The role of social participation in municipal-level health systems: the case of Palencia, Guatemala

Ana Lorena Ruano
The role of social participation in municipal-level health systems: the case of Palencia, Guatemala

Ana Lorena Ruano
To my grandfather, Lelo
Abstract

Background: Social participation has been recognized as an important public health policy since the declaration of Alma-Ata presented it as one of the pillars of primary health care in 1978. Since then, there have been many adaptations to the original policy recommendations, but participation in health is still seen as a means to make the health system more responsive to local health needs, and as a way to bring the health sector and the community closer together.

Aim: To explore the role that social participation has in a municipal-level health system in Guatemala in order to inform future policies and programs.

Methods: The fieldwork for this study was carried out over eight months and three field visits between early January of 2009 and late March of 2010. During this time, 38 in-depth interviews with provincial and district-level health authorities, municipal authorities, community representatives and community health workers were conducted. Using an overall applied ethnographic approach, the main means of data collection were participant observation, in-depth interviews, group discussions and informal conversations. The data was analyzed in two different rounds. In the first one we used documentary analysis, role-ordered matrices and thematic analysis (see papers I-IV) and in the second round, thematic analysis was utilized.

Results: We found four themes that frame what the role of social participation in the municipality of Palencia is. The first theme presents the historical, political and social context that has contributed to shaping the participation policies and practices in Guatemala as a whole. The second theme takes a deeper look at these policies and how they have been received in the municipality of Palencia. The third theme presents data regarding the three situated practices of participation, each occurring at a different level: municipal, community and the individual level. Finally, the last theme presents reflections on what it means to participate to the people that were involved in this study.

Conclusion: In the process of social participation there are two different and complementary kinds of power that depend on the amount and the kind of resources available at each level of the participation structure. Stakeholders that have higher levels of power to formulate policies will have better access to financial, human and material resources while stakeholders that have higher levels of power to implement policies will have resources like community legitimacy, knowledge of local culture, values and mores, as well as a deep understanding of local social processes. The coordination of financial, human and material resources is just as important as the legitimacy that comes from having community leaders involved in more steps of the process. True collaboration can only be obtained through the promotion and creation of meaningful partnerships between institutional stakeholders and community leaders and other stakeholders that are working at the community level. For this to happen, more structured support for the participation process in the form of clear policies, funding and capacity building is needed.
Original Papers

This thesis is based on the following four papers, referred to as Papers I-IV:


# Table of contents

**The Researcher** ........................................................................................................... 1

**Foreword: The Long Road To Palencia** ................................................................. 3

**Introduction** .................................................................................................................. 5

1.1 Primary health care ........................................................................................................ 5

1.1.1 Selective primary health care .................................................................................... 8

1.1.2 A call-back to Alma-Ata: the return to the original principles of primary health care ........................................................................................................ 9

1.2 Social participation ........................................................................................................ 10

1.2.1 Participation in primary health care ......................................................................... 12

1.2.2 Social participation in Latin America ....................................................................... 12

1.2.3 Social participation in health in Latin America ......................................................... 13

**Study Justification** ....................................................................................................... 15

2.1 Previous and ongoing research approaches to participation .................................. 15

2.2 Study justification ......................................................................................................... 16

**Aims** ................................................................................................................................ 17

3.1 General objective .......................................................................................................... 17

3.2 Specific objectives ......................................................................................................... 17

3.3 Research questions ....................................................................................................... 17

**The Conceptual Framework** ...................................................................................... 18

4.1 The health policy triangle ............................................................................................. 18

4.2 The structure of the thesis ........................................................................................... 19

**Background** .................................................................................................................. 20

5.1 Guatemala .................................................................................................................... 21

5.2 The Guatemalan health system .................................................................................. 22

5.3 The social and historical context of the study ......................................................... 23

5.4 The decentralization process and the legal framework ............................................ 24

5.4.1 Social development council system ....................................................................... 26

**Methods** ......................................................................................................................... 28

6.1 Setting: The municipality of Palencia .......................................................................... 28

6.2 Applied ethnographic approach .................................................................................. 30
The Researcher

I am the oldest of six children, and come from a large family that has always valued curiosity, education, openness and most importantly, having a sense of humor. While I was born in the US, I grew up in Guatemala with parents and grandparents that entertained all my questions about how the world works. Raised as a bilingual child in a family that valued my ‘double identity’, I was always curious about the effect of language and culture on everyday life. This had a profound effect on me, and led me to take up sociology and psychology in college.

