for Israel is more pragmatic. I have frequently visited that country and was astonished by the Israeli health system. In addition both countries show a resemblance to each other, in that they have both have gone through a major health insurance reform and their health system is of Bismarckian style i.e. have sickness funds.

Why focus on the participation of patient associations during health policy-making? First of all, I am convinced that within democracies patients who are affected by health decisions should be granted participation and equal opportunities. This conviction became more interesting when I read the recommendations of the Committee of Ministers of the Council of Europe (2000) and the Convention on the Rights of Persons with Disabilities of the United Nations (2006). These are instruments which can contribute and advance the participation of patient associations during health decisions (supplement 1). Furthermore, I considered it a challenge to inquire the role and influence of patient associations during policy-making, within the health field. The European Council recognizes the fact that empowering citizens/patients to participate in health policy-making improves the functioning of the health care system. In addition, this establishes a better balance of interests and partnership between various players in the system. Interesting and valuable is to inquire how well and how far recommendations of the European Union are integrated in the Netherlands, which is a European Member State. Moreover, during recent years the individualization and emancipation of patients has increased and more often patients consider it a "right" to participate in health decisions. Therefore, democratic governments should be committed to engage themselves with patient associations. I am fully aware this can take place on different levels in health decision-making. Patient associations can be regarded as patient

<sup>&</sup>lt;sup>1</sup> The health policy-making process consists of the following stages, in which patient associations can play a role and may influence: 1. Agenda setting. 2. Policy preparation. 3. Policy deliberations. 4. Policy decision-making. 5. Policy enactment. 6. The implementation. The term "policy-making process" discussed in this thesis refers to the first five stages.

representatives and collective actors which place themselves between society and the government. Patient associations are then regarded as interest (pressure) groups that attempt to influence the policy process to achieve specific goals (Buse et. al. 2005). The way patient associations interact depends for a great part on the democratic institutions and also on the chosen strategy. These factors and more, differ from country to country, making the subject of this Master Thesis highly interesting.

The governments of Israel and the Netherlands considered it of great importance to establish an efficient, qualitative and responsive health system, since they faced substantial problems within their health systems<sup>2</sup>. Therefore, both governments implemented a new health insurance law creating regulated competition between sickness funds. However, regulated competition in the Israeli health care system is based on the quality of medical care services while in the Netherlands regulated competition is based on price competition and quality of medical care services.

Before the national health insurance law in Israel (later referred to as the NHI law- 1995) and the new health insurance law in the Netherlands (later referred to as ZvW law- 2006) came into force a whole policy-process preceded. Public policies are the outcomes of intentional action and depend on the perceptions and preferences of the individuals involved (Scharpf, 1997). This also in the health policy arena which is characterized by the involvement of numerous actors. These actors have to abide by the (democratic) institutional settings, shaping their behaviour in the political arena. These institutions allow for predictability and they link government with the people and important groups (Huntington, 1968).

Is it possible to assess convergence or divergence, when comparing European versus non-European countries, with regard to patient participation in health decision-making? Are remarkable differences in institutional structures such as, corporatism in the Netherlands or pluralism in Israel, the cause for a different way of patient participation in health decision-making on the national level? Are there any developments and what can countries learn from these developments? These are interesting questions, which hopefully this thesis will give more insight into.

\_

<sup>&</sup>lt;sup>2</sup> One of the problems which high-income countries face, are the increasing health care expenditures, which makes up a substantial part of that countries GDP. A subsequent problem in Israel was a health system that was too politically affiliated.

#### 2. PROBLEM DEFINITION

## 2.1 Analysis of the problem

Health politics are complex and dynamic. Central aspects are the interaction between numerous political and non-political actors and the influence on the policy-making process. These actors interact in order to preserve and defend their interests in health policy decisions. Therefore, when the policy-making process is examined, the decision-making power of actors becomes clear.

Often patients are regarded as the vulnerable ones in society. But mobilization strengthens their position, respectively in society and in health policy-making. Therefore, when patients establish representatives, by the body of patient associations, participation during health decisions becomes more feasible. However, during health policy-making patient associations are for instance, confronted with notorious policy actors and the rules of the political game. As a consequence, the following statements are presented. It is not self-evident that: 1) Patient associations participate in health policy-making and 2) Once enabled to participate also really exert influence on policy-making.

Data reveals, that participation and influence during health policy-making is dependent on several factors. For example, political activity compels patient associations to take knowledge of the rules of the political game. The rules often are embedded in country's institutional systems and may determine the actions of patient associations during health policy-making. Of great interest however, is to determine the latitude patient associations have to abide by the political rules and perhaps the latitude to change them. On one hand, the rules may strengthen patient association's participation in defending interests and preferences. On the other hand, these interests and preferences determine the tactics, strategies and influence of patient associations during health policy-making. Besides, patient associations might feel compelled to appoint professional and strategic leadership which are familiar with the rules of the political game.

Hence for a substantive part the success of policy actors during policy-making are influenced by country's democratic institutions. Each country has a country specific institutional system which patient associations also have to confront. In the Netherlands, patient associations have

to manoeuvre in the corporatist system, also known as the Poldermodel<sup>3</sup>. In this system, they face the presence of the political establishment and numerous associations with their umbrella organisations<sup>4</sup>. During the policy-making process of the health insurance law, patient associations closely interacted with the Ministry of Health and umbrella organisations of insurers and providers. Patient associations in Israel on the other hand, have to manoeuvre in a pluralistic system and society. In this system, they face the presence of the political establishment, civic groups and religious, liberal and secular groupings combined within citizens from different cultural backgrounds. In this case, the Israeli government had the responsibility to consult patient associations on issues of the health insurance law. Yet within pluralist systems policy-making is not solely a quest for power. Nonetheless, a pluralist system is characterized by conflicts among actors, which requires of them to defend their interests. Of interest is to determine, the actions and reactions of patient associations in an environment where various actors want to retain attention from government and policy-makers.

Will the axiom hold, namely, that during health insurance policy-making patient associations within corporatist and pluralist systems differentiate in role and influence? Are mechanisms as: government funding and legislation crucial necessities? Both countries show a major contrast. Nonetheless, at this stage it is inappropriate to conclude that one democratic institution is more suitable than another.

Analysis is required in order to draw a thorough cross-country comparison. The aboveabridged description of the political institutions with these tactics and strategies, provide insight on the complexities for patient association's participation and influence during policymaking. These complexities are subject for analysis.

<sup>&</sup>lt;sup>3</sup> The Polder model often stands synonymous for the *Dutch consensus model*. It resembles a unique combination of policy, institutions and culture (Delsen, 2000).

<sup>&</sup>lt;sup>4</sup> Umbrella organisations are assemblies of civic groups which represent these civic groups for example, during policy-making.

# 2.2 The research question

Based on the issues previously discussed the research question of this Master Thesis can be derived:

"What has been the role and extent of influence of patient associations in the countries of Israel and the Netherlands during the National Health Insurance System reform, and how can patient associations effectively enlarge their role and influence in health policy-making?"

To answer the central research question the following sub questions are derived and will be answered in the following chapters:

#### General

- What frameworks are present explaining the dynamics of actors in health politics and health policy?
- What is the role of patient associations in health politics and health policy-making?
- Are there criteria depicting the strength of participation of patient associations?
- What tactics and strategies can patient associations apply in health politics?

## **Empirical**

- What is the context of the countries of Israel and the Netherlands?
- What are the typical characteristics of a health insurance reform with regard to health politics? (Health insurance policies affect different aspects of healthcare than for example, policies regulating vaccines distribution. These aspects partially determine and modify the actors involved and the policy-making process)
- What is the relationship between country specific variables and participation of patient associations in health insurance policy-making? (for example, the variables of governmental and political institutions but also the culture of a country determine and modify the actors involved and the policy-making process)
- Were there specific issues of the health insurance law that patient associations in both countries tried to influence and why? (by providing some insight on the issues of concern, partially the role and extent of influence of patient associations during the policy-making process might be explained)

• How did patient associations exert influence during the health insurance policy-making process? (the answer to this question will reveal the actions of patient associations during the policy-making process)

#### Recommendation

• What recommendations can be given to patient associations to enlarge their role and influence in health policy-making?

# 2.3 Importance of the topic

The analysis and comparison of both countries provide a scientific sight on the enabling and constraining factors during policy-making. With the obtained data, policy-makers are made aware whether their democratic political system provides sufficient room for patient associations to participate during health insurance policy decisions.

### 2.4 Study objective

Primarily, the study objective of this thesis is to enable patient associations to learn from one another and if required increase understanding concerning factors which establish effective skills for political participation. However, I am very much aware that caution is required; the success of one country may not work in another. The latter comment is made, due to the existence of various political and governmental institutions and rules of the game. It is necessary to quote that patient associations need to correct for their context.

Secondly, the obtained data provides insight on the amount of countervailing-power of patient associations during health insurance policy decisions. These data create options for prediction, ceteris paribus, on association's powers during future health insurance policy decisions.

Thirdly, this thesis will provide policy-makers in Israel and the Netherlands, of significant information on the participation of patient association's during the process of a health insurance reform.

# 2.5 The important terms defined

Defining the important terms at this moment will create consensus in the understanding and meaning of terms often applied in this thesis. Please refer to supplement 3 for the definitions of the important terms in this thesis.

#### 3. THE RESEARCH METHOD

# 3.1 The research methodology

The research question indicates observing specific empirical cases within their context i.e. the role and influence of patient associations in the Netherlands and Israel during the health insurance reforms. Therefore, I perform a qualitative research and apply the case study method. According to Bauer & Gaskell (2000) the real purpose of qualitative research is to explore the range of opinions and the different representations of the issue. In addition, a case study is valuable to research complex situations and explore them in-depth and retrospectively. The critique on the case study method is that it tends to over-emphasize historically sequences of events at the expense of structural explanations (Bowling, 2002). Furthermore, the external validity could be a problem. In such case the derived conclusions and explanations are not applicable in equal empirical cases.

However, it is suitable to line up the advantages of the case study:

- Extensive analysis and description of a complex case can establish learning.
- Data is gathered in such a way that the subject of analysis will remain the central focus of this study.
- The subjective perspectives are combined and used to support the subject of analysis in this study.

# 3.2 Data collection

In this study three data collection methods are applied. Data was collected from the following resources: thematic books on health politics and politics in general, policy journals, published documents from relevant organisations, microfiche articles, the Internet, press releases and publications of the Ministry of Health. The data was gathered on the following items: The Netherlands/Israel and patient associations, patient representation, interest group behaviour, health insurance, health insurance law, health care system of the Netherlands/Israel, public policy and health politics. The majority of the information was relatively easy to obtain. However, information on the involvement of patient associations in Israel from general resources was laborious to obtain. In spite of the latter the consequences for the analysis were confined by performing triangulation in order to reduce the hiatus.

The literature review was performed to construct the theoretical framework. Furthermore, face-to-face interviews were performed to obtain time specific data. By e-mail the respondents (supplement 2) received an invitation letter. The letter described the aim of the study (supplement 4). The respondents in the Netherlands were; two policy-makers of patient umbrella organisations, a deputy of the Ministry of Health and a health insurance expert on the 2006 reform. The health insurers however, turned down the invitation (supplement 5, 6 and 7). In Israel the respondents were; a patient representative, a chairman of a patient umbrella organisation and a health insurance expert on the 1995 reform (ibid). The health insurers turned down the invitation and it was not possible to arrange an interview with someone of the Ministry of Health. To overcome this data deficit the health insurance expert was questioned on the subject. The data provided some insight on the perspective of the Israeli government on patient participation. Subsequently, a number of Israeli respondents had to respond in English which is not their native language. However, the confusion of tongues was confined since the interviewer and respondent made clear if answers or questions were ambiguous. The interviews were audio taped after consent from the respondent.

By detailed questioning the in-depth interview enabled a thorough research on the subjective experience. In addition inconsistencies were investigated. Altogether this results in specific information of greater detail. Caution was required for the potential of interviewer bias (Bowling, 2002). The techniques of good interviewer skills described by Bauer and Gaskell (2000:51) were applied to reduce this bias.

The third method of document analysis made it possible to analyse societal values and practices. The documents were collected from media archives. This method has received some critique. It has been argued that the documents could be too subjective and reflect social biases. Bowling (2002) states that when using this method, the process of the documents their construction should be investigated, rather than the content of the documents.

Triangulation will take place due to the application of three data collection methods. This method compensates the more or less weaker data collection methods in order to increase the validity and reliability of the study.

## 3.3 Data analysis

The data will be analyzed conform the principle of explanation building. With *explanation building*, the researcher looks for casual links and explores plausible or rival explanations and attempts to build an explanation of the case (Yin, 1994). The systematic processing of the data obtained from interviews includes the following actions: the writing of transcripts, coding, high-lighting, labelling and methodological comparison.

# 3.4 Timeframe

At this moment it is of great importance to acknowledge the different time periods of the health insurance reforms in both countries. The NHI law in Israel was enacted in 1995 and the ZvW in the Netherlands on January first, 2006. Nonetheless, I expect this comparison is compatible, based on the assumption that the policy and social context of countries does not drastically and fundamentally change. Moreover, a thorough description of the Israeli context before the 1995 reform is portrayed, subtracted from adequate resources.

Furthermore, patient participation is a dynamic concept. Between the two study environments a time period of eleven years exists. For that reason a comparison of patient associations in Israel and the Netherlands might reveal time specific differences. Relevant is to assess whether situations and actions of Israeli patient associations have changed over these eleven years. Furthermore, it interesting is to determine whether patient association's role and influence during policy-making would differentiate when the reform had taken place in the current setting?

### 4. THEORETICAL FRAMEWORK

#### 4.1 Introduction

In this chapter theories for political analysis are presented. First, an introduction into the subject of political theoretical frameworks is given, followed by a description of the framework of actor- centred institutionalism (Scharpf, 1997). Subsequently, a complementary theory for analysis, the model of Arnstein's ladders of citizen participation (1969), will be discussed. Finally, several models and empirical data on interest group's participation will be discussed.

The world of health politics is very complex. Explanatory factors are: the policy problem, the presence of numerous (political) actors and the institutional setting of the country. Political science is essential because it creates significant ways and means to understand and improve policy conditions. Governments ultimately, want to achieve effective and legitimate health policy.

In political science there are several different theoretical frameworks and their utilization is based on the type of sociological phenomena they attempt to explain. In general, the reasons for utilization are summarized as follows; firstly, to diminish political complexity and create ways to look at every day's reality. Secondly, to make the analysis of politics, the policy process and the comparison of cross-national politics feasible. The reasons pursue the general aim to construct ways for scientists to form explanations about policies and the policy-making process (Howlett & Ramesh, 2003).

The process described in the next sentence has to precede in order to explore the role and extent of influence of patient associations during the policy-making process of the NHI (1995) and the ZvW (2006). The theoretical framework is constructed and utilized as a tool to define and describe the factors of interest, based on prior described reasons.

The framework of *actor-centered institutionalism* (Scharpf, 1997) and the *ladder of citizen* participation (Arnstein, 1969) construct the theoretical framework.

First, actor-centered institutionalism will be discussed<sup>5</sup>. It assumes policy is the outcome of structured interactions among intentional actors and that the outcome is shaped by institutional settings. The framework of actor-centered institutionalism aims to deepen the analysis of this study. Patient associations during a policy process display certain behaviour. This behaviour is influenced by more factors than only defending interests and preferences towards government and other political actors. In later stage, the explanations for this behaviour take into account the institutional context and the actors involved.

Fully aware of the small amount of empirical cases (the Netherlands and Israel) on which the comparison will take place, the advantage of this framework allows to rely on theoretical hypotheses. According to Scharpf (2000), these hypotheses should have high predictive power. In that case, it is possible to form precise expectations about significant causes and effects, based on relatively limited and easily obtained information.

Secondly, the model *Ladder of citizen participation* (1969) will be discussed. This model describes the *strength* of participation by stakeholders and the power holders during the policy process. The model is utilized to achieve a full description on the degree of participation of patient associations during the Health Insurance reforms. The degree of participation will explain the role during policy-making.

According to my consideration, the model is still applicable and accurate despite being a theory established in the late sixties, in the societal environment of the United States. Considering its establishment and critical application during decades, it is highly compatible for this subject (Rowe & Shepherd, 2002).

Political scientists assume that preferences, interests and institutionalized rules of actors change across time and influence the way of interaction (Scharpf, 1997). Therefore, the model is combined with the framework of *actor-centered institutionalism*. With the obtained data we observe how patient association's participation has evolved. The ladder of participation can be used to reflect on these developments.

<sup>&</sup>lt;sup>5</sup> Actor Centered Institutionalism is a game theory incorporating a high technical level. In this thesis the high technical side will not be discussed. For more information about the technical side of this framework, see Scharpf's publication of 1997, titled Games Real Actors Play.

#### 4.2 Actor-Centered Institutionalism

The framework of Actor-centered institutionalism (Scharpf, 1997), strongly emphasizes on the perception, preferences (i.e. actor orientations) and capabilities of actors. Moreover, this theory differs from other theories of institutionalism. The founders (i.e. Mayntz and Scharpf) state, that actor orientations are only influenced but not determined by the institutional structures where interactions occur. The institutional contexts around countries vary in time, place and external conditions. Besides, the capabilities and identities of actors vary across countries. For that reason, similar problems on the national level may still result in different policy outcomes across countries.

Scharpf (1997) distinguishes four factors that will shape the criteria for analysis (figure 4.1). These four factors stipulate the policy-process and the policy outcome. The emphasis is placed on patient associations during a health insurance system reform.

#### The Factors

- 1. Institutions
- 2. Actors
- 3. Actor constellations
- 4. Modes of interaction

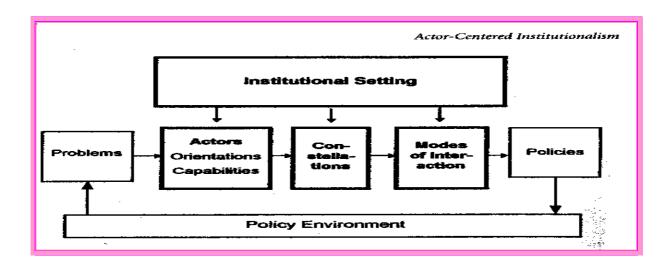


Figure 4.1. The domain of interaction-oriented policy research according to Scharpf's actor-centered institutionalism.

#### 1. Institutions

This factor is the most important one. It is the most useful source of information on actors and interactions. Several features of interest with regard to this study are referred to. An interesting feature in both countries is the type of parliamentary system. A multi-party system, for instance, enhances the relative strength and influence of political parties on legislators and policy-making. Both countries have a multi-party system which implies multi-actors. Within the multi-party system accountability is weak. Therefore, policy outcomes are a result of cooperation or conflict among veto-actors (Scharpf, 2000). Within corporatism veto points in general are low, due to its consensus approach. Within pluralism however, veto points are high, because actors are not integrated in the political system. Furthermore, the multi-party system is accompanied by high transactions costs and policy information is often incomplete or contested. Hence policy changes can affect the status quo and increase veto points by voters and members of organized (interests) groups (ibid.).

A subsequent feature of interest is the political system of both countries. The political system shapes the role and influence of interest groups during policy-making. Within corporatism, legislative power is given to civic assemblies that represent civic groups and where unelected bodies take a critical role in the decision-making process. According to Mansbridge (1992), corporatism treats interests groups as legitimate participants in policy-making with a legitimate role in policy-making. Besides, it encourage negotiations to keep focus on the shared conception of the public good, wherein it also is a matter of persuading others through dialogue. This system exemplifies how participation by interest groups is organized in the Netherlands. Within the political system of pluralism on the other hand, interests groups aggregate the preferences of their members and work to maximize those in a conflict-based arena. It is accepted for groups to primarily be motivated by self-interest, allowing little room to balance between private and public concerns (ibid.). This system, exemplifies how participation by interest groups is organized in Israel.

A subsequent feature of interest furthermore, is the separation of legislative and executive branches. According to Hays (2006), these can stimulate the role of interest groups during policy-making. Moreover, this separation of powers gives interest groups two separate pathways to exert influence during policy-making.

The final features of interest are, the constitutional rights of free speech and free press, working in both countries. Political actors and every citizen may utilize these constitutional rights. A political system which incorporates these rights creates opportunities for interests groups to exert pressure during the policy-making process. The rights construct political

transparency and interest group formation, since interest groups can express their opinions with regard to relevant issues (Hays, 2006). The above-discussed features are considered relevant, because it appears interest groups can increase influence and play a role amidst these institutional structures when policy-making is concerned.

#### 2. Actors

Throughout health policy-making strong political actors are involved i.e. the Ministry of Health, the Ministry of Finance, advisory councils and political parties. In addition, numerous socio-political actors i.e. interest groups are involved in health policy-making. They rely on resources as: members, funds, knowledge, persuasive skills, contacts with strategic actors, and the ability to sanction. Interest groups in high-income countries, for instance labour unions, play a significant role in certain policy decisions (Buse et al., 2005). Moreover, in certain health policy arenas the umbrella organisations of health providers and health insurers are notorious. These actors regard it of substantial importance to participate in health policy decision-making.

Health politics incorporates individual and composite actors. Scharpf distinguishes between individual actors, collective actors and organisations. According to Scharpf (1997) collective actors control critical action resources and staff. Besides, the collective actor is not autonomous but dependent on the preferences of their members. Collective actors in general serve public interests, whereas individual actors serve the interests of their members. The collective actor may be granted a mandate from individual members during policy-making. However, it is not self-evident that interaction within the collective organisation will produce strategic actions, for example, "the mandate to speak with one voice". Evidently, internal interactions between member organisations have consequences for the external activities of the collective actor during policy-making.

Actors furthermore, may chose for coalitions as part of strategic actions. According to Scharpf, coalition members act by agreement and separate action resources in coordinated strategies. These members only agree on strategies that are perceived to promote the self interests of all members at the same time (Scharpf, 1997). But coalition members individually retain control over critical action resources.