I started working as a research assistant in public health research projects when I was still an undergraduate student. Through my work I got to travel to rural areas of Guatemala and get to know my country in a different way: public health channeled my curiosity about the world and gave me a deeper and more grounded understanding of the things that I was reading about in school. These first years as a research assistant gave me the opportunity to ‘learn by doing’ and gave me a chance to get basic hands-on experience in planning and implementing research projects. After finishing college, I started to get more involved in public health research and divided my time between working in research and lecturing at my home university, where I taught undergraduate courses in sociology and social sciences.

The carrying out of this research project has been shaped by the way my family approached learning and by my experiences with conducting fieldwork in other public health projects. Curiosity, openness and a sense of humor allowed me to get to know the people in Palencia and to gather their experiences, and it was my studies and interests in sociology, psychology and public health that helped me to analyze and understand the process of social participation in Palencia.

Image 1: The researcher at the health center in Palencia
On this thesis:

This thesis has been shaped as much by my curiosity as a researcher as by the opportunities and reflections that arose during the process of collecting and analyzing the data. While I have strived to present a comprehensive picture of the process of participation in Palencia with my study, I am aware that it is impossible to cover every aspect of a social process.

The richness of this thesis lies in the qualitative data obtained from eight months of participant observation that focused on situated practices at the municipal, community and individual level. Through the daily and personal interactions with the participants of this study, I was able to present the human perspective of each of these practices while framing them in the overall social, political and historical context of the country. However, I am aware that my own background and interests have shaped the way I presented the data. Because I approached my doctoral project as a means of understanding the experience of social participation in health, this study does not have a health system approach that could have focused on how effective or efficient these practices were. I did not set out to only interview and work only with people that were participating in the health system, but this is the path that the fieldwork took. The voices of other community members could have painted a different picture of Palencia. It is important to state that I chose a municipality that has the same culture and language as my own. I did this because of my own interest in understanding social processes in non-indigenous settings and also because this would make it easier to conduct the fieldwork. Finally, I did not deal with the issue of gender and participation. I am aware that researchers with interests in indigenous populations, or that have a health systems or gender approach might have produced different conclusions than my own. Still, it is my belief that the perspective presented here has something to contribute to the way we approach, study and implement policies on social participation in the health system.
Foreword: The Long Road To Palencia

Today my thesis looks very different than the one I had imagined writing four years ago, when I first started my PhD studies. At the time, I was a research assistant in a research center that focused on democratic governance, equity, and health, and we were about to begin a study on social participation in health in the rural highlands of Guatemala. The project and the opportunity to start my PhD in Umeå seemed to come together perfectly, and so I set out the task of writing my research proposal. Originally I wanted to study five municipalities in two different provinces. The places I had chosen matched those of the project and my thesis would be an analysis and evaluation of that project. However, by mid-2008 and thanks to the economic crisis we lost our funding and the project was put on stand-by. By late 2008 it was clear that the project would not begin any time soon and that if I wanted to do my study it would have to change to something I could afford to do on my own.

Miguel, my main supervisor, suggested that I try contacting a health district that was not so far away from where I lived in Guatemala city to see if I could work there. At the suggestion of my home supervisor, I contacted two health districts: Santa Catarina Pinula and Palencia, both in the province of Guatemala and about a 40 minute drive away. From the start, it was clear that Santa Catarina would not work out. However, Palencia was a different story: after my first phone call I got an appointment to present my proposal and a week later I was set to begin my fieldwork.