Nowadays patient associations more frequently, are regarded as interest groups and have gained a more prominent role within health policy-making in democracies<sup>6</sup>. Patient

<sup>&</sup>lt;sup>6</sup> The Committee of Ministers of the Council of Europe as well as the General Assembly of the United Nations stresses the need for citizen and patient participation in health policy decisions.

associations can function as individual actors during policy-making. Of great interest however, is when patient associations decide to mobilize and behave as collective actors. Furthermore, patient associations active in health politics reach for a particular action strategy. This particular strategy is shaped by different actions and by the weight and severity of the represented sufferers. Besides, their strategy depends on the relevance of the health policy issues and the behaviour of political actors and interest groups. According to Scharpf (1997), actors have their own orientations and capabilities.

Policy actors have goals which are influenced by institutional rules. These rules depict actor's existence, define criteria for their success or failures and create differences between different actors. Alongside their goals actors have a survival interest i.e. strive for autonomy, achieve success and organize resources. Therefore, it is fair to distinguish between political actors and socio-political actors. Evidently, patient associations active during health policy decisions can be placed in the last category.

#### 3. Actor constellations

This factor concerns the set of actors within the policy-making environment i.e. a health insurance system reform. According to Scharpf (2000), institutional rules define the constellations of actors that participate in the adoption and implementation of policy. Furthermore, the plurality of actors with specific capabilities, choices and preferences determine the policy process. Scharpf uses two by two-game matrices to depict the real-world interactions among policy actors. He states that actors do care, positively or negatively, about the payoffs that others will receive. Within these games, the preferences of players are partially harmonious and partially in conflict<sup>7</sup>.

Hence for the analysis of actor constellations the following issues require clarity:

- 1.) *The scope of actors:* Are actors only confined to an advisory function or do they also have a role in the actual decision-making and beyond?
- 2.) The evaluation of the outcome by the actors involved: An analysis of choices made may establish effective choice selection during policy-making. Besides, this evaluation can establish learning for policy actors.
- 3.) *Actors activity*: Are actors active in maintaining the status quo or active to establish change during policy-making?

<sup>&</sup>lt;sup>7</sup> The most notorious game matrices of real-world interaction for social scientists are: Assurance, Battle of the Sexes, Prisoner's Dilemma and Chicken. These are nicknames. For more information about the game matrices of real-world interaction, see Scharpf's publication of 1997, titled Games Real Actors Play.

Ultimately, the analysis allows for a high level of abstractive description and the characterization of different levels and types of conflicts among actors (Scharpf, 1997).

#### 4. Modes of interaction

This factor concerns the actual interaction between actors which produce the policy outcome. This factor will support an attempt to explain the actual outcome i.e. the health insurance system reform (NHI, 1995 & ZVW, 2006). According to Scharpf, institutional rules define what actors really do. Once in the policy arena actors may interact on the basis of mutual adjustment, negotiated agreements, voting or by hierarchical direction.

Mutual adjustment includes a minimum level of rationality, where actors at least know their own strategy options, payoffs and outcomes but not of other actors. Interaction includes, actors only being able to respond to the status quo, which is created by former moves of all actors (modes of unilateral action). There is a lack of overall strategy to interact on potential moves of players involved. However, mutual adjustment can achieve effective welfare solutions theoretically spoken.

Negotiated agreement includes institutions provide the binding force for negotiated agreements. The outcomes are achieved by self-interested actors which disagree until the expected outcome is more attractive for them. To reach agreement may include difficulties due to numerous factors, for instance, information asymmetry. According to Scharpf, negotiation can take place in all types of institutional settings and these settings will affect the outcome.

Decisions by majority vote include the enforcement of majority rules based on the choices of a large numbers of actors, in order to reduce transaction costs. A set of actors needs to comply, even if the outcome on numerous areas is not beneficial for them. Majority vote implies explicit need for legitimation due to the important issues on which decisions are made. Examples of majority vote are; citizen's vote and referenda in democracies. However, Scharpf's states that these examples do not directly reveal citizens preferences towards policy issues. The above mentioned examples are rather seen as means for the legitimation and control of hierarchical government authority.

Hierarchical direction includes the imposition of state decisions on citizens by hierarchical authority, to maximize welfare. In that case, the preferences of other actors are overruled as well as ignoring their information. Democracies however, introduce institutions which limit state powers. It is important that government act as agents towards citizens and lower governments since they are considered to be the principals.

There is the assumption that in different institutional settings these four modes of interaction change actor's characteristics.

According to Scharpf (1997), an extremely powerful tool is established to explain the outcomes of specific policy, when systematically the analysis of actor constellations is combined with the analysis of modes of interaction.

# 4.3 Arnstein's typology on eight levels of citizen participation

Arnstein's (1969) view on citizen participation is based on a strong statement. Arnstein considers the ability of the "governed" to participate in their government as the cornerstone for democracy.

Citizen participation in politics intends to redistribute powers to enable the intentional inclusion of the powerless and stakeholders in decision-making. If there is no redistribution of power; participation is empty and a frustrating process for the powerless. However, if there is redistribution of power; power holders can claim that all parties are considered but in fact only some participants benefit (Arnstein, 1969).

Arnstein characterizes eight hierarchical levels of participation which represent the build up of citizen participation (figure 4.2).

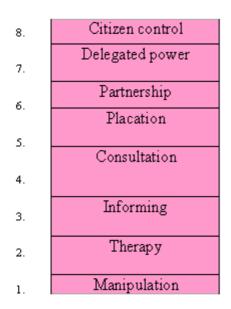


Figure 4.2 Eight Rungs on the Ladder of Citizen Participation

At this first level of *manipulation*, power holders deliberately constrain citizens to participate in policy. Power holders are in charge of policy-making and able to educate or 'cure' participants.

These features generally also occur at the second level named *therapy*. These two first levels stand synonymous for non-participation in policy-making. Arnstein considers this form of participation invidious, since patient associations may be at the policy table but do not have the abilities to influence the policy-making process. Arnstein is convinced that sitting at the policy table is not enough for citizens.

At the third level power holders should engage to *inform* citizens and disperse information concerning their rights and responsibilities. However, it is a one-way stream of information. Arnstein argues that citizens lack the power to ensure that power holders will take their views into account.

The fourth level of *consultation* contains some form of participation. Power holders invite citizens on a legitimate basis to share their opinion on policy. At this level participation is a window-dressing ritual since it is not assured that citizen's opinions, concerns and ideas will be considered.

At the fifth level of *placation*, powerless/stakeholders may arise and achieve some degree of influence on policy-making. However, power holders still retain the right to decide which ideas of the powerless will be adopted. Arnstein is convinced that at this level citizens start to have influence, to a certain extent.

At the sixth level of *partnership*, power is redistributed. Citizens negotiate and engage in trade-offs with power holders. They can even use veto power when necessary. According to Arnstein (1969) this level is most effective when there is an organized collective with financial resources. Interest groups, namely patient associations, try to gain influence in policy-making, they organize themselves and obtain technical assistance in articulating the priority of issues.

The seventh level of *delegated power* contains citizens achieve dominant decision-making authority during the policy-process as a result of negotiations. When negotiation is not sufficient, citizens again are able to use their veto power.

At the eighth level of *citizen control*, citizens have full control and managerial power. Arnstein states that at this level, citizens are guaranteed full charge of policy and they negotiate the conditions when others would like to bring change.

In society patient associations often balance between the fourth, fifth and sixth level of the ladder. Arguments against citizen control (at level seven or eight) are; it is more costly, less

efficient and appears to be incompatible with merit systems and professionalism. Arnstein however, state that the rhetoric should not be confused with the intent (Arnstein, 1969).

# 4.4 Interest groups: relation to the state

In modern democracies almost every social and interest group is organized in order to defend itself and to influence government policies (van Deth & Newton, 2005). According to Van Deth & Newton, it is of great importance to classify the groups of voluntary associations into political (also referred to as pressure groups) and non-political ones to avoid confusion. In general voluntary associations avoid politics because they are controversial and cause difficulties between people. However, non-political associations can mobilize quickly to defend their interests if needed (ibid.).

Another important classification for interest groups is the insider and outsider group distinction. According to Grant (1984) *insider* groups are not officially part of the machinery of the government, but are regarded as legitimate by government and policymakers. These groups are regularly consulted and are expected to play the rules of the game. Van Deth & Newton (2005) further elaborate that governments sometimes heavily depend on insider groups in close contact. Governments are in need for the technical information, the expertise and cooperation of groups to implement policies.

According to Buse et al. (2005) *outsider* groups have either failed to attain insider status or deliberately chose a path of confrontation with government. Van Deth & Newton (ibid) elaborate further and consider outsider groups have no special relationship with the government, based on the lack of bargaining power or of them being too critical of the government. Outsider groups are true action groups and to achieve their goals sometimes wield conspicuous actions.

Interest groups pursue a strategy to place issues of their interest on the political agenda. Some insider groups are more successful due to the differences between groups. The causes for these differences are: financial resources or the provision of public services by private entities. In the health policy arena these features favour physicians and insurers. It thereby strengthens their influence on the political agenda. Patients associations on the other hand, are not responsible for the provision of public services but serve other functions within society. Nonetheless the definition of Grant has a broad working domain. For example consider patient associations in the Dutch corporatist structure who are frequently consulted and

informed about policy plans. Of interest is to determine the consequences when patient associations do not follow the rules of the game. Thus, what does the insider or outsider status in a pluralistic and corporatist system entail for patient associations?

Yet according to Peterson (1999), interest groups perform multi-functions in society and some require a certain level of expertise. Peterson describes seven functions for interest groups (table 4.3). The implication for patient associations is that society demands a lot of them. Consequently, patient associations will be forced to determine which functions will be primary, for instance the association-bound services for its members or (additional) functions as presented by Peterson.

- 1. Participation Interest groups enable members via an alternative way to get involved in politics and register their opinions to politicians.
- 2. Representation Interest groups represent the views of the supporters, widening the range of opinions under consideration.
- 3. Political education Interest groups educate their members in political processes.
- 4. Motivation Interest groups can provide the government with information, even develop new policy options through their scientific and political activities.
- 5. Mobilization Interest groups build pressure for action and support for new policies.
- 6. Monitoring Interest groups assess the performance and behaviour of governments, thereby contributing to the public accountability of leaders.
- 7. Provision Interest groups use their knowledge of a particular patient group or policy area to deliver services with or without government funding.

Table 4.3. Functions of interest groups, Peterson, 1999.

# 4.5 Tactics and strategies of interest groups

Literature presents various theories and studies about the tactics and strategies of interest groups during policy-making (Buse et al., 2005; Binderkratz, 2005; Hays, 2006; van Winden, 2002). Since patient associations are regarded as interest groups it is necessary to determine the tactics and strategies available. It is certain that interest groups can play a role and exert influence within democracies, yet what does this exactly mean?

The approach by van Winden (2002) characterizes the influence and behaviour of interest groups from an interesting angle. Within this approach the *political economic view* is used as a mean to describe the influence and behaviour of interest groups<sup>8</sup>. This approach draws

<sup>&</sup>lt;sup>8</sup> The political economic view combines formal theoretical models of interest group behaviour and influence, with emphasis on the positive aspects of mathematical modelling.

further on the cooperative game models which focus on coalitions rather than individual actors. The policy outcomes of these models are efficient and in accordance with the maximization of a weighted representation of the utilities of the actors involved. A political welfare function is applied to reflect the benefits and political influence an interest group has on the policy outcome.

According to van Winden (2002) interest groups have many different channels of influence available. For example, they can choose between legislators, bureaucrats, political candidates and governmental levels. Interest groups can also choose to hire professionals or form alliances with others. Furthermore, influence can be pursued by lobby actions, exerting pressure, structural coercion and representation. Van Winden investigates the choice interest groups make between when to lobby or to exert pressure. Evidence revealed that pressure is exerted to build up a reputation and lobbying is used to maintain a reputation (van Winden, 2002). Thus, when the type of influence is selected it is necessary to distinct which channels will be influenced

Furthermore, a *Danish study* on interest groups strategies described by Binderkratz (2005) confirms the notion that interest groups have an action repertoire to exert influence. Binderkratz however, takes it a step further and distincts *indirect* and *direct strategies* of influence as part of the action repertoire<sup>9</sup>. As described earlier, Binderkratz also distincts insider and outsider groups. Binderkratz however, links the position of the interest group, within the decision-making process to the strategies it uses. Insider groups will use direct strategies which are generally seen as more effective. However, although privileged access may incur constraints on group actions, it does not prevent groups from combining direct strategies with indirect ones. Due to the complex environment, insider groups more often use indirect strategies which are used by outsider groups. The conclusion of the study revealed, as expected, that a privileged position as an interest group, vis-à-vis public decision-makers is highly correlated with direct strategies. In addition the study revealed that a non-privileged position does not lead to an increase of indirect strategies. According to Binderkratz (2005) this indicates that indirect strategies are not used as a last resort once excluded from insider

.

<sup>&</sup>lt;sup>9</sup> Direct strategies entails administrative & parliamentary strategies. For example, target bureaucrats, often pursued by groups controlling important revenues. Indirect strategies entails media & mobilization strategies. For example, contacting reporters is often pursued by groups which find themselves in a competitive situation to attract members. Van Deth & Newton (2005) elaborate further on the characteristic of indirect strategies by including the following strategies; Firstly, groups achieve their goals through the Courts. Secondly, groups operate at the international and multi-national government level by lobby actions (i.e. at the United Nations and the European Union).

politics. This study took place in Denmark which has a corporatist tradition. Binderkratz states that the results are specific to the Danish national context. Nonetheless, these results can shed a light on the use of different strategies of influence and the factors of influence.

Hays (2006) however, also indicates there are factors for limitations on interest group's influence. Namely: the number and cohesion of members, financial resources and the information distribution towards decision makers and supporters. Van Deth & Newton (2005) also consider the ability of the group to use sanctions. In addition fragmented groups also limits group's influence. United group are likely to have more influence than divided groups. Finally, veto powers and group competition create limitations on group's influence (ibid). The analysis on the strategies for influence and the role of interest groups incites curiosity when linked to the policy-making process of a health insurance system reform. It seems fair firstly, to analyse the specific contexts of the Netherlands and Israel. I therefore, refer to the

following chapter.

#### 5. THE CONTEXT

#### 5.1 Introduction

Once informed on the theoretical framework, the context of both countries will be explored. To comprehend the role and influence of patient associations during health insurance politics, ways and means are established for analysis and comparison.

First, an overview of the demography and macro-economy of the two countries is given. In addition, the political-institutional system and the social context are discussed, to conclude with the health system and patient association's activity.

#### 5.2 The Netherlands

# 5.2.1 Demography and macro-economy

The country of the Netherlands is situated in Western Europe. The Netherlands is a member of the European Union (EU) and the Organisation for Economic Co-operation and Development (OECD). In recent years the Netherlands has made a shift towards liberal welfare state characteristics, namely, that benefits are modest and available for low-income groups and the state encourages private initiatives to provide social security (Newton & Van Deth, 2005). The Netherlands has a total population of 16, 4 million people. Per one thousand live births the infant mortality rate is 5.0. The male and female life expectancy at birth is high. For males it is 76.2 and for women 80.9 (de Hollander, et al. 2006). However, with the expansion to twenty-five EU Member States, life expectancy of Dutch women is ranked half way the EU list. The average life expectancy of Dutch men equals the life expectancy of the fifteen "old" European Countries. Apparently, the health of Dutch population diminishes compared to the best EU countries. Per one thousand cases there is a standard death rate of 7.9. The total expenditure on healthcare is approximately 60 billion Euros. Healthcare expenditures per capita in US \$ PPP (Purchasing Power Parity) is 2,643. The healthcare cost as a share of GDP is 9.1 percent (HiT the Netherlands, 2004; CBS, 2006; de Hollander, et al. 2006).

## **5.2.2** Political and Institutional system

The Netherlands is a constitutional monarchy with a parliamentary democracy. The queen is the head of state and holds a symbolic position.

The political and governmental foundations are embedded in the Dutch constitution. Furthermore, the political and governmental system is characterized by the separation of executive and legislative powers. The *legislative authority* is reserved for parliament, which is divided in two Chambers (i.e. the first Chamber and the second Chamber)<sup>10</sup>. In the second chamber one- hundred-and- fifty members are seated and directly elected for a four-year term. In addition, the parliament monitors the government. The first Chamber has the duty to approve or disapprove bills represented by the second Chamber. It may even ask the second Chamber to adjust the represented bill. The first Chamber examines the decrees of the second Chamber. The differences in duties of the Chambers create differences in the application of power sources (Iedema et al., 2004).

The *executive authority* is mainly reserved for the cabinet. The cabinet always has been a coalition of parties and Ministers and Secretaries of State take place in it. However, the initiation of laws and policies is reserved for the Council of Ministers.

The head of government is the Prime Minister. The government (i.e. the queen, the Ministers and their departments) decides on major decisions.

Noteworthy, is the shift of legislation power from central government towards lower levels of government and the fact that European legislation has implications for Dutch national law.

The Dutch political system characterizes a multi-party system, due to its tradition of pillarization<sup>11</sup>. According to Becker (1990), this system of social and political networks was excellent for ideological and societal control. Within the system of pillarization the conventional philosophy became powerful for political parties i.e. the Catholics, Protestants and liberal and socialist parties. Nonetheless, with the de-pillarization the conventional philosophy remained for a reasonable amount of time in the world of politics and society (Becker, 1990).

The Dutch political culture is highly corporatist and characterized by consensus politics. According to Hendriks (2003), the Dutch political culture can be classified as corporatist,

-

<sup>&</sup>lt;sup>10</sup> The 'right of amendment' to submit bill alterations and the 'right of initiative' to submit bills.

<sup>&</sup>lt;sup>11</sup> The Dutch 'verzuiling' meant that the partisans of social, religious and political ideologies joined together in a column. Poor and rich worked together to reach their aim, primarily to enhance emancipation in society. This structure counteracted cleavages, namely, the rich – poor cleavage.

since the presence of corporatist institutions. However, Hendriks (ibid) states that the view of corporatism as consensus between actors or the ideology of "social partnership", requires a more cultural interpretation of Dutch politics and its relationships. Nonetheless, consultation, compromise and consensus play an important role within Dutch politics and society.

Dutch politics consists of different political parties. During the 1990's and the first years of the third millennium the most influential ones were: the conservative- right wing (VVD), the left wing (PVDA), the more progressive- left wing (D66 or Groenlinks) and the denominational party (CDA) (Bekker, 1990). Outstanding has been the advocation on behalf of Dutch patients, by the Social Political party (SP) during the debate of the ZvW law at the beginning of the third millennium. Furthermore, the Dutch society incorporates numerous organisations, like trade unions and employer organisations.

When health policy is formed it is of great significance to appoint the relevant actors. According to Trappenburg (2005) five crucial actors are present which determine health policy in the Netherlands, namely:

- 1) pressure groups
- 2) advice councils
- 3) civil servants of the Ministerial Departments
- 4) Members of the Parliament
- 5) Ministers and their Secretaries of State.

#### 5.2.3 Socio-economy

The Netherlands is an industrialized country with an open economy. During the eighties the Netherlands experienced high-low inflation periods with high unemployment rates and increasing government shortages. This period is often referred to in literature as the "Dutch disease" Government policy was constructed and aimed to ration on several policy areas i.e. welfare policy. During the nineties, as a consequence, economy flourished again. Per capita income increased as well as government budgets. According to some authors (Hogeboom & van Vliet, 2000), the Polder model contributed to the economic growth During this period

<sup>&</sup>lt;sup>12</sup> The period of the "Dutch disease", meant: "The disease where temporary revenues are used to finance perpetual continuing price increases and costs (Uitterhoeve, W., "De staat van Nederland", 1990).

According to Hogeboom & van Viet (2000) the Polder model of the 1990s' has contributed to the successful economic policy applied during these years.

social policy was constructed in such a way that all groups within society experienced some kind of advantage.

Nonetheless, challenges remain for the Dutch government. Through last decades society experienced changes. Dutch society includes 1.728.023 people of non- European origin (Dutch Centre of Statistics, 2008). Studies reveal that this group of society generally is less participant on the labour market. Causal factors are; a low standard of education and problems with the Dutch language. These factors contribute to other social and economic problems. Studies reveal that this group suffers more from certain types of diseases (e.g. diabetes and hypertension) and that health care to this group lacks on certain areas<sup>14</sup>. Furthermore, studies reveal that for this group the level of structural poverty is two times higher, than their Dutch counterparts (Rabobank Economists, 2006). In addition, studies reveal low membership by this segment of the Dutch population in patient associations (Tabibian & Gorter, 2005).

Another challenge for Dutch society, the coming decades, is population aging. These developments will create complex issues within the area of the Dutch health, social and economic structures. Studies reveal that aging will result in a tight labour market, higher wage costs and higher collective expenses (Hogeboom & van Vliet, 2000; Knaap, et al., 2003).

The Netherlands struggles with an economic impasse and minor growth persisting since the end of 2000. Vulnerable groups within society i.e. the unemployed and the sick have experienced harsh times. Noteworthy, is that during this period of challenge the Health Insurance reform in 2006 was implemented.

## **5.2.4** The Dutch culture

For a long time Dutch society and culture were based on religious groupings. These groups were able to coexist and dependent on one another. The relations contributed to the Dutch consensus-society of today. Furthermore, the Dutch value equality highly and are known for their pragmatism. They analyse an issue and use that to create a solution which suites all involved. In their open and honest interaction Dutchman can be very direct. This has the advantage that one knows what to expect from one another. However, others may experience it as being rude. For decades, the Dutch thrived on their tolerance mentality. However, in the

<sup>&</sup>lt;sup>14</sup> As a response several initiatives were introduced for example the care-consultant in several health care institutions.

last five years, society feels threatened which has brought Dutch tolerance to a turning point <sup>15</sup>. The Dutch consider themselves nowadays to be less tolerant (Frijhoff, 2007).