Image 2: ‘Welcome to Palencia: a prosperous land blessed by God’, the municipality’s welcoming sign
This change in location, the freedom that came with having no overall project in which to frame my research, and the kind and open people that I met in Palencia all gave me the opportunity to explore participation in health at will. In January of 2009 I had already written the first paper of this thesis and I also had a clear idea of what the second paper should be: a study on the process of participation in the municipal-level health commission. Palencia was new to me, so in order to familiarize myself with this new setting, I started going there every day. If I had not planned to interview anyone or to sit in on a meeting, I would go out to the rural communities with the basic health team. After three months of fieldwork I had what I needed to write one paper and I had ideas on other areas of participation that I thought were worth exploring, and that later became paper 3 and paper 4. This thesis is the result of many factors: I went to Palencia because my original study plan was unfeasible, but I stayed because I found a place that was worth exploring, and stories that needed to be told. This book is a reflection of my curiosity and of the people that were kind enough to let me into their lives with my little tape recorder and a notebook.
Introduction

Social participation has been recognized as an important public health policy since the declaration of Alma-Ata presented it as one of the pillars of primary health care (PHC) in 1978 (WHO/UNICEF, 1978). Since then, there have been many adaptations to the original policy recommendations, but participation in health is still seen as means to make the health system more responsive to local health needs, and as a way to bring the health sector and the community closer together. This first chapter is divided into two sections: the first one shows how the primary health care approach has changed and adapted to the larger political, social and economic context through the years and finishes in the present day. This includes the tenants of the original declaration, the adoption of selective PHC approaches and finally, the return to the original ideals via the World Health Report of 2008 and its 'call-back to Alma-Ata' (WHO, 2008). This provides a frame for the following section, which deals with social participation in health. Here I present the changing definition of participation and two ways of analyzing it: Arnstein's (1969) ladder of citizen participation and the World Bank's (1996) participation continuum. Afterwards, I talk more specifically about participation within PHC in general and in the Latin American context in particular.

1.1 Primary health care

Primary health care is essential care based on practical, scientifically sound, and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost the community and country can afford to maintain at every stage of their development... it forms an integral part of both the country's health system, of which it is the central function and focus, and to the overall social and economic development of the community. It is the first level of contact to individuals, the family and community with the national health system bringing health as close as possible to where people live, work and constitutes the first element of a continuing health care process (WHO/UNICEF, 1978)

During the second half of the 20th century, the political and ideological polarization of the cold war provided the context for the growing social and economic inequalities between different sectors of the world's population. When it came to health, this meant that while developed countries had well-funded health systems with technologically advanced hospitals and infrastructure, developing countries faced their burdens of disease with much more limited financial, technological and human resources (Tejada de Rivero, 2003; Hall & Taylor, 2003). In response to the resource constraints, countries like China, India, Tanzania and Venezuela implemented some form of community-based care
and their experiences were documented and disseminated by the World Health Organization (WHO). In a joint effort with the United Nations Children’s Fund (UNICEF), the WHO used these cases as the basis for a proposal to change the focus of the health system from the hospital to the community and from a biomedical approach to health to one based on social equity (WHO, 2010; WHO, 2008).

The Alma-Ata conference was held in September of 1978 and produced a declaration by the same name that recognized that health was the result of many different factors and that disarmament, wealth redistribution, higher social spending and community involvement would help people to live longer and healthier lives (Lawn et al, 2008; Hall & Taylor, 2003; WHO/UNICEF, 1978). The declaration’s ten points state that health is the product of social determinants that may fall outside of the spectrum of the health sector, that gross health inequalities were the result of social, political and economic policies, and that economic and social development are the foundations of a healthy people (see table 1). Health care should be delivered through the use of the PHC approach, a strategy that would reorganize health systems to make them more responsive to local needs. It was through the use and acceptance of PHC and its components that the goal of ‘Health for All by the year 2000’ was set (Gillam, 2008; WHO/UNICEF, 1978).