# 5.2.5. The Dutch health system before the ZvW law 2006

For decades, the organisation of the technical and institutional structures of the Dutch health care system relied on three social health insurance schemes, also known as compartments.

The first compartment entailed the Exceptional Medical Expenses Act (AWBZ, 1967). Citizens were insured for long-term care and entitled to benefits in kind or restitution. The sickness funds were obligated to contract health care providers, and partially responsible to finance this insurance scheme.

The second compartment had two sections. The first section concerned the Sickness fund Act (ZFW, 1966) which provided compulsory insurance for employed citizens and their families. Premiums consisted of an income-related and nominal part and for a few services copayments had to be paid. In this section, insureds were entitled to benefits in kind for predominantly cure services. The sickness funds were obligated to contract health institutions and individual health care providers, which were directly paid by the sickness funds. Furthermore, sickness funds had to negotiate with care providers to determine the quantity, quality and up to a certain extent the price of services. The second section concerned the Health Insurance Access Act (WTZ, 1986). It provided private health insurance to high-income population, who were not eligible for the Sickness fund Act scheme. Premiums consisted of a risk-related premium and deductibles. In this section insureds had free entrance to providers and were entitled to restitution.

The third compartment concerned a voluntarily insurance for supplemental health services. The insured carried complete financial responsibility. However, this private health insurance system became challenged, as it forced certain groups to spend large amounts of their income on premiums. Especially, the elderly were affected and other high-risks groups. To protect access to private health insurance the government enacted the Health Insurance Act 1986, WTZ (Schut et al., 2005; HiT the Netherlands, 2004).

<sup>&</sup>lt;sup>15</sup> Dutch society was shocked by the assassination of the political populist Pim Fortuyn by an animal rights fanatic in May 2002 and the assassination of Theo van Gogh an outspoken columnist and filmmaker, murdered by a religious Muslim extremist in November 2004.

## 5.2.6 The Netherlands and patient associations

At the end of the nineteenth century, patient associations became established in Dutch society as a mean for sufferers to socialize. During the ninety-seventies, mental health care patients fiercely mobilized to improve their position within society. Patient associations in principle brought sufferers in contact with one another. However, due to changes and dissatisfaction with issues in health care, patient associations focused more on being "a voice" in society (Blaauwbroek, 1996).

The amount of patient associations multiplied during 1980's and 1990's. There are more than three hundred patient associations present, which differ in size<sup>16</sup>. There are 2.2. Million supporters. (Nederland et al., 2003). According to Trappenburg (2005) and Nederland (2004), several explanatory factors contributed to the rapid growth of patients associations during this period. A factor of dominance is that patient associations received subsidies from government and provinces. Furthermore, with the planning and reform of the health care system patient associations received an important role (Trappenburg, 2005). Government increased their role and introduced mechanisms for regulated competition and cost control. The role of patient associations became secured by legislation. Since then, patient associations became a third party in health policy-making i.e. capable to negotiate with health care providers and health insurers about the quality and the planning of care (Nederland, 2004). With the introduction of patient umbrella organisations these issues became more feasible. During the 1990's Dutch patient associations joined forces and patient umbrella organisations on both, the regional and national levels were established. The regional umbrella organisation (the Regional Patient and Consumer Federation /Zorgbelang) originated in 1990 and the national organisation (the Dutch Patient and Consumer Federation/ NPCF) originated in 1992.

According to Trappenburg (2005), patient associations have a crucial role when there are plans to reform the health system. Furthermore, Trappenburg (2005) argues that the increasing role of patient associations as pressure groups, are a result of division- and ruling politics. Patient associations were deliberately forced to grow, to professionalize and establish countervailing power. These developments came as a reaction to the growth of other pressure groups, such as physicians and health insurers. However, according to Nederland (2004) it is correct to place a critical note towards this 'incorporating' of patient associations. She argues, that patient associations should clearly reconsider the issues of their negotiation and if this

-

<sup>&</sup>lt;sup>16</sup> For instance, the Dutch Diabetes Association with 60.000 members and the Alzheimer Foundation Netherlands with 210.000 members.

negotiation is sensible. Furthermore, Nederland (ibid.) remarks that patient associations should ask themselves first, if there are no better means or strategies to defend their interests, before joining the negotiation table.

### **5.3** The State of Israel

## 5.3.1 Demography and macro-economy

The State of Israel is situated in Southwest Asia and can be classified as a conservative welfare state. Even though Israel is not part of the OECD it is an industrialized nation. Israel has a total population of 7, 2 million people. Per one thousand live births the infant mortality rate is 5.4. The male and female life expectancy at birth is high. For males it is 76.1 and for females 80.0. Per one thousand residents the female mortality is 6.0 and for males 6.4. The total expenditure on healthcare is approximately 44 billion Shekel i.e. approximately 7 billion Euros. Health care expenditures per capita in US \$ PPP is 1,531. The healthcare cost as a share of GDP is 8.8 percent (HiT Israel, 2003 and Israel's CBS, 2007).

## **5.3.2 Political and Institutional system**

The country of Israel is a state, which refers to a sovereign territory with institutional and national foundations. The State of Israel's political and governmental structures is characterized as a Western European parliamentary democracy. The structures reflect European institutions and traditions with some Middle-Eastern socio-political patterns. These characteristics are inherited by history and the environment in which Israel is situated (Metz, 1990). The Western European democratic arrangement of the Israeli political system is reflected by the presence of an elected government and multi-party competition. The political and governmental foundations of the country are embedded within its constitution. The president is the ruling head of state.

Furthermore, citizens enjoy a large measure of civil rights, based on high standards of fairness in the justice administration. Government therefore, depends on the court system to safeguard those rights and liberties for Israeli citizens and also patients.

Within the Israeli political and governmental system there is separation of executive and

legislative powers. The parliament (i.e. the Knesset) is the highest authority of state. In the

Knesset one hundred- and -twenty members are seated and directly elected for a four-year

term. The Knesset has legislative authority which is unlimited. Neither the President nor the

Supreme Court can veto legislative enactments and legislation is generally introduced by the

cabinet (Metz, 1990).

Furthermore, authority to initiate bills is for Knesset committees and individual Knesset

members. However, Knesset public institutions and independent bodies formulate rules,

regulations and subsidiary legislation on a great variety of subjects.

The Cabinet holds executive authority and centres political power. The Cabinet always has

been a coalition of parties (Metz, 1990).

In politics numerous parties, groups and organisations are involved and numerous interests

play a role. Political power in Israel lies within the framework of multi-party competition.

Furthermore, the political culture in Israel is characterized as pluralistic, wherein it is difficult

to determine who has real power. The mean thesis of classical pluralism regards politics as a

battle of interests where the winner is not known upfront. It al depends on which interests are

prevalent, the specific point of battle and the historic moment (Becker, 1990). Within Israeli

politics, room exists for interest groups to influence the formulation of public policy. The

Histadrut, kibbutzim and moshavim have been such interest groups in the past<sup>17</sup>. Remarkably,

interest groups were affiliated with most of the political parties (Metz, 1990). During the late

1980's other economic oriented interest groups originated in Israeli politics, namely,

employer, artisan and retail associations. Around this time period Israel's economic ideology

shifted towards a more liberal perspective.

During the 1980's and 1990's two major dominant political parties opposed one another.

These two are known as the Labour party (centre-left) and Likud (centre-right). Smaller

parties (for example religious and Arabic parties) are able to govern in alliances with the two

major parties (Metz, 1990).

Noteworthy, are the limited powers of the local governmental institutions. To a great extent

they depend on national ministries. Nonetheless, with the establishment of local governmental

<sup>17</sup> Histadrut: a very powerful labor union.

Kibbutzim: collective farm communities and communal enterprises.

Moshavim: cooperative agriculture communities.

institutions, foundations of democracy are respected. Thereby, principles of the constitution, such as transparency and separation of powers are secured (ibid).

When health policy is formed it is of great significance to appoint the relevant actors. During the policy-making process of the NHI law (1995) the following actors participated in the policy process:

- 1) the Ministry of Health
- 2) the Ministry of Finance
- 3) representatives of sickness funds
- 4) representatives of health care providers
- 5) advice councils
- 6) the civic movement (HiT Israel, 2003).

# 5.3.3 Socio-economy

Since 1950 Israel's economy has grown rapidly. It resulted in a significant growth of per capita income and an exponential increase of high-tech companies. Alongside these developments was a high population growth of 330 percent and periodic wars, which impacted the economy of the country (Malhotra, 2000).

Adiv (2000) argues that with governments shift towards liberal policy, Israel's rich became richer while the poor got poorer. Governments passed reserves to the lower class, initially to buy them off. From 1994 until 2000 social expenditures rose significantly and national insurance payments rose by 50%. Israeli citizens can be added to the group which pay the highest tax rate in the world (Sper, 2004). Huge military defence expenses and economic inefficiency caused these effects to originate. However, Israeli's have the general assumption that the rich should take care of the poor (ibid). Yet the increasing poverty and disadvantaged circumstances occur in particular groups, which are most vulnerable to poverty. This results in greater problems for population health, the labour market, the health system and education. Studies reveal that more than a quarter of Israelis cannot afford comprehensive health care (Werczberger, 2001).

### 5.3.4 Israeli culture

Israel's culture is a mix of subcultures and Jewish ethnicities. The younger Israeli-born generation worries less about the past than their parents. The youth produced an industrialized, capitalist, Western-style and middle-class society as the norm (Metz, 1990). Important for Israeli society are issues, such as family relations, national security, quality of education, social status, economic conditions and also the comfort of modern life.

Even though Israel's society is very mixed there is notion of a general "Israeli culture". Israeli's interact in a direct, honest and straightforward manner. On the other hand this can be regarded as rude or arrogant. Furthermore, the Israeli alternative approach to time management can sometimes seem disorganised and unprofessional. Israeli culture however, tends to view people equally, rather than to give special treatment according to status (Jacobs, 2004). In general Israeli's work hard and are great nationalists (Metz, 1990).

## 5.3.5. The Israeli health system before the NHI law 1995

The technical and institutional structures of the Israeli health system relied on four political affiliated sickness funds. Several private insurers were also present. The four sickness funds functioned like health maintenance organisations (HMO's) and were competing. The largest one, *Clalit*, dominated the market and covered 80% of the insured. In 1920 Clalit was founded by the General Federation of Labour i.e. the Histadrut, which was affiliated with the Labour party. The three smaller sickness funds functioned as independent population practice associations (IPA's). In 1933 the *Leumit* health service sickness fund was founded by the smaller Revisionist party. In 1936 the *Meuhedet* health service sickness fund was founded. It was born out of a merger between the Mercarit fund, which was affiliated with the Liberal party and the Amanit fund, established by the Hadassah Medical Organisation. The most non-political affiliated sickness fund was *Maccabi*, which was founded to ease unemployment for immigrant physicians.

All four sickness funds exercised considerable latitude over the design and implementation of the benefit package and practiced selective enrolment. The sickness funds provided their members with curative health services which could be provided directly or by contract with other health service organisations. Furthermore, the sickness funds were financed by health care taxes at different levels and each sickness fund determined their own policy standards. The insured had to pay an earmarked employer tax, an income linked membership fee and a direct payment to the insurer. The tax contributions went into the sickness fund or sponsoring

party and the Ministry of Health allocated a certain percentage to each sickness fund. The Ministry however, had hardly any say about the policies and services provided by the sickness funds (Chinitz & Israeli, 1997; Geva-May & Maslove, 2000). Thus, sickness funds acted as insurers, health care providers and employers (Chinitz & Israeli, 1997; HiT Israel, 2003).

The organisation of the Israeli hospital sector, forced sickness funds to provide health care in joined coalition with health institutions of the government, or independently cover a small share of the health care market. Sickness funds owned clinics and hospitals, where doctors and nurses were salaried. According to Chinitz & Israeli (1997) the hospital sector in Israel was dominated by the government and the largest sickness fund, Clalit. Hospitals were prospectively budgeted by the government on per diem rates and differential treatment rates. Private hospitals were few and received funds retrospectively from the Ministry of Health and subsidies from organisations (HiT Israel, 2003; Geva-May & Maslove, 2000)

## 5.3.6 Israel and patient associations

After the establishment of the State the amount of patient associations multiplied. These associations were established by patients, relatives of patients or by health professionals. Primarily, associations were established to guard the interests of their sufferers by: providing information, cooperation with the research community on Development and Research and providing the government of relevant information. Patient associations originally were autonomous and not political active. However, during health policy changes, disease-specific associations could be active. Political activeness at that point meant: appear at public hearings of the law and engage in lobby activities (Chinitz, 2000).

Furthermore, the Israeli government did not commit themselves to financially support patient associations and the establishment and organisation of the Israeli sickness funds contributed to the absence of patient association's participation (Expert-Israel, 2006).

Around the 1990's approximately fifty independent patient associations were present in Israel. They were not joined into a patient umbrella organisation. The development of some kind of "patient perspective" by patients, health consumers and health field parties originated at this time. Consequently an important coalition was established between patient associations and patient representatives, during the policy-making process of the NHI law (1990-1994). Hence, during this period patient association's participation commenced.

Furthermore, equivalent with the introduction of the NHI law (1995), a number of patient and consumer associations formed a coalition and established the patient umbrella organisation

Z.V.I (the Israeli Health Consumer Organisation). According to Chinitz (2000), patient associations besides can share a joined function under the leadership of Z.V.I even though they primarily function on an individual basis. Z.V.I was established without financial support from the government. However, a non-governmental organisation funded Z.V.I during the first years of its existence. Z.V.I was established to create an effective lobby group on behalf of the Israeli health consumers (Z.V.I, 2007). It is recognized as the formal representative of Israeli patient and consumers, by medical, governmental and legislative authorities. However, not everyone is convinced that Z.V.I objectively represents all Israeli patients. Currently, Z.V.I is present at several discussion forums and is a strong advocate on the protection of health consumer's rights within the health system (ibid). Over the past decade Z.V.I monitored the negative effects of the NHI law on patients and discussed negative information with health actors responsible (i.e. sickness fund/ health care providers).

### 6. HEALTH REFORMS PRESENTED

#### **6.1 Introduction**

Having obtained all relevant information, it is now suitable to assess the role and influence of patient associations in the empirical environment of the Health Insurance reforms.

In this chapter, the health insurance systems reform of the countries of Israel and the Netherlands is described. First, the introduction of the health insurance system reform is discussed, followed by a discussion on the policy-making process. In addition, the new Health Insurance Laws will be discussed. First, this will be described for the Netherlands followed by Israel. Finally, the data gathered from previous chapters on both countries is used to characterize the similarities and differences between them.

What is considered a policy reform depends on the angle of researcher's study and analysis. According to Schut et al. (2005), a policy reform should not be conceived as a single political event, but more appropriate to consider as a lengthy process of accumulating incremental changes. Maionie (1998) further elaborates, that reform builds on the idea that rules of the political game impose certain constraints and opportunities, which condition legislative outcomes. Reforms may occur as a result of crisis (the so called big bang) or through stepwise emerging incremental policy shifts (Geva-May & Maslove, 2000).

The delegation of regulatory authority to associations of providers, insurers and employers by the state, is typical for public health systems with private arrangements. The health insurance system lies at the heart of the health system, and when priming goals are challenged governments in many cases focus on their health insurance system. Policy-makers often assume that reforming the health insurance system will contribute to financial changes, which are beneficial for the health system in general. However, Geva-May & Maslove (2000) state, that reforms might be prompted by financial conditions, but that the underlying incentive for change and the directions of change, are determined by political power contests.

The deliberate health insurance system reforms are examined to register the behaviour, strategies and influence of actors during the policy-making process.

### 6.2 Process of the Dutch health insurance reform

### **6.2.1** The Dekker commission

During the 1970's and 1980's the government became forced to search for solutions, since health care expenditures rose and cost containment problems were of great concern. Solutions were necessary to establish an efficient health system and maintain equal access. The Dekker commission was appointed by the centre-right government in 1987 to investigate solutions for the Dutch health care system. As a result "the Dekker plan" was constituted and includes the following basic principles; the establishment of national health insurance for all citizens, the introduction of competition between health insurers and providers, increase of consumer choice while sickness funds should become risk-bearing organisations and receive a prospective budget (VWS, 2004; Schut et al, 2005). In politics this plan was generally accepted, although government and other health actors were aware that certain conditions had to be guaranteed within the new health system.

## **6.2.2** Reforming the Dutch health system

The reform of the Dutch health system took approximately eighteen years. This covers a considerable timeframe. Several reasons explain this sluggish reform process. For instance, during eighteen years there were shifts from centre-right to centre-left governments, which had to deal with the negative side effects of rationing policy. According to scientists and politicians, these governments however, chose other means rather than working towards regulated competition<sup>18</sup>. Nonetheless, support for the Dekker plan remained during these shifts of government (HiT the Netherlands, 2004)<sup>19</sup>. Another explanatory factor has been the necessity to introduce institutional changes and pre- conditional mechanisms to establish regulated competition (Douven & Westerhout, 2000; Schut & van de Ven, 2005). The following institutional changes were performed, namely; simplification of entry rules for new health insurers and the abolition of the restriction for insurance for regional health insurers. Consumer choice was enlarged by the introduction of annual open enrolment. Furthermore, a system of maximum prices for medical services was installed. Sickness funds, were not longer

<sup>1</sup> 

<sup>&</sup>lt;sup>18</sup> During the "purple government" the Minister of Health became pressured by public and political opinion to deal with the persisting problem of waiting lists for health services. To counteract budgetary limits would reduce the waiting lists.

<sup>&</sup>lt;sup>19</sup> This Dekker plan became reshaped in several areas by different governments during the years.

obligated to contract physicians in their region and were allowed to collect community-rated premiums. Subsequently, policies were introduced to reduce retrospective reimbursement of insurers to stimulate the efficient purchase of health services. Several changes on one hand favoured patients and consumers, while on the other hand sickness funds and providers benefited. Especially sickness funds became powerful in the area of health services. For a significant part this also applied for patients and consumers with the introduction of the exit and voice option. With the voice option patient and consumers can speak up for themselves and when dissatisfied have the exit option to switch from health insurer.

The Ministry of Health arranged the establishment of these institutional changes and preconditions in negotiation with health providers and health insurers. As an effect, there were numerous mergers between health insurers, hospitals and health care providers (Schut et al., 2005). Patient associations then joined the umbrella organisation (discussed in 5.2.6). According to Schut et al. (2005), government depends on the cooperation of health care providers, health insurers, employers and employees to get reforms implemented. Remarkably, patient associations were not mentioned in their line-up of relevant health actors.

At a certain moment, all institutional changes and pre-conditions for the future health system were realized. At the end of the year 2000, all political parties had submitted their plans and desires concerning the health system reform. The advisory board, the Social Economic Council (SER), also submitted an advice rapport concerning the future health system. Health insurers and providers ultimately, favoured the market-oriented reform. However, critique remained. According to the Director-General of care, health providers were not strongly involved in the policy process (van Lieshout, 2000). The Director-General argued it was important that health care providers stipulated a substantive part of the debate (ibid.).

Patient associations ultimately, also were in favour of the reform. Their patient umbrella organisation, the NPCF, represented a substantive part of Dutch patient associations during the health insurance policy-making process. The directorship of the NPCF, regarded the introduction of consumer choice, actual pricing of delivered care services, more latitude for health care providers and competition between health care providers and insurers, favourable and beneficial steps for patients (Bennekom, 2004). The NPCF realized these steps were not without risks, however, the risks were considered manageable (ibid.).

To minimize the risks for patients and secure the position of the chronically ill in the new health system, the NPCF submitted their concerns towards the Ministry of Health and other health actors. (NPCF, 2005). The NPCF sent in letters to government officials, insurers and

others, they organized information meetings in cooperation with the Ministry of Health, they published important topics in: the media, on their website and in magazines, the NPCF set up cooperation bonds with research institutes, and introduced a complaints-hotline for the public to report difficulties when shifting from health insurer.

The NPCF had set 5 goals which had to be incorporated in the new Health Insurance Law: i.e. acceptance rule for health insurers of patients, a ban on premium differentiation, an improved risk-rating system, collective purchasing power for patients and other groups, and the presence of regulatory pre-conditions for the working methods of insurers (NPCF, 2005). On the subject of improving the risk-rating system the NPCF presented (in the second quarter of 2005) a report to the Minister of Health. The report revealed that the system needed further improvement and refinement, in order to limit the incentives for premium differentiation and risk selection by insurers. These mechanisms could be applied by insurers in order to assure financial stability since they are obligated to accept everyone; the young, the old and the sick. In the annual rapport of 2005 the NPCF acknowledged being satisfied with certain achieved results, namely; the aspects of increasing consumer choice, better information and opportunities for "measured care" (zorg op maat), which are reflected and guaranteed in the new Health Insurance Law.

The ZvW law was passed during Cabinet Balkenende 2. The cabinet was a coalition of the CDA, VVD and D66, a centre-right cabinet.

## 6.2.3 The new Health Insurance Law, ZvW 2006

The National Health Insurance law (ZvW) was enacted at the end of 2004 and implemented on January 1<sup>st</sup>, 2006. Based on the ZvW law population is obligated to take out health insurance for a statutory health care package. The health insurer is obligated to provide health care and accept everyone. Besides, they can make profits and pay dividends to shareholders. Furthermore, health insurers can offer a range of policies and are required to operate nationwide. Health insurers however, with less than 850,000 insureds are excepted not to operate nationwide but at least one province. In addition the insured is entitled to health care and receives benefits in kind or reimbursement of the costs incurred. They can select for contracted or non- contracted health care providers while providers compete with one another on the basis of price and quality (Ministry of Health, 2004). Furthermore, citizens pay a tax-based payment collected by the employer, and two direct payments to the insurer. These are ultimately collected into the Health Insurance Fund. Citizens with an income below the

average receive a health care allowance, to compensate those who are financially restricted to buy health insurance and to guarantee access to health care. Subsequently, insureds were entitled to receive a no-claim refund payment but that stopped by 2008. As from 2008 every citizen is obligated to an individual risk payment of 150 Euros per year.

## 6.3 Process of the Israeli health system

## **6.3.1 The Netanyahu Commission**

During the 1970's and 1980's the government became confronted with an increase of health expenditures, as a result of population aging, an increase of immigrants and an increase in demand for health care services. Equivalent with these challenges, consumer dissatisfaction with health care services increased. Waiting lists for elective surgery grew and the Israeli health system became challenged by labour unrests. Furthermore, the "black-market" for medicine grew and cream skimming was practiced by several sickness funds (HiT Israel, 2003).

In this background the government in 1988 appointed the Netanyahu State Inquiry Commission. The commission had to examine the efficiency and functioning of the health care system. The commission discovered the following problems: an inadequate service provision to the public and the dual role of the Ministry of Health as service provider and regulator. Very troublesome were also the vague financing and budgeting procedures. Moreover, the report of health system in transition, reports additional problems, which are also taken into account, namely; the terms and entitlements of the benefit package were vague and 5% of population was not insured. Besides, the sickness fund Clalit had a competitive disposition, since its insured population were the old and the poor. Furthermore, the system was too politicized, since two sickness funds had ties with major political parties (HiT Israel, 2003).

Nonetheless, the Commission also presented recommendations. They emphasized the need for legislation to secure universal health insurance. The attempts to introduce universal health insurance had been opposed and shifted across decades, due to power struggles (Geva-May & Maslove, 2000). The commission stressed the need for a centralized financing system with capitation payments. Besides, they emphasized on the concept of regionalization and decentralization, the increase of competition and the reorganisation of the Ministry of Health (HiT Israel, 2003).

## **6.3.2.** Reforming the Israeli health system

The National Health Insurance law (NHI law) became the government's focus at the beginning of the 1990's. A timeframe of four years was determined to enact the law. The law dealt exclusively with community-based and secondary medical services. Furthermore, the NHI law was designed to financially stabilize the health system, secure universal health insurance coverage, increase consumer choice and enhance transferability options for insureds (HiT Israel, 2003). The NHI law ensures the proportional distribution of resources among sickness funds according to health needs and it improves the quality of services and equality in the provision of services to different populations and geographical areas (Gross, 2003).

Noteworthy is the shift towards regulated competition between sickness funds, which is not based on price competition but on quality of services. According to Gross (2003), the ban on price competition was related to the high valuation of equality by Israeli society. Besides, the ban was related to opposition from the powerful sickness fund, Clalit. If price competition was allowed its income would become jeopardized. Gross (ibid) however, states that the NHI law created a regulated market that embodied many of the principles of managed competition as formulated by Enthoven<sup>20</sup>.

Moreover, the supporters of the NHI law were committed to inform the public about the problems of the current health system. These efforts some argue, have positively influenced the legislation process of the NHI law (HiT Israel, 2003).

These changes created a centralized system where autonomy was given to health care providers (i.e. hospitals and clinics). The acquired autonomy was accomplished by influence of powerful sickness funds, hospitals and related interest groups (i.e. doctors and nurses associations) (Geva-May & Maslove, 2000)<sup>21</sup>. For instance, the professional association of physicians, the Israel Medical Association (IMA), is very powerful and besides functions as a trade union. IMA leaders generally, have a large amount of influence over national health policy (Gross, 2003).

At first all four sickness funds opposed the NHI law, which would deprive them of financial resources and power given by direct taxation. In addition, the law was strongly opposed by

<sup>21</sup> The different interest groups advise the Director-General of care on long-term goals and place important topics/ issues on the agenda which require an immediate policy response (HiT Israel, 2003).

-

<sup>&</sup>lt;sup>20</sup> According to Enthoven managed competition as a mean, is compatible with pluralism, individual choice, responsibility and universal coverage (Enthoven, 1993).

the Histadrut labour union, which threatened with strike actions (Geva-May & Maslove, 2000).

During the policy-making process of the NHI law consumer and patient representatives were present at several policy-tables, rather than delegates of the patient associations themselves. An expert (Israeli health reform, 2007) argues that the absence of patient association's participation was a result of the establishment and organisation of Israeli sickness funds. Remarkably an amount of fifty-three individual patients were visible during the policy-making process at Knesset Committee meetings. In this Committee all-relevant health actors were seated, including representatives for patients and consumers<sup>22</sup>. The committee had fifty-three meetings about fifty-three health topics and remarkably in all meetings individual patients were heard. The latter was realized since individual patient representatives, advocated at government level for the participation of patients during the policy-making process<sup>23</sup>.

Therefore, during this period participation increased and an important coalition was established between patient associations and patient representatives. A change of relations occurred in the health field and equality in participation was initiated. However, the entrance for patients was merely based on the politeness of government (Patient representative, Israel 2007). Contrary to the Dutch case, patients present at the meetings were not delegates of patient associations, but citizens with a disease or handicap. Meanwhile, another strong relationship developed between patients and the media.

The aims or specific issues which patient representatives and individual patients brought forward during the meetings are not clear due to the absence of participation. However, certain patient associations were successful in convincing the Health Ministry to add certain costly procedures to the benefit package (Chinitz & Israeli, 1997). According to Chinitz & Israeli, a number of disease interest groups exerted pressure with regard to this issue. Furthermore, the NHI law adopted the provision of two seats for patient representatives in the National Health Council<sup>24</sup>. The Ministry of Health however, is not obligated to follow the

-

<sup>&</sup>lt;sup>22</sup> The Knesset Committee meetings took place during 1992 and 1994. However, this Committee might be the permanent Health Committee of the Knesset, which is referred to in literature findings. The Health Committee is formally charged with the leading role on health issues (HiT Israel, 2003).

<sup>&</sup>lt;sup>23</sup> This development occurred during the period of 1992-1994.

According to Chinitz & Israeli (1997:207): "The National Health Council includes representation of officials of the sick funds, consumers, health policy experts, and government officials and is chaired by the Minister of Health. The Health Council is intended to monitor implementation of the law and to advise the government on various related issues, including the contents of the basic basket and the level of health expenditures".

advice presented by the National Health Council. Besides, the Patient Rights Law was adopted and in 1996 the Patients Rights Committee was introduced. The law safeguards the rights of patients within countries health system. Furthermore, the Patient Rights Committee empowers patients and provides them of relevant and accurate information. The obtained new roles in participation for patients and their associations became secured by legislation.

Patient representatives and patient associations supported the NHI law. The patients welcomed compulsory insurance and the possibility to shift from health insurer. Patients associations and other health actors had to compromise even when restrictions were introduced. Under support of patient representatives, members of patient associations performed the following activities: critical reading of law proposals, lobby actions under members of parliament and professional advisors and the distribution of information towards members. Patient representatives were convinced patients and their associations became empowered during the policy-making of the NHI law, since they received information (Patient representative, Israel 2007).

Relating to these developments several patient associations mobilized. The patient umbrella organisation (the Israeli Health and Consumer Organisation-Z.V.I) was established swift after the introduction of the National Health Insurance Law. It monitors and discusses the negative effects of the NHI law. Moreover, when required the patient umbrella organisation can subject complaints against health actors (mainly health insurers) before the Court on behalf of their members.

What did eventually create the window of opportunity for the health system reform? In accordance with pluralistic theories, the window of opportunity opened when parties at power had something to win and to offer to their constituencies (Geva-May & Maslove, 2000). The Likud (centre-right) and Labour (centre-left) party competed for power. Initially, the rightwing Likud initiated the NHI law in an attempt to undermine the left-wing Labour whose financial resources were affiliated with the largest sick fund (ibid.). Nonetheless, the Labour party supported the NHI law. Furthermore, as pluralistic theories suggest, the Labour party saw the NHI law as beneficial to help the Histadrut (i.e. labour union) cover its deficit, created by Clalit their sickness fund. On one hand, it meant the loss of financial resources for Clalit. On the other hand, a new taxation formula was introduced, based on specific characteristics of insured population. The final trade-off was related to electoral powers. According to Geva-

May & Maslove (2000), the support for liberal views and loyalty for health care principles implied political status. By this, the Labour party ensured a way to regain future electoral power and prevent bankruptcy of the biggest sickness fund, Clalit. The latter would not be appreciated and have electoral consequences.

The NHI law was passed during the Labour party government of late Prime Minister Yitzhak Rabin. The government prevented coalition instability in the face of crucial decisions concerning the peace process (Geva-May & Maslove, 2000).

# 6.3.2 The new Health Insurance Law, NHI law 1995

The NHI law was enacted in 1994 and implemented on January 1<sup>st</sup>, 1995. Based on the NHI law, universal health insurance is facilitated and citizens are entitled to a basic benefit package. The four sickness funds compete on quality of services and every citizen is obligated to join one of these funds. In turn, the sickness funds are obligated to accept everyone. Citizens pay a health tax-based payment, which is collected by employers and is transferred to the National Insurance Institute (NII). To enhance equity among the sickness funds, an age-adjusted capitation formula is applied and professionals from the Ministry of Health were responsible to secure this capitation formula (Chinitz et al., 1997; Swirski, et al., 1998; HiT Israel, 2003). Sickness funds however, are allowed to offer supplemental insurance for other services outside the basic benefits package and in addition private insurers may provide health insurance for basic and supplementary services.

## 6.4. Cross-country comparison of the Netherlands and Israel

At this moment it is required to give a graphic line-up on the differences and similarities between Israel and the Netherlands. Furthermore, it is necessary to recapitulate the findings acquired from the previous chapters before the case is presented in the following chapter. The similarities and differences between the two countries are of great significance for the central research question of this study. The graph (6.1) beneath will portray the findings for each country.

	Israel 1995	The Netherlands 2006
	the NHI policy-making process	the ZvW policy-making process
Country's foundation	Democratic and Conservative welfare state. Shifts towards liberalism also in health policy. Shift affects the vulnerable groups in society, for instance, the poor and sick.	Democratic and Liberal welfare state. Enhancement of private entities, also effectuated by health policy. Shift affects the vulnerable groups in society, the poor and sick.
Political and governmental institutions	To govern the nation and introduce policies, government relies on its pluralistic system. The private interests of multi parties enhances power struggles. Consequently, the smallest parties are not heard, especially the not political but voluntary organisations, such as patient associations. The division of legislative, executive and judicial authority enhances transparency of government actions and enables interest groups to guard their interests.	To govern the nation and introduce policies, government relies on its corporatist system. Consensus is required and realized by existence of numerous group-representatives. Power struggles take place within this environment. It proves arduous to oppose or reject to 'polder' since you face the danger to be placed outside the process. Apparently, patient associations were apprehensive for this to happen.
Period of the Health Insurance Law enactment	The Commission Netanyahu heralds the change required to reform the health insurance system. The period to enact the NHI law was restricted to last only 4 years. The period is characterized by economic and security difficulties. Besides, patients were discontent with health care services and the waiting lists of certain health care services/ treatments.	The Commission Dekker heralds the change required to reform the health insurance system. Remarkably, the period to enact the ZvW law took 18 years. The period is characterized by economic fluctuations and the reconstruction of health system institutions. Besides, patients were discontent with health care services and the waiting lists.
Relevant actors in health politics	Notorious political actors were: the Minister of Health, Minister of Finance, Members of Parliament, Political parties and Advice councils. Socio-political actors were: Delegates of sickness funds & Health providers and Civic groups, such as the Association for civil rights.	Notorious political actors were: the Minister of Health/Secretary of State, Civil servants, Members of Parliament, Political parties and Advice councils. Socio-political actors were: Umbrella organisations of sickness funds and health providers, the Patient umbrella organisation (NPCF) and several individual patient associations.

Graph 6.1 A. Differences and Similarities between the Netherlands and Israel

	Israel 1995	The Netherlands 2006
	the NHI policy-making process	the ZvW policy-making process
Type of health system	Bismarckian style. 4 sickness funds were present which functioned as HMO's. Several private insurers were also present. Sickness funds determined own policies and were affiliated with political parties and labor unions. Before the NHI law a highly centralized system by the MOH. However, the MOH had no influence on health insurer's policies, yet owned a large amount of hospitals. Citizens were entitled to benefits in kind at their HMO's.	Bismarckian style. More than 35 sickness funds were present which were private entities. Health institutions were private entities. Before the ZvW law citizens were subjected to 3 Types of health insurance laws, one of which provided private insurance. Citizens were entitled to benefits in kind or restitution.
The new Health Insurance Law	One law to deal with political affiliations and the absence of a legal framework to regulate sickness funds activities. Under the law every citizen becomes insured. It introduced managed competition based on the quality of health services between the sickness funds and more autonomy for health providers. The exit-voice option for citizens and risk-rating for sickness funds were introduced. Besides, decentralization of the MOHs' influence on certain areas of the health system was processed. Citizens pay a direct health-tax to the NII. The law established a mixed financed system.	One law instead of three to provide health insurance for every citizen as every citizen is obligated to take out health insurance. The law introduced regulated competition based on price and quality between health insurers and health providers. 10% of hospital care became subjected to competition. The exit-voice option for citizens and risk-rating for sickness funds were introduced. Citizens pay a direct premium to the insurer and a tax payment of their salary. The law established a mixed financed system.
Patiënt associations	A number of individual and self-oriented patient associations. They were not supported by government financing. Patient associations did not actively participate during health policy-making. However, certain patient groups were capable to convince government to add high costly services during the policy-process of the NHI law. Their relationship with health actors however, remains unclear.	A substantial amount of patient associations and umbrella organisations. Patient associations receive government funding and are considered a third party in health decisions. Patient associations are active during health policy-making. During the ZvW law-making the NPCF was the vanguard.

Graph 6.1 B. Differences and Similarities between the Netherlands and Israel

7. CASE PRESENTED: DATA ANALYSIS

7.1 Introduction

In this chapter the data analysis will take place. The data from theoretical and empirical resources will be

analysed. To perform the analysis, Scharpf's actor-centred institutionalism and Arnstein's model of

participation are utilized in the Israeli and Dutch case. The application will create a thorough description on

the four factors of Scharpf's framework and on the level of participation by patient associations during the

health insurance system reforms. The following factors will guide the analysis: 1.) Institutions. 2.) Actors.

3.) Actor constellations and 4.) Modes of interaction.

In addition, the analysis will allow for comparison of the findings. Thereby, the differences and similarities in

role and influence of patient associations during the health insurance reforms are analysed. In addition to the

findings explanations can be given in reference with the theoretical framework.

7.2 Institutions

In this paragraph, countries political and governmental institutions which influence patient

association's capabilities during policy-making are examined. Institutions as: the political

system, the parliamentary system and constitutional rights are analysed during the course of

the policy-making process of the health system reforms.

7.2.1 The Netherlands

During the 1980's, a centre-right cabinet iniated the health insurance system reform, based on

the advice of Commission Dekker (Schut et al., 2005; HiT, 2004)). Data reveals, that

government during the policy-making process and the actual implementation, relied on the

cooperation and negotiations of political parties and several interest groups<sup>25</sup> (ibid). Hereby

Dutch corporatism becomes reflected were in general veto points remain low but on certain

aspects may increase. Especially when a substantial amount of actors with private entities,

participate in the policy-making process. These types of actors can increase their veto powers,

which may complicate to compromise and consent, a threat for the policy-making process. In

the corporatist setting two options remain for policy actors; 1.) Decide to let the deadlock

<sup>25</sup> Being fully aware the policy-making process exists of different stages this distinction is not made during the analysis. When the word policy-making process is written all phases during the policy-making, which are open to influence by interest groups, are referred to.

Role and influence of patient associations

exits or 2.) Decide to let go and concentrate on other beneficial subjects. Yet on one side multiple political parties in Parliament debated but agreed on the introduction of privatisation in the health system. On the other side, groups of insurers, providers, employers, employees and patients made sure their interests and preferences received government attention.

The institutions provided interest groups of several channels to engage in dialogues and negotiations with the government and other actors. These dialogues and negations enabled them to express their concerns but rarely actors opposed the preferences of one another. The explanation for the latter lies in the corporatist setting where opposition yields significant disadvantages. Because when actors turn away from dialogue and negotiations the chances for exclusion from the policy-making process increase.

Remarkably, consensus during the policy-making process of the ZvW law was accompanied by high transaction costs, since the reform took eighteen years. The latter as an effect caused by the implementation and readjustments of intricate institutional changes of the health system (Schut et al., 2005).

Equivalent with the pace of the health insurance reform, the political landscape experienced a transformation since patient associations became actors on the national level of health policy-making. This transformation came with the change were patients claimed self determination in health care. As a consequence, government created an institutional structure to equip patient associations as equal partners during negotiations of the policy-making process of the ZvW law. The by the MOH appointed patient umbrella organisation (the NPCF), received an important role during the policy-making process (Trappenburg, 2005). Essentially to represent their members and all of nations patients. Patients however, did not have any direct influence on the selection or election of the directorship of the patient umbrella organisation. Yet data reveals the patient umbrella organisation was capable to issue patients interests towards powerful actors as: the MOH, Parliament, health insurers, health providers and employers. With this transformation the MOH turned away from paternalism and created more businesslike relations in line with their policy that time.

The legislative authority i.e. Parliament proved accessible during the policy-making process of the ZvW law. Data reveals legislators of the 1<sup>st</sup> and 2<sup>nd</sup> Chamber were approached by patient associations and the NPCF. This accessibility was utilized to inform: Members of Parliament, the cabinet and the Minister of Health on issues they considered important. By

these actions, patient associations secured their interests and concerns were placed on the political agenda. Hereby the democratic institutions become reflected (Scharpf, 2000).

Furthermore, data reveals patient associations conveniently practiced the constitutional rights of free speech and press. For instance, during the policy-making process publications of patient associations provided patients of information about the reform. In addition, patients and member meetings were held wherein political issues of interest were discussed. Hereby, patients were informed about the intentions of politicians and transparency of the policy-making process increased. The NPCF furthermore, utilized the media as a mean to inform citizens and politicians. For instance, with the presentation of the risk-rating report to the Minister of Health (2005). Vice versa patient associations were also approached by the media to express their opinion with regard to relevant issues of the reform, for instance, media coverage on problems experienced when shifting from insurers (NPCF, 2005).

Patient associations inevitable became part of the media game. But they were capable not to engage in empty media hypes. In some cases however, health actors presented distorted information in the media to influence public opinion (Policy-maker regional patient association, 2006). In these cases, patient associations were aware to provide patients of the right information. The chance for restlessness under patients amidst these events would increase if patient associations would refrain. Besides, this restlessness could affect the unity between individual, regional and national patient associations. Division would jeopardize patient association's capability to speak with 'one voice'. Therefore as proven, patient associations benefited from unity within and between their associations, during the policy-making process of the ZvW law.

In essence, patient associations (primarily the NPCF) became acquainted with countries institutions and the rules of the political game, during the policy-making process of the ZvW law.

### **7.2.2** Israel

For many years the subject of a health insurance system reform resembled a true conflict in Israeli Parliament (Geva-May & Maslove, 2000). Explanatory factors were; the political pluralist setting with many veto actors and the considerable time period in Israeli politics under Labor authority. The Labor party successfully detained the adoption of a health insurance system reform, although it remained on the political agenda. The strong affiliation

of Labor with its sickness fund (Clalit) and the General labour federation (Histadrut) determined its relative strength. Clearly, these structures forced Labor to consider the preferences of the two above mentioned organisations. Especially, since Histadrut resented liberalisation of the health system (Geva-may & Maslove, 2000). Full cooperation and agreement with the liberalisation process would deprive Labor of their relative strength and influence during policy-making. Apparently, Labor had to stay in close dialogue with these organisations. First of all, to get information and secondly, to preserve unity between the affiliated organisations. Hereby, Labor secured their financial stability and influence during the policy-making process (Geva-May & Maslove, 2000).

Nonetheless, countervailing powers as the Likud political party together with other socio political actors, have proven capable to keep the reform on the political agenda. But their relative strength and influence alone appeared not sufficient to actually change the status quo. Stakeholders as proven, are willing to allow changes when the trade-offs are significantly beneficial (Scharpf, 1997). Data reveals the window of opportunity came when Labor's political affiliated sickness fund (Clalit) was threatened with bankruptcy and government had to react due to challenges in the Israeli health system. Evidently, at this point Labor realized their negotiation power and position were solid because they were at power and capable to set the conditions for the reform. As a party they made sure, this would be in best interest for Labor itself but also its supporters.

Besides political parties, many socio political parties were part of the policy-making process. The political system of pluralism allowed groups of health providers, insurers, employers and civic groups in the policy-making process. The latter does not include patient associations. Although these groups were not officially part of the machinery of government they were regarded as legitimate and therefore characterized as insider groups. This is proven since the MOH maintained consultations and dialogues with representatives of these groups during the policy-making process of the NHI law (HiT Israel, 2003).

Evidently, also in pluralist settings the negotiation powers of actors affect negotiations during policy-making. Contrary to the Netherlands however, Israeli government does not rely on the consensus of interest groups for the actual implementation of health policies.

Remarkably, during the policy-making process the legislative authority i.e. Parliament proved accessible for patients and their associations. Hereby, patients and their associations could secure their concerns reached the political agenda. To what extend patient associations actual utilized this accessibility during the policy-making process could not be retrieved. Nonetheless, this accessibility was utilized by powerful health actors. Hereby the democratic institutions become reflected (Scharpf, 2000)

Striking has been the absence of political participation and mobilization of patient associations at time of the policy-making process of the NHI law. An important explanatory factor has been the structure of the Israeli health system where the purchaser/regulator-provider split is absent. Besides, with the establishment of the state a strong linkage between sickness funds, labor unions and political parties submerged (Geva-May & Maslove, 2005; HiT, 2003). Countries governmental institutions did not naturally invite patient associations to participate and patient associations had to address the policy-making process from the outside. Clearly, the above mentioned structures have worked for decades in Israeli society but as a consequence of health and economic trends, these structures were challenged. Further down this chapter the structures will be thoroughly analysed.

Although political participation was absent, patient associations also lacked knowledge on how to raise their 'voice' during policy-making. Several structures, on the political and organisational level can be introduced to support patient and their associations. Of interest is to determine whether health organisations were aware of the latter. Did sickness funds or health providers pay attentiveness to patient's interests during the policy-making process of the NHI law? For instance, the establishment of patient boards in institutions allows a level of formal participation by patients during health policy decisions. Yet contrary to the Netherlands, data lacked to provide evidence of such developments during the policy-making process of the NHI law. Secondly, patient associations could pursue becoming a solid organisation with vast financial resources. But citizens, some of which residing in patient associations, had other priorities besides pursuing a role during policy-making process since social issues like, peace and security, demanded their attention (Social worker/patient representative, 2007).

Clearly, when means and a voice are absent superiors will decide what works best for nation's patients. Particularly the behaviour of the MOH during the policy-making process resembled the paternalistic approach.

Furthermore, the practice of the constitutional rights of free speech and press created initiatives during the policy-making for patients and their associations to openly discuss political issues. But patient associations were not acquainted with various media aspects and media games. The news media however, approached individual patients for their stories and experiences with the consequences of government policy (Social worker/patient representative, 2007). Clearly, the media provoked an open public debate on health related issues and individual patients could use these publications to strengthen their position during the policy-making process. Evidence for the latter however, is hard to retrieve.

### 7.3 Actors

In this paragraph patient associations and health actors together with their goals and orientations are examined. These goals, orientations and interests, differentiate respective actors during the policy-making process. Combined with the institutional rules, actor's success and failures during policy-making are predetermined.

### 7.3.1 The Netherlands

During the last decades the "patient perspective" has thrived on all levels in Dutch society. Many patient associations were established under influence of government policy to pursue own interests (Trappenburg, 2005). But as Dutch corporatism requires, patient associations during the policy-making process of the ZvW law were joined into a collective. Accordingly the patient umbrella organisation i.e. the Dutch Patient and Consumer Federation (NPCF) represented the interests and preferences of Dutch patients during the policy-making process of the ZvW law. Initially, the patient umbrella organisation was established and subsidized by the government<sup>26</sup>. By doing so the government attempted: to strengthen the position of patient associations as a third party in health decisions and to establish a countervailing power within the health field (Nederland, 2004). Clearly, financial resources together with these roles guaranteed the NPCF of an extent of influence on the ZvW law policy-making process.

Nonetheless, besides these successes the position of the patient umbrella organisation (NPCF) remains vulnerable. The following quotation clarifies this.

\_

<sup>&</sup>lt;sup>26</sup> To receive these subsidies patient associations have to perform certain key activities: information supply, interest representation and sufferer contact. From the latter the NPCF is excepted.

The financing still occurs on the basis of incidental subsidies and that does not advance future prospects, if every time you have to wonder if you still will exist the following year, or over three years. You then would have another position. But also additional subsidies, otherwise we wouldn't make it (Senior policy-maker- Patient umbrella organisation)

An amount of 35 patient associations are conjoined under the umbrella organisation, compared to the more than 300 patient associations residing in the Netherlands. The NPCF defines itself as rather small, based on the amount of working staff. Furthermore, this conviction is based on the presence of bigger umbrella organisations in the health policy arena. For instance, the umbrella organisation of physicians (KNMG) and health insurers (ZN), which they argue possess more financial resources (Senior policy-maker- Patient umbrella organisation, 2006).

Data reveals these actors were prominent during the policy-making process of the ZvW law.

The Royal Dutch Society for Promotion of Medicine (the KNMG: De Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst) incorporates various physician organisations and has 41.560 members. The KNMG has a long tradition and nowadays secures a strong position in health policy decisions on behalf of Dutch physicians. Several factors have contributed to the strong position of the KNMG in health politics. First of all, members of the KNMG perform social obligations in society. Furthermore, they have control over vast financial resources and knowledge of the rules of the political game (Jaarverslag KNMG, 2006). These factors stipulate the difference in position when compared to the patient umbrella organisation, the NPCF. Besides, KNMG's position during the policy-making process became enhanced by its mandate from member organisations. Clearly, for strategic action the KNMG was availed by internal unity.

Similarly, Health Insurers Netherland (ZN: Zorgverzekeraars Nederland) incorporates Dutch health insurance corporations. Government policy resulted in the establishment of a collective actor for all forms of health insurers (ZN) around 1995. Evidently, ZN needed a mandate from member corporations to secure its position, during the policy-making process. However, to bring interests of private and public insurers together might proven to be a challenge. Especially, since public insurers were compelled to enter the regulated competitive health insurance market, in the new health insurance system.

Identically the NPCF as a collective actor needed a mandate of its member organisations. The NPCF considered the mandate a requisite to stay true to the interests and preferences of those members during the policy-making process. But also to prepare for strategic action. The following quotation clarifies this.

By the General Membership Board and the Executive Board we receive our mandate to carry out the work plan, and by no means are we helped if on all kinds of things we would need to return once more to ask authorization of the member organisations. Would we do so, one would be crippled and it is possible the moment some issue arises you cannot say anything, because you have to discuss it with your supporters and then a half year has passed and the topic is no longer a current issue. (Senior policy-maker- Patient umbrella organisation)

The NPCF had to consider the preferences of their members and weigh those against the preferences and interests of stakeholders as, the Ministry of Health (MOH), health insurers, and health care providers. However, health actors were not reluctant to form coalitions when necessary, as part of strategic actions. The behavior of Dutch collective actors during the policy-making process, highly reflect the Dutch corporatist setting which heavily relies on negotiated agreements. The following quotation clarifies this.

At the beginning, discussion meetings were organized. Not separately with every patient association of course but also with the providers, insurers, employers and employees. In a further stage the outlines of the ZvW law became visible. In the construction the issues which patient associations and other discussed were taken into account. At a certain stage there is a draft of the law. On this concept all relevant parties were asked to comment. And that has been the input for further decision-making. (MOH Deputy)

During the policy-making process Dutch patients pursued specific interests and orientations, besides their goals. Individual patient associations but predominantly the patient umbrella organisation (NPCF), proved to be a successful advocator. It approached health actors to express concerns about the health insurance system reform. For instance, towards individual Members of Parliament, the Ministry of Health, health care providers and health insurers. The Dutch patient umbrella organisation advocated for orientations which relate to the position of the 21<sup>st</sup> century kind of Western patients (see their 5 goals described in 6.2.2). Self-determination ranked high on their list of interests. Patients demanded self-determination in healthcare and health actors realized the positive effect thereof on the health system. As the following quote underlines, self-determination was an important goal. Its significance is indicated when a senior policy-maker states, that with self-determination everything else holds! But to establish self-determination for patients requires possession of: information resources, social skills, a solid legal position, solid patient associations and much more. Apparently, the NPCF supported the ZvW law since it enlarged self-determination for Dutch patients. The following quote clarifies this line of reasoning.

One of the reasons we approved the ZvW law so quickly, was because we saw more potential for self-determination. The ZvW law aimed to achieve this. So, there are possibilities for collective health insurance contracts, for example for patient organisations. Also the preservation of the PGB (the Personal Budget) in the ZvW law, for care that is transferred out of the AWBZ (Health insurance for long term health care) into the ZvW law<sup>27</sup>. PGB is the most suited instrument for self-determination. One can fill in care and organize it how you want it and whatever is best for you. So, self-determination was an important goal, and with that everything holds, like a solid legal position. (Senior policy-maker-Patient umbrella organisation)

Furthermore, the NPCF advocated for a good risk-rating system since the position of health insurers became stronger. The MOH realized the NPCF did not settle with only words or inaction but only when they reached agreement. After all, the NPCF has proven capability to stress their issues during the policy-making. The next quote reveals the main issues of the NPCF during the policy-making process had the attention of the MOH

Well, I think they (NPCF: db<sup>28</sup>) had two main issues. In the first place secure access and decent payment. Furthermore, ensure that the less healthy and less prosperous would be covered sufficiently in the health system. Also on the other hand, the word empowerment. How do I ensure that a patient, when freedom of choice is not only lip service, is made capable of making his own decisions about his own care process. Too much power for the health insurer was also an issue and whether the insured have enough instruments to be a countervailing power. (MOH Deputy)

The NPCF advocated on behalf of vulnerable groups within society since the policy-making process and introduction of the ZvW law took place during turbulent times. The Netherlands struggled with an economic impasse and other challenging developments. Besides, critiques as the socialist party (SP) argued that the centre-right administration, which favors regulated competition, paved the way for the ZvW law. Clearly, these factors made the NPCF advocate on behalf of vulnerable groups within society and align with the socialist party (SP) on certain issues.

Despite the successes, data reveals the NPCF has the task to monitor the possible negative effects of the ZvW law on patients (Senior policy-maker- Patient umbrella organisation, 2007). The latter is required to preserve the goals of equality and quality in healthcare for Dutch patients. The following quote reflects on one of the challenges.

<sup>28</sup> Initials db = Diola Bijlhout

\_

<sup>&</sup>lt;sup>27</sup> The Personal Budget (PGB) is provided by the government to citizens who are entitled to healthcare or healthcare related services and want to manage these services themselves. Citizens can hire and thereby pay everyone they think suitable of performing these healthcare services in their interest.

The Health Insurance Act (AWBZ) is compulsory for all Dutch citizens and insures citizens for catastrophic or long-term healthcare services i.e. long hospital admissions and nursing homes admissions.

The collective contracting is not yet used as a mean for risk selection by health insurers. However the following year needs to be monitored closely. Insurers might want to increase their profits based on the collectives which incorporate favorable individuals. With this development at the end, the solidarity principle is affected and that is something you want to prevent from happening. (Expert health insurance reform 2006)

Collective contracting incorporates a premium deduction for a group, e.g. patient groups. Predominantly the NPCF advocated for these types of contracts for patient groups in health insurance. But as the expert reveals close monitoring on the effects remains necessary.

### **7.3.2** Israel

The structure of patient associations in Israel during the policy-making process reflects a total opposite picture. The approximate fifty patient associations were and remained independent, self-oriented associations. Noteworthy, is their absence of political participation during the policy-making process of the NHI law. Apparently, the development for political participation by patients associations within Israeli society was less prominent that time. Data revealed the pluralist society proved arduous for patient associations to mobilize into a collective (Social worker/patient representative, 2007). Majority of patient associations were characterized by an enormous diversity of opinions, interests and preferences which hampered motivations to compromise and mobilize. Especially, when other important policy issues are presented by the government to society. The next quote reflects on the dynamics.

In Israel it is very complicated. Because we have a lot of different groups with different cultures and skills. It's not only the newcomers, Russian, French, North American and the citizens. No, its even differences between the periphery and the center, Jewish and the Arabic, religion and no religion. So if I give you one answer, it's not fair, but you see some progress. (Social worker/Patient representative-the Knesset Non-MP)

According to Deth & Newton (2005), non-political organisations on a voluntary basis in general restrain from political activity since they conceive politics as the cause for difficulties and controversial (ibid.). Clearly, patients were preoccupied and dealt with general distrust in politics of the 1990's. This is nicely reflected in the next quote.

We had a lot of subjects in Israel. You know the policy problems, security, the private problems and the economic problems. So most people are tired. (Social worker/Patient representative- the Knesset Non-MP<sup>29</sup>)

Moreover, the expert on the Israeli health reform argued, that the absence of patient associations participation was a result of the establishment and organisation of the Israeli

-

<sup>&</sup>lt;sup>29</sup> Non-MP refers to not being a member of the Parliament/Knesset

sickness funds. Accordingly, members of labor unions often were members of the affiliated sickness fund, unlike in the Netherlands were sickness funds are private entities. Members of Israeli sickness funds and labor unions assumed their sickness fund would mainly act in their interest.

Besides, most of Israeli patient association relied on funds and donations. Government did not commit to financially support these associations, like in the Netherlands. Government financing however, can function as mean to establish resourceful patient associations. According to Scharpf (1997) financial resources contribute to policy actor's possession of vast action resources during policy-making. Hays (2006) accordingly states, that limited financial resources limit interest group influence on policy-making.

What also needs observation is that with the presence of a firm civic movement, political participation of modest interest groups diminishes. The civic movement in Israel had strong sympathies for the vulnerable ones in society. The Association for civil rights in Israel, together with other specific groups were advocators and consultants towards government (HiT, 2003). They represented the rights of Israeli patients during the policy-making process. Apparently, with any actor present on patient's behalf the urgency to become active themselves diminished.

Although patient associations were absent, patient representatives were present at several policy-tables. Remarkably, these patient representatives were not a direct representative of patient associations. In principle they were consultants from the social welfare field which linked policy-makers to nation's patients and their associations during the policy-making process of the NHI law.

Moreover, it has been during the policy-making process of the health insurance system reform that individual patients got acquainted with policy-making and health actors. For instance, the Ministry of Health, the Ministry of Finance, health care providers, representatives of labour unions and sickness funds (Geva-May & Maslove, 2000; HiT, 2003).

The existing sickness funds were corporate actors since they acted autonomous from beneficiaries and possessed critical action resources. Equally as in the Netherlands, labor unions and health care providers in Israel were represented by their umbrella organisations. These collective actors relied on the preferences of their members. Also in Israel, unity was

essential for collective actors during the policy-making process. For instance, the Israeli Medical Association (IMA) strongly negotiated with relevant health actors on their member's behalf (Gross, 2003). This type of health actors were powerful and possessed critical action resources. When necessary health actors, like in Dutch corporatism, compromised and entered into coalitions to: enlarge strategic actions, exert pressure and enhance specific benefits.

Yet data reveals a gradual development during the policy-making process of the NHI law since patient associations were made aware of a possible future role. Predominantly, individual patient representatives lobbied at government level for the involvement and participation of patients during the policy-making process of the NHI law<sup>30</sup>. As a result, individual patients (or relatives) were allowed to represent their group members during formal policy meetings (Social worker/patient representative, 2007). Individual patient's capacity on action resources was limited. Especially, since they were not professionals but citizens with a disease and mental or physical handicap. Individual patients however, provided health actors of information. A huge contrast with the Netherlands, there its umbrella organisation of patient associations acted as a policy actor during the policy-making process. Evidently, Dutch government preferred a professional patient representative body (NPCF) during and after the policy-making process. Obviously, health actors and patients in Israel had to adjust to new developments in the health policy arena. This is reflected in the next quotation.

At the same time I started talks with the Knesset to grant me this right to bring patients, to give their point of view, 'tell their needs'. It took a considerable time before they said it was ok. I started parallel talks with patient groups. Including those for cancer, mental illness and osotomy. When I went to them, no one was sure that it would work. (Social worker/Patient representative- the Knesset Non-MP)

The goals of Israeli patient associations were self-oriented and specific orientations regarding the reform were absent. Nonetheless, patient associations were content with two aspects of the new health insurance law, but remained skeptical. As is underlined in the next quote, patients welcomed compulsory insurance and the possibility to shift from health insurer. With the latter patients received means for self-determination, a subject the NPCF stressed in the Dutch case.

When the law started, two things, two good things were decided. One, that every person in Israel from his birth will be insured in the health system. And the second that everyone can change from sickness fund you can move from one to another, without any questions about your health situation. You can be a very sick person, a very sick patient with cancer, with all kinds of things and you can decide to move to another sickness fund. (Chairman – Patient umbrella organisation)

=

<sup>&</sup>lt;sup>30</sup> This development occurred during the period of 1992-1994.

Contrary to the Dutch case, the specific orientations of patient representatives during the policy-making process are hard to retrieve. Yet of interest has been the adoption of two aspects in the NHI law. Remarkable was the adoption which demands two patient representatives in the National Health Council<sup>31</sup> and the adoption for the institute of an Ombudsman for the national health insurance law. Not clear are the factors that contributed this outcome and the role patient associations played in its establishment. Clearly, government realized mechanisms for the securement of patient's rights and position were vital once the reform was implemented.

### 7.4 Actor constellations

In this paragraph actors constellations during the policy-making process of the Israeli NHI law and the Dutch ZvW law are examined. Besides, the types of relationships between patient associations and health actors in both countries during the policy-making process are analysed.

### 7.4.1 The Netherlands

The types of relationships between health actors during this policy-making process were essential. Relative good or bad relations say something about real interactions during the policy-making process. The Dutch consensus politics formed the context for these relationships. According to Mansbridge (1992), corporatism encourages negotiations where it is a matter of persuading others through dialogue. On a pro- active basis the MOH listened and connected with all relevant parties during the policy-making process. The approach of the MOH was clear; with regard to the main principles and viewpoints of patients, it interacted with the patient umbrella organisation i.e. the NPCF. In addition, the MOH maintained individual contact with individual patient associations on specific viewpoints. The relationships between the MOH and health actors differ due to diverse interests. The following quote reflects on relationships.

\_

<sup>&</sup>lt;sup>31</sup> According to Chinitz & Israeli (1997:207)

<sup>&</sup>quot;The National Health Council includes representation of officials of the sickness funds, consumers, health policy experts, and government officials and is chaired by the Minister of Health. The Health Council is intended to monitor implementation of the law and to advise the government on various related issues, including the contents of the basic basket and the level of health expenditures".

Well, I think we (MOH: db) choose to maintain a good cooperative relationship with the NPCF and in a later stadium with the Consumer Federation. From the beginning we (the MOH: db) had an intensive relationship. Especially the NPCF has been the most intensive discussion partner. The Department has periodical meetings and actually underneath there has been a lot of exchange of information on an ad hoc basis. We have and so have they, always involved each other with for example, discussion meetings in the regions and these kind of matters. (MOH Deputy)

Government during last decades reformed the institutional structures of the healthcare system and defined cooperation mechanisms between field parties (Schut et al., 2005). Subsequently, these mechanisms defined cooperation between the NPCF and health actors, during the policy-making process of the ZvW law. The NPCF had close relations with the umbrella organisation of health insurers (ZN) and physicians (KNMG). Apparently, not only the MOH depended on negotiations with health actors. Health actors among themselves negotiated and bargained in order to reach mutual agreement (Scharpf, 1997). Yet interaction among health actors will always occur between the borders set up by the government. It requires underlining that these borders affect the relationships the NPCF want to establish or maintain. Thereby, their influence is also affected as well as their third party position. The following quotes reflect on interaction between governments borders.

I think that they (MOH: db) indicate the scope in which things are possible. Herein they place the borders within which can be played. I think they (MOH: db) prefer that providers, insurers and patients together sort out things. And that it especially does not cost more than the national budget. But that the government can not completely pull itself out of this relation, in order to be involved on certain issues, or to initiate things. All this to eventually leave it open to the field. (Senior policy-maker- Patient umbrella organisation)

What we (MOH: db) have not done, we considered it but did not do it, is to place all parties together in some kind of structural discussion meeting. We didn't do this because it would very quickly induce strategic behavior around these meetings. It is an enormous Polder. And of course it has been the intention to reduce the Polder element and steer it more into businesslike relations. That is also part of the course, right? (MOH Deputy)

The expression 'businesslike' almost indicates that health actors are free to select their counterpart. However, the aspect to withdraw from or leave a not interesting or willing party for another 'better one' (like in business) is not possible within corporatist policy-making. Yet the policy-making process of the ZvW law reflects equality in relationships between health actors. Within these relationships compromise appeared extremely important to reach consensus. Health actors realized that with compromise part of their demands are fulfilled and deadlocks averted. Nonetheless, the NPCF is aware that compromise is part of strategic behavior, reflected in the following quote.

The MOH will not come with a proposal before it has an agreement with the umbrella of Health Insurers (ZN). So, yes there are shifting coalitions, that's how you have to see it. It is an art to have these shifting coalitions without damaging the long-term relation with one another. (Senior policy-maker- Patient umbrella organisation)

The MOH heavily relied on the cooperation and agreement of relevant health actors during the policy-making process of the ZvW law. Nonetheless, due to countries democratic foundation it was the centered-right government which ultimately determined the final ZvW. The next quote clarifies this process.

The final decision is made by politics which balances interests against one another. The truly important things are always trade-offs. Where the balance is reached, yes, that is ultimately a matter of political taste, political preference and if there is a political majority. (MOH Deputy)

### **7.4.2** Israel

Where there has been a tradition of relationships between patient associations and health actors in the Netherlands, patient associations in Israel were just commencing participation during the policy-making process. Within the Israeli pluralist environment certain parties had privileged access and power which apparently, patient associations lacked. It requires underlining, that the unequal power balance resembles hierarchical relationships during the policy-making process. Patient associations were not official part of the policy-making process which affected their role and influence. Moreover, the government was rather independent and predominantly needed the confidence of the MOH and MOF to promote the NHI law (Gross & Harrison, 2001). Besides, the MOH was in close contact with parties and maintained in dialogue.

The relationships between strong health actors and patients of patient associations during policy-making process of the NHI law reflect a fragile, young and complex picture. Especially since those patients were confronted with health actors with strong political affiliations. Data reveals more elucidative factors, reflected by the following quote.

It depends. You know in Israel the Minister of Health is the fifth or sixth in six or seven years. So when you start to develop some relationship they change. I must say again you see some movement, you see some changes. But it's talking more than it's the truth. (Social worker/Patient representative- the Knesset Non-MP)

Apparently social health actors were familiar with this type of government action; issues are discussed by the government, but it holds back to actual define actions when necessary. But there are more factors influencing relations, reflected by the following quote.

The government creates the relationships to create health policy. But in Israel we have some other problem. The government is not only the regulator, they have employment, and they have the Health Institute. (Social worker/Patient representative- the Knesset Non-MP)

Evidently, it becomes difficult for a government with a dual role in the provision, planning and control of health care services (i.e. absence of the so called purchaser-provider split) to define actions and construct a solid solution.

According to Mansbridge (1992), the political system of pluralism views interests groups as aggregating the preferences of their members and working to maximize those preferences in a conflict based arena. In spite of the latter, the MOH in Israel choose to place all parties together in a structural meeting, contrary to the Netherlands. The MOH apparently did not fear any strategic behaviour of actors since actors were subjected to mutual competition during policy-making. Within these circumstances it may prove difficult to form coalitions against the government. Yet powerful health actors in such circumstances are then more willing to employ actions to build up pressure. For example, the Israel Medical Association (IMA) threatened with strike actions during the policy-making process (Gross, 2003). It is evident government averted these actions, especially across public sectors.

The equality in role and position of the patients during policy-making process had to develop, as did their capability to create relationships. Contrary to the Netherlands were the NPCF heavily relied on preestablished relationships. Very likely, the constellation of actors influenced patient association's capabilities to create relations during the policy-making process. For essential reasons, such as, knowledge on creating and maintaining political relations and the adapting time factor. Especially since patient associations did not receive any government assistance. The following quotation clarifies this.

You must give it (the development of participation: db) time, because it is not easy to change (health actors: db) way of looking at this relationship. (Social worker/Patient representative- the Knesset Non-MP)

The centre-left government took political responsibility and introduced the NHI law. Health actors had to compromise even when restrictive disadvantages were introduced. The following quote reflects patient's viewpoint.

No one in the health system approved it (NHI law: db) completely. But everyone understood too that everyone had to compromise! If you want a law, everyone should comprise. So we the patients compromised despite the health law made some limitations in the services we received. Previous to the NHI law we received it from the sickness fund but there came some limitations. The Treasury Department didn't approve of course. (Chairman – Patient umbrella organisation)

### 7.5 Modes of interaction

In this paragraph actual interactions between patient associations and health actors during the policy-making process are analysed. The analysis will reflect on patient association's strategies and tactics by which they actually attempted to influence the policy-making process.

#### 7.5.1 The Netherlands

The analysis of the Dutch policy-making process (ZvW law) reveals that patient associations and the patient umbrella organisation i.e. NPCF, participated and advocated for the interests of their members and nations health care consumers. The Dutch patient umbrella organisation and individual patient associations were considered insider groups since they were regularly consulted but expected to play the rules of the game. The way the Dutch corporatist setting incorporates interest groups namely, patient associations is exceptional. As proven, government heavily relied on the NPCF for technical information, expertise and cooperation to smoothly implement the ZvW law.

On a structural basis during the ZvW law policy-making process, the NPCF joined periodical discussion meetings with civil servants of the Ministry of Health (MOH) and information was exchanged on both sides. This partially reflects the insider status. These periodical meetings were part of the strategy of the NPCF to influence the policy-making via formal channels. Based on the findings, the NPCF was capable to negotiate and engage in trade-offs with powerful stakeholders. One can argue however, that the benefits of these negotiations and trade-offs determined the actual behavior of the NPCF. Patient associations conceive this negotiation as the ultimate way to achieve their aims and goals. The participation of the NPCF during the policy-making process is classified as partnership i.e. the sixth level of Arnstein's ladder of participation (1969). The following quotes provide insight on the establishment of the strategy of the NPCF during the policy-making process. The NPCF realized early in the process that opposition would not yield sufficient outcomes as reflected in the following quotations.

Its has been a philosophy of our Directorship; when you notice at a certain point that something will be pressed through, like a ZvW law and becomes clear that it will come, then you can choose to stay against it no matter what, or you can say I go along and try as much as possible to get out of it. And for that last strategy the Directorship clearly has chosen. (Senior policy-maker- Patient umbrella organisation)

Once it became clear the ZvW law would be passed, the NPCF went into the right gear. I consider it very clever work, administratively. They were critical but realized at a certain moment the law would come, or the chances of it being passed were great. At that certain moment it is better to try to talk constructively rather than merely oppose. I consider their good timing resulted in acquiring more than would have been originally received. (MOH Deputy)

Apparently the 'right gear' indicates a readjustment of strategies. At the beginning, the NPCF opposed the law but calculated their opposition did not affect the policy-making process effectively in order to block the law. Because of that they compromised and tried to score on as many subjects during the policy-making process.

Furthermore, the NPCF participated at periodical discussion meetings with different health actors i.e. umbrella organisations of health insurers and health providers. Discussion meetings were part of the strategy of the NPCF and formed the basis for coalitions. Clearly, the NPCF practiced the game and made sure they were a member of effective coalitions. Scharpf's (2000) statement that actors do care, positively or negatively about the payoffs others will receive is proven to be true. The next quote reflects on the latter and on the NPCF's decision-making strategy.

In any case there are periodical discussion meetings. Thus, they (the NPCF and counterpart: db) talk everything through and many issues are discussed. In that way a plan gets formed. In any way you have to come to a win-win situation. It all happens on the basis of relations. That is true lobbying, politics. Yes, I think it also works like this in the politics at The Hague. Now you join the other on a subject, but then they also expect your support. You have to make sure you do not support issues you do not agree with. (Senior policy-maker- Patient umbrella organisation)

Although the insider status, it was possible for the NPCF to be forced into a weaker role during the policy-making. In most cases, the NPCF proved capability to correct this favorably. The following quotes however, show there still is the possibility to be passed over.

Well, we (NPCF: db) are very popular, I can say. It might happen that in some cases we are not present or that we hear that there has been a meeting. When our Directorship discovers this, they instantly contact one or the other (health actors: db). The next time however, we politely receive an invitation. So, in general we do not have anything to complain about regarding being approached in order to attend. (Senior policy-maker- Patient umbrella organisation)

Well, you have to keep in mind, would the NPCF immediately have opposed, and said we reject! We do not want this! Yes, then they would have placed themselves at a certain moment, I guess out of the game. (MOH Deputy)

Apparently, the support for the ZvW law conditioned the strong role of the NPCF. The former quote is very remarkable for a corporatist environment which stimulates patient associations to function as a third party. The quote implies that patient associations which oppose need to get around the game rules to influence policy. It is evident actor's positions weaken when it becomes difficult to constructively discuss and negotiate on issues you oppose. Yet the possibility of a weaker position for the NPCF seems rather small, due to the significant amount of supporters which make up for a substantial constituency. The next quote reflects on the patient umbrella organisation's perspective on these dynamics.

They (the government: db) are afraid of us. I have to say that everywhere they ask us to be present. This is to prevent us from making a row of not being present. But if it is warm-heartedly granted to us, the role? They cannot get around it and they establish, and that is of course also crazy their own contra-power. Because they finance us, but we say all kinds of things about them. Also good things by the way. I mean, we are happy with the law, but we also say things which they do not like. So I can imagine they do not want to have us strong and solid. Because then they have to keep us in an iron grip. (Senior policy-maker- Patient umbrella organisation)

Yet data reveals the MOH is not concerned about a rising patient power. This is not a surprise since government institutions determine the pathway and the behaviour of actors during policy-making (Schut et al., 2005). Evidently, patient association's power is mainly required during direct negotiations with health insurers and health providers in the health field. But patient association's power proves equally important during health policy-making. The balance of power among health actors however, worried the MOH during the policy-making process of the ZvW law. The latter is clarified by the next quote.

Well, it has been an enormous and complex operation in an enormous power field. The popularity of the Cabinet was shaky, that's a difficult position to initiate a reform. The Labor Party (PVDA) at a certain moment voted against the ZvW law. With such an operation you want to have a Parliament majority. More and more providers agitated. Well in such a situation it was very important that the representatives of the people it concerned nonetheless remained supporters. (MOH Deputy)

The initial opposition of insurers (ZN) and health providers created opportunities for the NPCF to benefit and lobby at parliament members, bureaucrats and others. Apparently, the MOH considered the opinions of patients and consumers as sufficient to proceed the passing of the ZvW law.

Moreover, the role of the NPCF during the policy-making process of the ZvW law has proven to be of high character since it was the first time they participated in such a major reform. It required of them to represent the interests and preferences of their members within a strong

political environment (Trappenburg, 2005). In order to be able to achieve the latter a combination of lobby actions and pressure was applied during the policy-making process. The next quotes reflect the self confidence of the NPCF with regard to their actions and the affects thereof.

No one (health actors: db) will be able to keep us quiet on how we want things to be! You only use different inputs. When and how you're going to say something is accurately weighed. Also with whom you will be talking about something. (Senior policy-maker- Patient umbrella organisation)

It's better the more we receive publicity with our messages, press bulletins, articles, interviews and presentations. In fact we do not refuse anything, because with that you also secure your position and others cannot ignore you. (Senior policy-maker- Patient umbrella organisation)

At this moment a closer look into the strategies of patient associations is required to determine the actions taken to influence the policy-making process. As the study of Binderkratz (2005) revealed, also in the Dutch case the NPCF as an insider, predominantly applied direct strategies to influence the policy-making process. The tactics focused to influence formal channels and various actions to exert pressure. Nonetheless, the direct strategies were combined with several indirect strategies. This proves the patient umbrella organisation also adapts and readjusts its tactics when proven not successful.

The following graph (graph 7.1) categorizes the strategies and tactics of the NPCF during the ZvW law policy-making process.

Direct strategies during the policy-making process of	Indirect strategies during the policy-making process of
ZvW law:	ZvW law:
Critically read law proposals	Cooperation with the media
<ul> <li>Lobby actions</li> </ul>	<ul> <li>Information dispersion to members and other health actors (e.g. publishing pamphlets)</li> </ul>
<ul> <li>Regular meetings with MOH and other health actors</li> </ul>	Forming coalitions
■ The route of diplomacy	Establish relationships with research institutes
<ul> <li>Write letters to the Fixed Parliament Commission (Vaste Kamer Commissie)</li> </ul>	

Graph. 7.1. Strategies applied by the patient umbrella organisation to exert influence and enlarge their role during the ZvW policy-making process.

The patient umbrella organisation however, did not perform demonstrations. Demonstrations explicitly confront policy-makers with the opinions of patients and their associations. Apparently, the corporatist environment withheld the NPCF to combine direct strategies with certain indirect ones. Because the NPCF might lose the position to negotiate or lose credibility as a rather professionalized patient organisation within the health policy-making arena. The next quotes reflect on how the NPCF conceives demonstrations.

Thus, we follow the course of diplomacy and lobby. This has also been the case during the ZvW law and in case it is not successful, we take a more firm approach like raising questions in Parliament and if that does not work, then we place something in the newspaper! But demonstrations, we do not do that, that is something for our member organisations. (Senior policy-maker- Patient umbrella organisation)

Nederland (2004) argued that other actions such as demonstrations, besides negotiations might be more effective. Patient associations however, rarely practice them. Evidently, as much as it seems the NPCF practices indirect strategies it withholds itself of confrontational actions. It appears the NPCF behaves as a true 'polder party' while individual patient associations are exposed to the hazardous side of the political game.

The strategic directorship of the NPCF made sure they were visible for all health actors, during the policy-making process. However, they clearly separate this of 'always being heard' by the health actors or 'capable' to change policy. These assumptions should not be confused with their strong conviction of being capable to influence the policy-making process. These assumptions resemble Arnstein's (1969) distinctions of participation during policy-making. The NPCF in a pro- active manner defined criteria for the ZvW law which were taken into consideration by the MOH. The latter is made clear by the following quote.

The NPCF always has been the actual "forward". They were very active on set moments making clear their points, like ten points for a good health insurance or the measuring rod for a good health system. They published that very compact, so you could catch the points. With that they clearly let their voice be heard and it also was a message for us to pay attention to this and that. (MOH Deputy)

Furthermore, the establishment of a "research culture" forced the NPCF to establish relationships with research institutes as a mean to place issues on the political agenda. Subsequently, the provision and presentation of science-based patient related information, contributed to their professionalization. The report the NPCF published in cooperation with a research institute exemplifies their capabilities in the research culture.

Furthermore, even in the Dutch corporatist setting of negotiations health actors might stir up conflicts to issue their interest. This might be to gain or regain power or to place their interests on the political agenda (Scharpf, 1997). Contrary to the NPCF, the General Practitioners (GP) did not support the ZvW law. GP's confronted patient associations with their tactics during the policy-making process of the ZvW law. The strategic option of the GP's was to prevent health insurers to receive more power. The GP's stepped out of negotiations with health insurers (ZN) and the MOH. Moreover, they provided patients with certain information to create sympathy on their behalf. Evidently, health actors which had patients on their side attained more influence and pressure during the policy-making process. This strategic action of the GP's prompted the NPCF to stay in close contact with their member organisations. The following quote portrays the conflict.

What has been very difficult is that the General Practitioners during the process and discussion of the ZvW law have seized on that moment to strengthen their own position. They chose a very confusing strategy and tried very hard to get the patients on their side. So in the spring of 2005 there was a mutual difference between the national and regional patient associations. (Policy-maker- Regional patient umbrella organisation)

Apparently, patient associations on the regional level were in closer contact with GP's than the NPCF on the national level. It is more likely on the regional level patient associations and member organisations could be influenced by the GP's. This would threaten the position of the NPCF towards health actors since they approved the law and already functioned as a representative of their member organisations during the policy-making process.

When health policy regards health insurance, most of health actors focus attention towards health insurers and the MOH. Therefore, it not a surprise the NPCF conceived the umbrella organisation of health insurers (ZN) and the MOH as most dominant actors during the policy-making process. Evidence does not give any substance to support this notion since the NPCF has proven capable to stress their issues towards the MOH, health insurers (ZN), physicians (KNMG) and vice versa. The NPCF approached and maintained contact with health actors and hereby influenced the policy-making of the ZvW law.

Ultimately, health actors were content with their achievements. The negotiated agreements and interactions produced the ZvW law, as it was implemented. When health policy actors were questioned to rate the extent of influence by the patient umbrella organisation (NPCF) during the policy-making process of the ZvW law, the average number mounted up to 7.

When the NPCF itself had to rate their extent of influence, they were modest and rated a 6.5. The modest rating might be a result of the new role of the NPCF and their first introduction with health politics during a major reform. In addition, the modest rating can be influenced by NPCF's conviction of being a rather young actor compared to the establishment (ZN, KNMG and MOH).

## **7.5.2** Israel

Contrary to the Dutch case patient associations in Israel did not attain the insider status. They were not legitimate actors and not in close contact with the government. Besides, patient associations did not maintain relations with other health actors, during the policy-making process. Causal factors were: patient associations abstained from difficulties, they lacked political awareness, the structure of the four sickness funds, the presence of a civic movement and the presence of patient and consumer representatives.

Patient representatives participated during the NHI law policy-making process on behalf of Israeli patients and consumers. They were seated in Knesset committee meetings together with other relevant health actors as: directorships of sickness funds and health care providers, members of the Knesset and the MOH<sup>32</sup>. However, individual patients (in some cases relatives) were present in these Knesset meetings based on the strong advocation of a patient representative. Patients otherwise, would be total invisible during the policy-making process. Perhaps on their own, patient associations in Israel failed to attain insider status by lack of bargaining power or they had too much critique on the government, as Deth and Newton (2005) argue. Discontentment with government policy may increase the critique on government's performance on the health field. Moreover, an explanatory factor for the outsider status is the pluralistic political and governmental structure of the country. In the pluralist setting the plurality of all interests can easily drive the smallest party i.e. the patient out.

\_

<sup>&</sup>lt;sup>32</sup> These Knesset Committee meetings took place during the years 1992 and 1994. However, this Committee might be the permanent Health Committee of the Knesset, which is referred to in literature findings. The Health Committee is formally charged with the leading role on health issues (HiT Israel, 2003).

However, some kind of patient participation generated during the policy-making process of the NHI law. Contrary to the patient associations in the Netherlands, patient participation in Israel could be classified at the fourth level of Arnstein's (1969) participation ladder. At this level of consultation, patients are granted the right to be present during the policy-making process on a consultation basis. The following quote reflects on certain contributing factors.

Before 1995 there was nothing in the health system of patients influence! No one considered the patients! The doctors were like second to god! The sickness funds decided themselves what to give and what not to give. We didn't have any influence on the decision making of the sickness fund, because every sickness fund before the law had independent policies. However after the law everything changed. (Chairman – Patient umbrella organisation)

Although individual patients were allowed to attend the Knesset committee meetings, this position does not guarantee capabilities to influence the policy-making process. Evidently, Arnstein (1969) appropriately argues that sitting at policy tables is not enough for citizens. Nonetheless, the following quote reflects on the rather unique method utilized by patient representatives.

In Israel I think it's the most interesting way, no other country in the world, I have checked it. No other! During the time of the law making, fifty-three meeting were held with the patients, members of the Knesset, the head of Insurance groups, the head of professional unions and the head of law. (Social worker/Patient representative- the Knesset Non-MP)

To the contrary, it is not very likely the NPCF in the Netherlands will allow individual patients to be present at policy-tables. Apparently, in order to maintain credibility and a degree of professionalization. To present individual patient experiences during formal meetings would be exceptional in the Dutch setting of health policy-making. Data reveals Dutch health actors favor empirical findings that also include patient experiences. However, the substance of the findings is of greater importance. Therefore, in most cases experiences of Dutch patients are combined by the NPCF and presented as a whole to relevant health actors. The Israeli institutions however, did not provide patient associations of such mechanisms. In Israel institutions enabled individual patients to directly submit their personal problems before health actors. In return individual patients in this political setting could be exposed to the straightforwardness and high policy jargon of health actors. Patient could become intimidated by the structure and interaction of actors during these meetings. Patients did not participate on a realistic basis, but were merely present to share their story. The following quote resembles the course of action.

In one of them (the meetings: db) there was a little boy of twelve or something like that, with brain injury after birth. We gave him some empowerment to understand and we told him, say what you feel! Say what you need! I must tell you, I 'm very sorry there were no pictures of this meeting. The members of the Knesset were clearly affected by the boy's performance. (Social worker/Patient representative- the Knesset Non-MP)

As newcomers in health politics, patients conceived provision of experience-based information the basic tactic to influence policy-making. To what extent this tactic remains appropriate further down the participation process (i.e. when the rules of the game are clear), depends on the aims and goals of patient associations. Evidently, if patient association's goals shifted so would their action resources. The choice to mobilize might create more action resources and in some cases more influence. Respondents had their own opinions about factors that contributed to the absence of a patient umbrella organisation in Israel. The next quote reflects on how the latter.

I can tell you that X was the president of the XXX associations for 16 years. In the previous 5 years before the law, X didn't once address the sickness fund or the Ministry for any problem. Because, we (the patient association: db) didn't think they would help us. That does not mean that there were no problems, there were problems. But we tried to solve them as a patient organisation. We did not even have any connections with other patient organisations. (Chairman – Patient umbrella organisation)

This quotation reflects on the aspect of distrust in the government as Deth and Newton (2005) discussed as a factor which prevent the insider status.

As proven, patient associations effectiveness was limited during policy-making. What has proven beneficial is when they aligned with coalitions. The latter often occurs in the Israeli pluralistic environment and might be practiced by patients associations, during the policy-making process, to build up pressure to defend their interests. As mentioned earlier it is plausible that patient associations formed some alignment with civic groups. However factual data of the latter is hard to retrieve. During the NHI policy-making process another important coalition was established between patient associations and patient representatives. This coalition produced a change among relations in the health field and with that channels for influence since the patient representative indicated patient associations of their right to participate during policy-making.

In addition, health actors during the policy-making process were confronted with patients 'voice' through the media. Between patients and the media a strong relationship developed since after every Knesset meeting a health journalist interviewed the individual patient or his

relatives (Social worker/patient representative, 2007). As Hays (2006) argues, the right of free speech when exercised constructs political transparency and patient associations can express their opinions.

Yet literature findings reveal some patients associations were capable to constitute some kind of action to place their points on the political agenda. According to Chinitz & Israeli (1997), certain patient associations pressured government during the policy-making process, to add high costly services in the benefit package. However, by which actions this was achieved remains unclear. Interesting questions remains whether patient associations achieved this outcome on their own or in joined actions with other health actors? Nonetheless, this reflects on the self-interest oriented behaviour of patient associations. Presumably when the number of patient associations which pressure government increases, it would induce competition amid patient groups themselves.

At this moment a closer look into the strategies of patient associations is required to determine the actions taken to influence the policy-making process. According to Binderkratz (2005), outsider groups apply indirect strategies. For example, media or mobilization strategies. The above described tactics support this notion. Patients associations were in a way free and not bound by the rules of the political game since they were not active, contrary to the Dutch case and to impose sanctions seems pointless. For instance, in general children are not part in politics. Yet a twelve year old boy was allowed at a policy table. As proven, with some help patients were able to modify game rules. However, once patient associations would participate they were considered to follow the rules of the game. Remarkably, demonstrations were not part of patient association's strategy in Israel. Effective demonstrations require to be convincing and represent the convictions of a substantial amount of patients. These conditions were absent during the policy-making process.

The following graph (graph 7.2) categorizes the applied strategies of patients and their associations during the NHI law policy-making process.

Direct strategies during the policy-making process of	Indirect strategies during the policy-making process of
NHI law:	NHI law:
Critically read law proposals	<ul> <li>Information dispersion to members and other health actors</li> </ul>
<ul> <li>Lobby actions: contact members of parliament and professional advisors</li> </ul>	Cooperation with the media (health journalists)
<ul> <li>Attend 53 Knesset Committee meetings</li> </ul>	
<ul> <li>Coalitions with patient representatives of Knesset</li> <li>Committees and civic groups</li> </ul>	

Graph 7.2. Strategies applied by individual patients, patient associations and patient representatives to exert influence and enlarge their role during the NHI policy-making process.

Patients associations in Israel were convinced that the participation of individual patients enhanced their visibility during the policy-making process. However, like in the Netherlands, patient associations clearly differentiate this conviction from the possibility of always being 'heard' or 'capable' to change policy. The following quote clarifies this conviction.

Let's say we brought them (patients: db) to the meeting, they (Knesset committee members: db) heard from them what they say. But as usual it's not strong enough. (Social worker/Patient representative-the Knesset Non-MP)

During the policy-making process, patient representatives perceived the Ministry of Finance the most dominant actor. Yet according to Geva-may & Maslove (2000) the Histadrut (labor union affiliated with the largest sickness fund-Clalit-) opposed certain aspects of the NHI law. Clearly, the financial aspect of the NHI law and the role of the MOF were very dominant. Within the conflict based arena the interests and preferences of powerless actors were overruled. Stakeholders in Israel, were capable to impose their interests and preferences, as supported by Scharpf's (1997) interaction modes of hierarchical direction. However, Scharpf states that within democracies state powers are reduced due to certain institutions. Also in Israel state powers were reduced by the structure of legislative and executive bodies. However, the strong affiliation of the government, political parties and labor unions with the health field might have distracted the powerless.

When patient representatives were asked to rate the extent of influence of patient associations during the policy-making process of the NHI law, the average number mounted up to 3, but an 8 was scored for the educational process of the patient associations in health politics. Evidence reveals, that during the NHI policy-making process patient associations became more aware of their possibilities to present their interests and preferences towards health actors and to influence health policy-making. The grade 8 resembles this maturation which partially contributed to the establishment of the patient umbrella organisation ZVI in 1995.

#### 8. DISCUSSION

In the previous chapter the acquired data was analysed alongside the theoretical framework. Subsequently, it is in this chapter were the discussions on these findings will take place. Here it is possible to determine if the hypotheses are supported by sufficient evidence. The discussion will be performed on a subdivision of two paragraphs, namely, the evolution and the convergence in role and influence of patient associations in Israel and the Netherlands.

At this moment, it is required to appoint a remark of critique. The obtained data may portray differences which are time specific due to the different timeframe utilized. The health insurance reform in Israel took place in 1995, while in the Netherlands the reform took place in 2006. The typical time period modified the role and influence of patient associations during the health insurance reforms. Therefore, it is fair to indicate that these differences in role and influence might be smaller if the reform in the Netherlands had occurred eleven years earlier or eleven years later in Israel. With an identical timeframe the findings could resemble more similarities than differences. However, in general the implementation of health policy never occurs simultaneously around countries. As a result, scientific research of health politics often employs few cases.

## 8.1 Evolution of patient association's role and influence in health policy-making -The Netherlands and Israel-

In the previous chapter, Scharpf's theory of Actor- centred institutionalism secured the analyzing criteria on which explanations were given. Consequently, after the analysis an interesting feature submerged which are related to a time specific period. As concluded in chapter 7, the patient umbrella organisation (NPCF) in the Netherlands had a role and exerted influence during the policy-making process of the new health insurance law, compared to patient associations in Israel. Yet a limited amount of individual patients were visible at certain policy tables during the policy-making process in Israel.

Interestingly, when the role and influence of the Dutch patient associations during the policy-making process of the ZvW are observed it becomes clear the Dutch patient umbrella organisation (NPCF) had a leading role. The NPCF was initiated by the government and established during the 1990's. As a consequence the maturity of the patient umbrella organisation increased its capabilities for a substantial role and influence during the policy-making process of the ZvW law, fifteen years later. However, when the relative absence in role and influence of patient associations in Israel during the NHI law are observed, it becomes clear that patient associations did not participate during the policy-making process of the NHI law. Yet, short after the implementation of the NHI law several patient associations mobilized and issued the establishment of the patient umbrella organisation (Z.V.I), halfway of the 1990's.

Based on Scharpf's theory (1997), the analysis revealed as hypothesized, that capabilities for a role and influence during policy-making relied upon countries institutions and influential health actors. Yet the theory slightly neglects the influence of the combination of the four factors with a specific time period. The time period of the 1990's proved eminent for specific factors which influenced patient associations participation, from the last part of the 1990's into the first years of the third millennium.

Based on acquired data it is possible to subtract 3 factors which were time specific and subject for further discussion. Namely: institutional factors, historic traditions of the health system and circumstantial factors. With institutional factors are meant countries political systems. With historic traditions of the health system are meant the developed structures and traditions of the public health sector and circumstantial factors mean the specific political circumstances at that time.

## *Institutional factors*:

During the 1990's the governments of Israel and the Netherlands dealt with challenges in the provision of health care and health care expenditures. Governments considered that privatisation of certain aspects in the health system would counteract current and future problems. With the introduction of privatisation governments were able to shift part of the responsibility to the patient and create self responsible patients in health care.

Clearly, within the Dutch corporatist setting of policy-making these developments required attentiveness from government, especially towards patient associations. As a result, the policy-making process of the ZvW law exposed the shift from a paternalistic approach to a

more private sector approach. These developments are remarkable but not a coincidence. Government established this framework to strengthen the position of patient associations as a third party in health decisions and to enhance self-determination. Ultimately to create an efficient health system. The incorporation of patient associations during policy-making contains benefits for countries health system since patient preferences are considered. Yet a recent study reveals this incorporation holds several disadvantages, namely, that patient associations get overburdened (Trappenburg, 2008)<sup>33</sup>. Clearly, government institutions and nation's patients benefit when patient associations perform their primary functions in society (e.g. sufferer contact, information supply and interest representation). Additional functions, for instance influence/participate in policy-making, therefore are believed to be secondary and optional. But patient associations rarely conceive those as such, as the seven functions of interest groups lined up by Peterson (1999) indicate. However, the chance for the NPCF to be directly affected by such disadvantages remains small but on the long run may increase.

Yet two questions remain induced by the Dutch institutional setting. First, if it is possible for the NPCF to stay true to the interests and preferences of members as long as they lean on government financing? Secondly, does the strong position of the NPCF solely rely on government financing? These questions may be answered in future time.

Nonetheless, the pace of the reform strengthened the position of the NPCF and enabled it to develop as a policy actor during the eighteen years of the reform. This incorporation and mobilization of patient associations can be characterized as a top-down approach induced by the government.

The Israeli government during the 1990's equally encountered similar problems in their health care system and equally considered aspects of privatisation as the solution. Although certain aspects of the new health system highly relied on self-responsible patients, the policy-making process does not reflect this. First of all, patient associations in the first part of the 1990's were absent during the policy-making process. Yet political institutions were present to provide channels which allowed participation and influence on policy-making by groups such as, patient associations. The causal factors explaining this absence will be discussed further down this chapter. Secondly, the pluralist setting forced government to mainly emphasize on patient participation after the implementation of the NHI law. The latter was conditioned by mechanisms government introduced by law. For instance, the institution of an ombudsman of

\_

<sup>&</sup>lt;sup>33</sup> The study results of M. Trappenburg (2008) research were published during the time I wrote this discussion. Yet the results were striking and considered relevant. Therefore the choice to briefly refer to this new literature.

the NHI law, two seats for patient representatives in the health council, court procedures and the implementation of the Patients rights law in 1996. These mechanisms reveal government did not choose to exclusively rely on the 'best practice' of health providers and the sickness funds. Still patients could be confronted with the tendency that aspects of the NHI law, which secured these mechanisms, became altered overtime.

It is evident that the political pluralist setting did not restrain patient associations to mobilize and conjoin during the 1990's. Yet, it is hard not to get the impression that government and other health actors regard the establishment of the patient umbrella organisation (Z.V.I/1995) as mere patient initiative. Besides, government mechanisms enacted by the NHI law, might force the patient umbrella organisation (Z.V.I.) a smaller role during policy-making since government can refer to their own mechanisms. Yet data reveals the patient umbrella organisation (Z.V.I) has acquired tactics to use government mechanisms on patients behalf during health decisions. The latter has proven to be an asset since patient associations before the NHI law did not had a role and influence during policy-making.

## Historic traditions of the health system

Patient associations in the Netherlands, especially during the 1990's realized changes were required to strengthen their future position on the health field. The efficiency of health providers and health insurers in health care and health insurance diminished. As a consequence, patient and their associations started to pursue patient choice and self determination in health care. As a counter effect, consumer choice was highly welcomed by government since privatisation on the health insurance market relied on consumer choice. Clearly, patients were strengthened since health care providers and health insurers should become more receptive to patients signals. Since the reform took eighteen years patient associations could let go of their historic position and accustom to their new role in policy-making and the health market.

Equally, patients associations in Israel during the 1990's were confronted with the disadvantages of their health system. Over time the efficiency of health providers and sickness funds in the provision of health care services diminished. But even though patients were content with the introduction of consumer choice on the health insurance market (in 1995), they feared this choice option would not proof sufficient since political affiliated health institutions could have other concerns and priorities than mere patients demands. Contrary to the Dutch top-down approach, several patients associations realized these developments

demanded the establishment of a countervailing power. Preferably, established by patients themselves since general distrust dominated on government's performance.

Even though the Israeli pluralist setting of old incorporates the establishment of civic groups, this did not apply for a collective actor of patient associations. The capability of voluntary organisations to mobilize in such an environment indicated that individual patient associations were capable to place their differences aside, pursuit self-determination in health care and did not longer desired to be left out of health policy decisions. Clearly, the mobilisation of patient associations in the Israeli case resembles a bottom-up approach.

## Circumstantial factors

Patient associations in the Netherlands during the 1990's and the first years of the third millennium were confronted with a political landscape which favoured liberal aspects in government policy. Politicians mainly focused on aspects of free markets. Clearly, during this period a gap originated between the government and Dutch patients due to perpetual shortcomings in health care. Apparently, government fought for the maintenance of its creditability from Dutch patients. These developments most likely, made individual patient associations highly welcome the establishment of a patient umbrella organisation. The patient umbrella organisation (NPCF) since then has acquired knowledge on the corporatist health policy environment and the rules of the political game. Based on this knowledge it could prepare for a future role during the policy-making process of the health insurance system insurance reform in 2006.

Patient associations in Israel during the 1990's were confronted with relative frequent shifts of governments and political power struggles. Due to challenges government mainly focused on peace policies, national security and pressures from powerful groups in society. Besides, due to these developments countries economy was challenged. Clearly, patients focused on politicians to bring change, stability and security.

However, it is here were patients might have felt abandoned by the government and a gap originated. Citizens were dissatisfied with government effectiveness in general and the fact that patient associations lacked knowledge and influence on health policy-making increased these sentiments. It is not a surprise the NHI law of 1995 was welcomed by patient associations but that scepticism remained. The mobilization of several individual patient associations into the patient umbrella organisation (Z.V.I) may underline the latter. Since 1995 Z.V.I acquired knowledge on the rules of the political game and participates in the

pluralist health policy environment of Israel. Of great interests remains what role and influence Z.V.I would have had, when established before the policy-making process of the NHI law.

# 8.2 Convergence of role and influence by patient associations during health policy-making

Evidence reveals that across countries health systems and health policies converge, due to developments as, globalization and population aging. As a consequence, the role of patient associations during policy-making equally converges, due to similar challenges and difficulties within countries.

This study provides evidence for this line of reasoning since the following features in both countries i.e. Israel and the Netherlands are affirmed: the mobilization of patient associations into a patient umbrella organisation, the realization for political participation, the realization to secure patient positions by law, the realization to work with a strategic action plan and the move from an emancipation approach to a lobbyist approach. These features modify the potential role patient associations have during policy-making. On their turn these features contribute to an increase of influence during policy-making.

To elaborate on the above requires including Scharpf's statement (2000) that government's institutions shape the behaviour of actors during policy-making.

As proven, the NPCF acquired an insider status during the corporatists policy-making process of the ZvW law. They were legitimized actors and in close contact with government and health actors during the policy-making process of the ZvW law. As a consequence, the NPCF predominantly applied direct strategies and several indirect ones to influence the policy-making process. The NPCF shuns away from demonstrations and the action to allow individual patients at policy tables which are considered indirect strategies to influence the policy-making process. Possibly they assume these types of actions impose uncertainty of their position during policy-making. Although on the national level negotiations are the basis for policy-making the NPCF has to discover the act to practice confrontational actions, as established parties (labor unions) already have.

Since subject and aims during policy-making differentiate between patient associations, the application of tactics and strategies as proven, are influenced. Yet, I am fully aware the

chosen tactics and strategies are carefully weighed by individual patient associations and the patient umbrella organisation –NPCF- based on their subjects and aims.

Patient associations in Israel had an outsider status and were not officially part of the pluralistic policy-making process of the NHI law. Unlike the Dutch case, patient associations in Israel experienced no predefined route to interact with the MOH and other health actors. Until a certain extent patient associations were free to choose their tactics and strategies in order to exert influence. Yet, individual patients lacked two important capabilities. They lacked political awareness on the rules of the game and knowledge about methods to exert influence.

At present time however, the behaviour of the Israeli patient umbrella organisation Z.V.I, resembles characteristics of the insider status. Z.V.I is present at certain policy-tables and equally applies direct tactics as well as indirect ones to influence policy-making. At this point, health actors and government in this pluralist setting are required to allow patient's voice, in order to listen to their interests and preferences. Remarkably, Z.V.I also shuns away from demonstrations and individual patients are not longer present at policy-tables. These are considered indirect strategies to influence the policy-making process. The latter resembles Z.V.I develops more into a professional policy actor.

Evidently, both direct and indirect strategies entail advantages and disadvantages which patient associations carefully weigh during policy-making. As patient associations consider indirect strategies they carefully take the disadvantages into account. For instance, the loss of credibility at respect of health actors and the loss of professionalization. Yet evidence reveals powerful health actors in Israel and the Netherlands apply and threaten with several indirect strategies contrary to patient associations. An explanatory factor is that most of these health actors perform public functions. And government for instance wants to avert strike actions by health providers since such actions affect the public and the health care system. However, a demonstration of patients does not directly impose pressure on the public health system. Clearly, patient associations are aware of their capabilities, position and the effects as they opt for direct or indirect strategies during policy-making.

#### 9. CONCLUSIONS

## 9.1 Introduction

The final stage of the study has arrived. In this chapter the central question will be answered.

The gathered data – from the empirical and literature research- will be used to provide an answer. In addition conclusions will be derived to which recommendations will be given.

In this study the main subject of research has been the role and extent of influence of patient associations during the Health Insurance Reform. The central question of the thesis is:

"What has been the role and extent of influence of patient associations in the countries of Israel and the Netherlands during the National Health Insurance System reform, and how can patient associations effectively enlarge their role and influence in health policy-making?"

The central question was divided into several sub questions, which all have been discussed in the previous chapters (see 2.3). Subsequently, the conclusions derived and the recommendations given, will answer the second part of the research question.

## 9.2 Conclusion

Patient associations, residing in pluralist Israel and corporatist Netherlands, were subject of this study. To investigate their role and influence during the policy-making process of the health insurance system reforms, Scharpf's theory on actors and institutions was utilized. The application of this theory revealed a major contrast in role and influence of patient associations during policy-making.

It is fundamental for patient associations to be aware that their voice needs to be taken into account, when national health policy is formed. After all it is a fundamental right, and patients input may stimulate health actors and policymakers to consider other options. Besides, all this may contribute to a more efficient health system. Therefore, patient associations should constructively participate during policy-making.

Once patient associations participate, they need to determine their role. This role is based on their aims, goals and objectives which are related to institutional, social, cultural and

economic conditions of the individual country. Furthermore, a role during the policy-making process for patient associations may entail: entire or partial dedication to influence policy-making. For the ones with larger roles, influence may even entail: to enact legislation, to initiate legislation, to affect certain provision of the legislation and/or to block legislation.

Patient associations in the Netherlands, especially the Dutch Patient and Consumer Federation (NPCF), had an important role during the policy-making process of the ZvW law. This position was granted by government policy during the 1990's and was essential within the Dutch corporatist setting. They successfully provided inputs and placed issues on the agenda, which in some cases forced the MOH (Ministry of Health) to alter legislation. Moreover, the current position of the NPCF resembles a salient stakeholder position. Evidently, the NPCF can be added to Schut's et al. (2005) list of health actors on which government depends for the implementation of health reforms. For these reasons, the participation of the NPCF during the ZvW law-making resembles the sixth level of Arnstein's ladder of participation i.e. partnership.

Evidently however, the patient umbrella organisation underestimated its own action repertoire of influence on the policy-making process. It regarded itself as a young political actor and considered the interests and powers of other health actors more often. As a result this might have contributed to their swift acceptance of the ZvW law. Possibly the NPCF had to discover the less attractive strategies applied in a corporatist setting. For instance: strike actions, stay away from the negotiation table and the stirring up of members (patients/insureds) for opposition. All these actions incorporate two uncertainties: 1.) Will their impact reach beyond the aims set? 2.) What are the chances to be permitted to return at the negotiation table? Clearly, patient associations but predominantly the NPCF, considered the trade-offs. Currently however, the assumptions of the NPCF may differentiate due to their acquired strong position which involves significant veto power.

Patient associations in Israel were absent during the policy-making process of the NHI law. Individual patients however, occasionally provided government of experienced based information. The self-orientation of patient associations resembles the specific time period, shaped by the Israeli society and governmental institutions of the 1990's. The position of patient associations resembled the outsider status. Because as an insider, patient associations would have gained more than only presenting personal stories and preferences towards health actors. Besides, patient associations would try to influence the policy-making process and

actively influence channels through dialogues and negotiations during the course of health policy-making. Several factors explained the absence of patient participation. Interesting was the establishment of the sickness funds but also the pluralist society which constrained patient associations to join into a collective. Therefore, according to Arnstein's ladder of participation patient associations in Israel resembled the fourth level i.e. consultation, during the NHI policy-making process.

Patient associations, whether with a significant or less significant role during policy-making, remarkably have disposition over several identical strategies in order to influence the policy-making process, even when advocated points differ across countries. The democratic foundations of countries are an explanatory factor. Based on these foundations, patient associations can choose for a mix of indirect and direct strategies to influence the policy-making process.

Yet the methods of application may differ between associations and evidently between countries. These differences in application of strategies, as mentioned previously, are influenced by the aims, goals, the power and the structures of patient associations. It is evident however, that patient associations across countries can learn from each others strategies, since learning is considered to be role independent. For instance, patient associations can learn: to publish their viewpoints in the media (consider the NPCF's ten points-plan), how to decide whether the individual or patient umbrella organisation will be active or to boycott negotiations at crucial moments with the ability to return. Important is how do you 'play the game' as patient associations and are you capable to surprise your counterparts.

Furthermore, any relation between political and governmental institutions and the strategies of patient associations are important. The two institutions *influenced* the strategies applied by patient associations in both countries, but in no way *determined* them. In the corporatist environment of the Netherlands the NPCF found external ways, such as ludic actions, to influence the policy-making process of the ZvW law alongside their privileged access. The pluralist environment of Israel ultimately granted individual patients access at a formal meeting, where patients could attempt to persuade health actors and policymakers. Although government was independent of patient association's participation during the policy-making process, patients acquired knowledge about health policy-making in general and on the possibilities to influence this process. This stimulated Israeli patient associations, to become political reactive after the policy-making process of the NHI law.

Clearly, countries institutions impose significant differences in the way patient associations in the Netherlands and Israel behave during health policy-making. In a pluralist Israel, patient associations are in dialogue to solely bargain for their interests without considering others. These 'others' occasionally are fellow patient associations. Consequently, this behaviour may induce competitiveness between patient associations during health policy-making, and create hazards for the patient umbrella organisation's unity. Patient associations in corporatist Netherlands on the other hand, have to consider the publics interest and their long term relations in the health policy arena. These issues may hamper the patient umbrella to radically defend patient interests or may threaten the established consensus between member organisations of the patient umbrella organisation.

Subsequently, since different stages of the policy-making process can be influenced, the exerted influence by patient associations might be effective but not recognized as such. The latter as a result of certain stages being more transparent than another. For instance, the NPCF has been capable to influence the agenda setting, and certain patient associations in Israel presumedly influenced the policy deliberation period. The latter however, is less transparent. Therefore, trying to describe the extent of influence on the policy-making process by means of quantification can be an ambiguous matter.

#### 9.3 Recommendations

Following the main conclusions, the second part of the central question is addressed i.e. "How can patient associations effectively enlarge their role and influence in health policy-making?" The provided recommendations will form an answer to this question.

## Role enhancement

To increase the role of patient associations, the establishment of strategic leadership within relatively professional patient associations is to recommend. This can be achieved on the national level i.e. by a patient umbrella organisation, but is also in reach for individual patient associations. Certain patient associations may function as a vanguard in positioning their role during health decisions. As a start on the local level, towards health insurers and providers and gradually work up to the national level. Nonetheless, in order to increase patient's power and enhance their countervailing power during health decisions, patient associations need to have a solid work plan to anticipate on relevant health issues at governmental level.

However, this all is not without risks. In order to increase professionalism patient associations need to realize it may result in adapting their goals and aims, or that the cohesion of the patient umbrella organisation becomes challenged. In the Israeli context it requires from member organisations to agree and constructively participate on the new course the patient umbrella organisation takes. For instance, decide to employ staff or acquire financial resources as a collective. Patient associations however, might want to stay relatively independent from the patient umbrella organisation but intensify relations to increase benefits during policy-making. The latter partially induced by the pluralist society. Yet since patient associations will intensify on subjects of interests but withdraw when subjects prove less important, the patient umbrella organisation its size and bargaining power are constantly affected which affects their influence on policy-making.

Moreover, in the Netherlands the consequence of high professionalization of the patient umbrella organisation can affect the relationships with member organisations as it considers individual issues on patient level a matter for individual member organisations. Besides, with the professionalization member organisations their identity and diversity becomes challenged since the pressure for consensus is prominent and a reciprocal factor. These issues create an actual tension between patient associations and umbrella organisations.

## **Influence enhancement**

To increase the extent of influence by patient associations on policy-making, it is recommendable that it is necessary to make use of all formal channels of influence at their disposal. However, the formal channels in a corporatist and pluralist environment differ. Patient associations in Israel present at policy-tables should realize that the outcome, partially based on their participation solely provides government of an advice. The outcome of policy-tables becomes more influenced when patient associations form coalitions with other health actors and together influence the policy-making process. The true build up for pressure is by the informal channels: for example, lobby actions by targeting parliament members and coalitions.

In the Netherlands it requires patient associations present at numerous policy-tables, to stay alert and bold. This might imply to opt for more confrontational strategies during policy-making. Yet to maintain the position of a negotiation partner, but prevent to be overruled in order to maintain this position. However, the informal channels do not need to be underestimated. The way of lobbying often conceals its dimensions. The strategy at forehand requires to be clear and defined (part of the work plan) and based on the predetermined goals

and aims. Thus patient associations must realize to apply certain actions when possible and necessary which are not part of the rules. Consider: strike actions, demonstrations or exposure of personal stories. Caution is required; the latter attempts to exert influence, but requires not to damage the formal role of patient associations.

## **Policy-makers and patient associations**

For Policy-makers it is recommended to closely engage with patient associations since patients are affected by government health policies. In both countries some kind of relationship exists between the MOH and patient associations. Nonetheless, policy-makers should consider if the political system creates sufficient room for patient associations to have a role during policy-making. Especially since market oriented health systems with health insurers or sickness funds and health providers requires a third party i.e. representatives of patients. By this the health insurance market system becomes strengthened.

From governments it requires courage to permit entry of one more opposition party which at certain moments can impose a serious threat due to veto powers. Yet patient associations sometimes may prove an interesting coalition partner for governments during health policy-making. Patient participation after all, is on the global and regional agenda. Evidently, government systems provide different and challenging latitudes for patient associations to partake in health decisions. This became exemplified in Dutch corporatism and Israeli pluralism.

#### REVIEW

## Tips for fellow health policy researchers

In retrospect of my research I can conclude several aspects which may prove an asset to fellow researchers.

It is required to formulate solid hypotheses upfront to the research. With that it is more feasible to form explanations about relations of intermediary variables which will submerge. Hereby also the validity of your research increases.

When performing health policy research of multiple countries, it is to recommend to work with researchers which possess country specific knowledge. With that, researchers can complement each other and is it more feasible to perform a thorough in-depth research. Health policy research of multiple countries, as I have experienced, is very time consuming when there is the desire to perform a high scientific policy research.

When as a researcher you decide to include 'document analysis' as one of your data collection methods, it is to recommend to also examine the process of the construction of these documents. There may be cases were documents were constructed with the aim to influence public opinion rather than to objectively inform the public. To unraffle these issues is necessary when you decide to employ these as data facts during the research.

## Recommended practices for possible follow-up study

In order not to neglect the role and influence of individual patient associations in the Netherlands during health policy-making, it is to recommend to perform a follow-up which monitors these factors for this specific group. Certain factor is that individual patients are less professionalized, possess less vast financial resources and have other primary functions than the patient umbrella organisation (the NPCF). Clearly these matters affect individual patient association's role and influence in health policy-making.

Furthermore, based on the preceding recommendation it is to recommend to perform a follow-up study on the relationship between individual/ regional patient associations and health insurers/ sickness funds in the Netherlands and Israel. Evident factor is that individual patient associations relatively well can express their interests and preferences towards health providers and the Ministry of Health. However, my research could not conclusively support this fact for the entity of health insurers / sickness funds. Main questions are if individual patient associations are capable to sufficiently express their interests and preferences toward this rather significant health policy actor or how this may be improved?

## **REFERENCES**

Adiv, A. 2002. 'Israel's economy in trouble: The wrong horses'. *Challenge*. 71. [Internet] [Access date on 1 May 2006] Accessible at www.challenge-mag.com/71/economy.html

Arnstein, S.R. 1969. 'A ladder of citizen participation'. *American Institute of Physics Journal* 35 (4):216-224.

Bauer, M.W., Gaskell, G. 2000. *Qualitative researching*. London: Sage Publications.

Becker, U. 1990. Maatschappij, Macht, Nederlandse Politiek: Inleiding in de politieke wetenschap. Amsterdam: Het Spinhuis.

Bennekom I. van. 2004. 'Federatienieuws'. Medisch contact. 59 (45):1803.

Binderkratz, A. 2005. 'Interest group strategies: Navigating between privileged access and strategies of pressure'. *Political studies association*. (53):694-715.

Blaauwbroek, H. 1996. 'Patiëntenorganisaties en patiëntenrechten in de Nederlandse gezondheidszorg'. [Internet] [Access date 1 July 2006]. Accessible at <a href="https://www.bbvz.nl/vraagsturing/pdf/patientenorganisaties\_en\_patientenrechten\_in.pdf">www.bbvz.nl/vraagsturing/pdf/patientenorganisaties\_en\_patientenrechten\_in.pdf</a>

Buse, K., Mays, N and Walt G. 2005. *Making health policy*. Open University Press.

Bowling, A. 2002. Research methods in health: Investigating health and health services. Open University Press.

Chernichovsky, D. 1995. 'Health system reforms in industrialized democracies: an emerging paradigm'. *The Milbank Quarterly*. 73 (3):1-25.

Chernichovsky, D. 2002. 'Pluralism, public choice, and the state in the emerging paradigm in health systems'. *The Milbank Quarterly*. 80 (1):5-38.

Chinitz, D. 1994. 'Reforming the Israeli health care market'. *Social science medicine*. 39 (10):1447-1457.

Chinitz, D., Israeli, A. 1997. 'Health reform and rationing in Israel'. *Health affairs*.

Chinitz, D. 2000. 'Regulated competition and citizen participation: lessons from Israel'. *Health Expectations*. (3):90-96.

Delsen, L. 2000. Exit poldermodel?: Sociaal- economische ontwikkelingen in Nederland. Assen. Van Gorcum.

Deth van, J., Newton, K. 2005. Foundations of comparative politics. Cambridge University Press.

Douven, R., Westerhout, E. 2000. Reimbursement systems in Dutch sickness funds. CPB report. (3):51-55.

Duyvendak, J.W., Nederland, T. 2006. 'Patiënten in de politieke arena'. *Sociologie*. (2):178-187.

Exter den, A., Hermans, H., Dosljak, M. 2004. *Health Care Systems in Transition: the Netherlands*. Copenhagen. WHO Regional Office for Europe on behalf of the European Observatory on Health Systems and Policies.

Frijhoff, W. Th. M. 2007. Cultuur en indentiteit (Nieuw Nederland: Cultuur onder vuur). Den Haag. NWO.

Geva-May, I., Maslove, A. 2000. 'What prompts health care policy change? On political power contests and reform of health care systems (The case of Canada and Israel)'. *Journal of Health Politics, Policy and Law.* 25 (4):717-741.

Gress, S., Okma, K., Hessel, F. 2001. *Managed competition in health care in the Netherlands and Germany: Theoretical foundation, empirical findings and policy conclusions*. Discussion paper. Lehrstuhl für Allgemeine betriebswirtschaftslehre und gesundheitsmanagement. Ernst-Moritz-Arndt Universität Greifswald.

Gross, R., Rosen B., Chinitz D. 1998. 'Evaluating the Israeli health care reform: strategy, challenges and lessons'. *Health Policy*. (45): 99–117.

Gross, R., Harrison M. 2001. Implementing managed competition in Israel. Journal of Social Science & Medicine. (52): 1219-1231.

Hays, A.R. 2006. 'The Role of Interest Groups'. *Democracy Papers*. US department of State's Bureau of International Information Programmes. [Internet] [Access date on 1 July 2006] Accessible at <a href="http://usinfo.state.gov/products/pubs/democracy/dmpaper9.htm">http://usinfo.state.gov/products/pubs/democracy/dmpaper9.htm</a>

Hendriks, C. 2003. *Dutch Consensualism 1970-2003*: On how the Dutch play their game. Smallcons Workpackage1. Amsterdam.

Hirschman, A. O. 1992. *Rival views of market society and other recent essays*. Harvard University Press Cambridge. Massachusetts.

Hogenboom, R., Vliet van, M. 2000. *Uitgepolderd? Over het welvaartscheppende vermogen van Nederland anno 2000*. Research Memorandum. Ministerie van Economische Zaken. (2). Den Haag.

Hollander de, A., E., M., Hoeymans, N., Melse, J., M., et al. 2006. *Zorg voor gezondheid: Volksgezondheid Toekomst Verkenning*. Bilthoven: RIVM. Howlett, M., Ramesh, M. 2003. *Studying public policy*. Canada: Oxford University Press.

Hunold, C. 2001. 'Corporatism, Pluralism and Democracy: Toward a deliberative theory of bureaucratic accountability'. *Governance: An International Journal of Policy and Administration*. 2 (14):151-167.

Huntington, S., P. 1968. Political order in changing societies. Citation. [Internet] [Acces date on 1 July 2006] Accessible at <a href="https://www.-personal.umych.edu~gmarkus/berman.html">www.-personal.umych.edu~gmarkus/berman.html</a>

Iedema, R., Wiebinga, P. 2004. *Profiel van de Nederlandse overheid*. Bussem: Uitgeverij Coutinho.

Israel, S. 2006. 'On Israeli culture'. *Department of Jewish Zionist Education*. [Internet] [Access date on 1 July 2006] Accessible at www.jafi.org.il/education/culture/onisrael

Israeli, A., Ashkenazi, Y., Chinitz, D. 1998. 'Israel a health system in transition'. *Physician Executive*.

Jacobs, K. 2006. 'Understanding culture Part 1'. [Internet] [Access date on 1 July 2006] Accessible at <a href="https://www.hagshama.org.il/en/resources/view.asp?id=1460">www.hagshama.org.il/en/resources/view.asp?id=1460</a> access date on 1 July 2006.

Jaarverslag KNMG, 2006.

Knaap, T., Bovenberg, L.A., Bettendorf, et al. 2003. *Vergrijzing, aanvullende pensioenen en de Nederlandse economie*. OCFEB in opdracht van het Ministerie van Sociale Zaken en Werkgelegenheid en de Stichting Pensioenwetenschap.

Lieshout van, P. 2000. 'Organisaties laten nog te weinig van zich horen'. Vaktijdschrift voor sociale professionals – Zorg en Welzijn.

Malhotra, Y. 2000. 'Knowledge asset in the global economy: Assessment of national intellectual capital'. *Journal of Global Information Management*. 8 (3):1-15.

Maso, I., Smaling A. 1998. Kwalitatief onderzoek: praktijk en theorie. Amsterdam: Uitgeverij Boom.

Metz Chapin, H. 1990. A country study: Israel. The library of Congress. Washington D.C./U.S.G.P.O.

Ministry of Health, Welfare and Sport. 2004. The new health insurance system in brief.

Nederland, T., Duyvendak, J., Brugman, M. 2003. *Belangenbehartiging door de patiënten- en cliëntenbeweging*. Verwey-Jonker Instituut.

Nederland, T. 2004. Patiëntenorganisaties zijn soms te braaf. Staatscourant. nr. 140.

Nederlandse Patiënten en Consumenten Federatie. 2005. Tussenbalans: naar een gezond stelsel.

Nederlandse Patiënten en Consumenten Federatie. 2005. Jaarverslag.

Neuberger, B. 1990. 'Does Israel have a Liberal-Democratic tradition?'. *Jewish political studies review*. nr. <sup>3</sup>/<sub>4</sub>.

Rosen, B., Thompson, S., Mossialos, E., et al. 2003. *Health Care Systems in Transition: Israel*. Copenhagen: European Observatory on Health Care Systems. 5 (1).

Rowe, R., Shepherd, M. 2002. 'Public participation in the new NHS: No closer to citizen control?'. *Blackwell Publishers*.

Scharpf, F.W. 1997. Games real actors play: Actor- centered institutionalism in policy research. The United States: Westview Press.

Scharpf, F.W. 2000. *Institutions in comparative policy research*. Max Planck institute for the study of societies. Cologne.

Sper, D. 2004. *The future of Israel*. Library of Congress. Printed in the United States.

Swirski, B., Kanaaneh, H., Avgar A. 1998. 'Health care in Israel'. *The Israel Equality Monitor*. nr.9.

Tabibian, N., Gorter, K. 2005. Allochtonen en de nierpatiëntenvereniging. Verwey-Jonker Instituut.

The Council of Europe. 2000. The development of structures for citizen and patient participation in the decision-making process affecting health care. Council of Europe Publishing.

The Ministry of Health Welfare and Sport. 2004. *The new health insurance system - in brief.* VWS.

Trappenburg, M. 2005. Gezondheidszorg en democratie. Oratiereeks Erasmus MC.

Werczberger, R. 2001. The advancement of the status of women. Israel: Research and information centre. The Knesset.

Winden van, F. 2002. *Interest group behaviour and influence*. Creed, Department of economics. University of Amsterdam.

Yin, R. K. 1994. Case study research: Design and Methods. Thousand Oaks: Sage publications.

Z.V.I. 1995. *Information brochure*.

## Internet resources

Allochtonen steeds belangrijker voor Nederlandse economie. Persbericht. [Internet] [Access date on 1 July 2006] Accessible at <a href="https://www.rabobankgroep.nl">www.rabobankgroep.nl</a>

Centraal Bureau voor de Statistiek, Nederland. [Internet] [Access date on 2 February 2006] Accessible at <a href="https://www.cbs.nl">www.cbs.nl</a>

Integratie allochtonen belangrijk voor economie. [Internet] [Access date on 1 July 2006] Accessible at www.nu.nl

SP: Nieuw zorgstelsel vooral schraal en toegankelijk. Nieuwsbank Interactief Nederlands Persbureau, 2004. [Internet] [Access date on 1 July 2006] Accessible at www.nieuwsbank.nl/inp/2004/04/21/R242.htm

The Central Bureau of Statistics, Israel.
[Internet] [Access date on 2 February 2006] Accessible at
www.http://www1.cbs.gov.il/reader/cw\_usr\_view\_Folder?ID=141

The United Nations. Final report of the Ad Hoc Committee on a comprehensive and Integral and International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities .General Assembly.

[Internet] [Access date on 28 December 2006] Accessible at <a href="https://www.un.org/esa/socdev/enable/rights/ahcfinalrepe.htm">www.un.org/esa/socdev/enable/rights/ahcfinalrepe.htm</a>

Visie op provinciale dynamiek. Rabobank Nederland Kennis en Economisch Onderzoek. [Internet] [Access date on 1 July 2006] Accessible at <a href="https://www.rabobankgroep.nl/asp/default.asp?node\_id=13984&version\_id=1">www.rabobankgroep.nl/asp/default.asp?node\_id=13984&version\_id=1</a>

## **SUPPLEMENTS**

## **Supplement 1 UN Charter Article 4 and 29**

## **Article 4 (3) General obligations**

In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.

## Article 29 (a) Participation in political and public life

State Parties shall guarantee to persons with disabilities political rights and the opportunity to enjoy them on an equal basis with others, and shall undertake to:

Ensure that persons with disabilities can effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives, including the right and opportunity for persons with disabilities to vote and be elected.

## Article 29 (b i/ii)

Promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:

- (i) Participation in non-governmental organisations and associations concerned with public and political life of the country, and in the activities and administration of political parties.
- (ii) Forming and joining organisations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.

## **Supplement 2** Important terms defined

Policy-making	Process through which political actors make, take,
	enforce and evaluate decisions which commit all
	members of a society (EUR/ Politics and Policy of
	Health Reforms, 2006).
Institutions	Are systems of rules that structure the courses of
	action that set of actors may choose. These are not
	only formal rules but also social norms which actors
	respect.
Health policy	Set of interrelated decisions taken by political actors
	about selection of goals and means for achieving them
	in a given situation (EUR/ Politics and Policy of
	Health Reforms, 2006).
Health politics	Process through which political actors make, take and
	enforce decisions which commit all members of a
	society (EUR/ Politics and Policy of Health Reforms,
	2006).
Social context	Pressures external to the health care system i.e. socio-
	economic factors, cultural factors and conjuncture
	factors, shaping the social context (EUR/ Politics and
	Policy of Health Reforms, 2006).
Role	Part played by an actor trying to influence policy-
	making, using different means.
Influence	To effect the development of policy.
Political system	A set of institutions, political organisations, interest
	groups (i.e. political parties, trade unions, lobby
	groups) and the relationships between those
	institutions, political norms and rules that govern their
	functions (i.e. constitution, election and law)

## **Supplement 3** Invitation letter



institute of Health Policy and Management

## **Purpose of the interview**

The interview will be part of the Master Thesis in order to obtain the Masters degree in Health Economics, Policy & Law at the Erasmus University in Rotterdam. My supervisor during this research is Mr. K. Grit, Assistant Professor at the Erasmus University Rotterdam.

## The research question of this Master Thesis

The concrete subject of my Master Thesis focuses on the 2006 Health Insurance Reform in the Netherlands, introducing regulated competition in healthcare and the 1995 Health Insurance Reform in Israel also introducing regulated competition in health care. The unit of interest and analysis is the role of patient associations in both countries during these major health insurance reforms.

The health insurance policy-making context includes strong actors and health actors, such as, the Ministries of Health/Finance, political parties, advisory councils, health providers, and health insurers but also patient representatives can partake. What I would like to examine is how significant the influence of patient representatives has been during the policy-making process of the Health Insurance Reforms in the Netherlands and in Israel. I am very much interested to what extend and in what particular way patient representatives were involved and participating during the policy-making process within these two democracies.

#### The research question is:

"What has been the role and extent of influence of patient representatives in the countries of Israel and the Netherlands during the Health Insurance System reform, and how can they effectively enlarge their role and influence in health policy-making?"

In order to be able to answer this question, interviews with key actors (patient representatives, health insurers and ministry of health officials) will provide substantial information depicting the health insurance policy-making context.

With the obtained information I will be able to draw a comparison and analysis of the participation of patient representatives with regard to health insurance policy-making in these two countries, looking at important and relevant variables (i.e. political/social context, power resources, etc.). This will make it possible to form conclusions about involvement, participation and the power of patient representatives in health insurance policy making in the Netherlands and in Israel. Very interesting will be to determine what patient representatives in both countries can learn from one another, in turn policymakers will also be able to learn.

The interview will take approximately 60 minutes. The obtained data will be processed anonymous and confidential in the Master Thesis. Before having the interviews you will receive an indication of the important questions and the preparations for the interview will not take an amount of time. Your opinion will be asked concerning the situation in the past but also the present and the future guided by a number of topics. If there is no objection the interview will be recorded and if appreciated a copy of the final report will be transmitted.

## **Supplement 4** Topic list- patient associations

## **TOPIC LIST**

## General

## Patient organisations & patient umbrella organisations

- 1. Can you give a description of your organisation?
- 2. Can you explain what are the major goals, tasks and function of your organisation?
- 3. Can you give a description of your view on your relationship towards supporters and connected member organisations?

## **Cooperation bonds?**

- 4. Can you describe your view with respect to the relationship you have with the government, health care providers and health insurers?
- 5. Can you give a short description of your role during health policy-making with regard to other parties?
- 6. Does the government to your opinion undertake steps to enlarge patient associations their role and influence when creating health policy with respect to other parties?

## **Specific** (the reform- the health insurance law)

## The National Health Insurance Law

- 7. Can you explain/give your opinion on what happened resulting in the 1995 NHI law?
- 8. Which objectives the organisation considered of great importance, during the health insurance system reform?
- 9. Which matter or issue, during the health insurance system reform had your concern?

#### Role and influence

- 10. How would you typify your role during the health policy-making process now looking back?
- 11. Was there, to your opinion an intensive interaction from other parties (e.g. employer associations, physician associations) during the policy-making process?
- 12. What kind of activities did you do in order to intensify your influence?

## Tactic and strategy

13. Can you describe what you did in order to be able to reach predetermined goals?

#### **Evaluation**

- 14. Is there anything you have learned with regard to this health policy-making process?
- 15. Now looking back, are there matters/things you would have approached differently, knowing now what you know?

## **Supplement 5** Topic list- Expert health insurance/ reforms



institute of Health Policy and Management

## **TOPIC LIST**

Expert Health Insurance Law (ZvW 2006)

## **Democratic institutions**

1.Can you give a description of the relationship between the health insurers and patient associations during the policy-making process of the National Health Insurance Law? 2.Were patient associations regarded as a valuable party with regard to constructing this new Law? Why yes/no?

## Role and influence

- 3. What role did patient associations had during the policy-process of the National Health Insurance Law?
- 4. Which patient representatives tried to inform health insurers on the interests and preferences of patients with regard to the National Health Insurance Law (e.g. patients, patient umbrella organisations, health field workers, etc.)?

## Health insurance reform- National Health Insurance

- 5. Were health insurers aware of the aims and goals of patient associations?
- 6. Were health insurers aware of the main concerns, patient associations had with regard to the new National Health Insurance Law?

## **Tactics and strategies**

- 7. Did patient associations try to convince health insurers, raise their points on the agenda, during the policy-making process?
- 8. What actions were taken by them to achieve the above mentioned?

## **Satisfaction**

- 9. Were health insurers satisfied with the policy outcome?
- 10. What did health insurers learn about the involvement and participation of patient associations during health policy-making?

## **Supplement 6** Topic list- Ministry of Health Deputy



institute of Health Policy and Management

## **TOPIC LIST**

Health Official (Ministry of Health)

#### **Democratic institutions**

1.Can you give a description of the relationship between the government and patient representatives during the policy-making process of the National Health Insurance Law?

2.Were patient representatives regarded as a valuable party with regard to constructing this new Law? Why yes/no?

#### Role and influence

- 3. What role patient representatives had during the policy-process of the National Health Insurance Law?
- 4. Who were these patient representatives which tried to inform you on the interests and preferences of patients with regard to the National Health Insurance Law (e.g. patients, health field workers, etc.)?
- 5. Did you consider the patient representatives a legitimate actor/party during the policy-making process? Explain further.
- 6. Did you consider the patient representatives having a major/minor influence? Why yes/no?

## Health insurance reform- National Health Insurance

- 7. Were you aware of the aims and goals of patient representatives?
- 8. Were you aware of the main concerns, patient representatives had with regard to the new National Health Insurance Law?

## **Tactics and strategies**

- 9. Did patient representatives tried to convince you, raise their points on the agenda, during the policy-making process?
- 10. What actions were taken by them to achieve the above mentioned?

#### Satisfaction

- 11. Were you as the Ministry of Health satisfied with the policy outcome?
- 12. What did you learn about the involvement and participation of patient representatives during health policy-making?
- 13. Were you satisfied with the role and influence patient representatives had during the policy-making process?

## **Evaluation**

14. Did you have an evaluation afterward with regard to the process of the policy-making, namely, the role of patient representatives therein?