Table 1: The ten elements of the Alma-Ata declaration

| I. Health is a state of complete physical, mental and social wellbeing and is a fundamental human right. Attaining the highest possible level of health is a worldwide social goal that requires actions of many sectors. |
| II. The existing gross inequality in people’s health status is unacceptable and is of common concern to all countries and people. |
| III. Economic and social development is essential to attaining health for all, and health is essential to sustained development and world peace. |
| IV. People have the right and the duty to participate in planning and implementing health care. |
| V. A main goal of governments and the international community should be the attainment by all peoples by the year 2000 of a level of health that will permit them to lead a socially and economically productive life. Primary health care is the key to attaining this goal. |
| VI. Primary health care is based on practical, scientifically sound and socially acceptable methods and technology made universally accessible through people’s full participation and at a cost the community and the country can afford. It is the central function of the health system and its first level of contact, bringing health care as close as possible to where people live and work. |
| VII. PHC evolves from a country’s own conditions and addresses the main health problems in the community. It should lead to progressive improvement of health care for all while giving priority to those most in need. |
| VIII. Governments should formulate policies and plans of action to make PHC part of a comprehensive national health system, in coordination with other sectors. This requires political will to mobilize domestic and external resources. |
| IX. The attainment of health in any one country concurs and benefits every other country. All countries should cooperate in the development and operation of PHC throughout the world. |
| X. An acceptable level of health for all people by 2000 can be attained through better use of the world’s resources, much of which are spent on military conflict. |

Source: Author’s elaboration from Tejada de Rivero (2003) and WHO/UNICEF (1978)
At the end of the Alma-Ata conference, 136 countries had signed the declaration in a show of commitment to making PHC the blueprint for their health systems. In addition to the points in the declaration, countries agreed to increase the health budget to 5% of their gross national product, to work with food safety and reduce child malnutrition so that 90% of the country’s children would have a weight for age that corresponds to reference values and to make safe water available either in homes or no more than 15 minutes walking distance away. In regards to maternal and child health, skilled birth attendants should be made available for all women, and children should receive care at least during their first year of life (WHO, 2008; Hall & Taylor, 2003).

The primary health care approach is grounded on a series of principles that act as the basis for all health policies, and according to the Pan American Health Organization (PAHO) (2007) these serve as ‘a bridge between broader social values and the structural and functional elements of the health system’. The first of these is responsiveness: health systems need to be able to respond to people’s health needs, this links with values around the use of an evidence-based approach as well as with the balance between scientific information and with local values and beliefs. Additionally, accountability policies allow for clear responsibilities and roles, and sustainable health systems that work together with other sectors and are better able to carry out long-term commitments. The final principle of PHC is participation because through active partnerships with communities, local values can help shape health policies (PAHO, 2007; WHO/UNICEF, 1978).

The Alma-Ata declaration stated that a primary health care approach included at least the following components: health education/health promotion, proper nutrition and food supply, safe water and basic sanitation policies, maternal and child health (including family planning), immunization, prevention and control of local and endemic diseases, appropriate treatment of common diseases and injuries and the provision of essential drugs (WHO/UNICEF, 1978). In order to be able to implement them, the PHC approach relies on four pillars (WHO, 2010) (see figure 1): the first one is equity defined as the absence of systematic and remediable differences in health across social, demographic or geographical populations or population subgroups (Starfield, 2007). The second pillar is health promotion and prevention, defined as the process through which people exercise increased control over their health (WHO, 1986). The third pillar refers to a multi-sectoral approach to collaborations between health and other sectors (CSDH, 2008). The final pillar is social participation, understood as the involvement of community leaders and members in all the steps of the policy cycle, that is, the means through which decisions are made on the design, implementation and evaluation of policies. By including social participation in decision-making and formulation stages, and continuing with it through the implementation and monitoring and evaluation stage, participation can strengthen the health system and contribute to the sustainability of its policies (WHO, 2011; WHO/UNICEF, 1978).
1.1.1 Selective primary health care

There were social, political and economic factors that contributed to hindering the implementation of primary health care and of the other health system reforms that the Alma-Ata declaration called for. In the years following the declaration, many countries faced civil war and internal strife, and budgetary cutbacks on social spending that came from structural adjustment programs restricted the countries’ health expenditure even more. Elevated levels of corruption and the reticence that many governments felt towards decentralizing decision-making power to the local level also contributed to the demise of PHC before it was even started (Gillam, 2008; Hall & Taylor, 2003).

In this social context, the Alma-Ata declaration’s comprehensive strategy to deal with health problems at the community level came to be seen as too idealistic and expensive for most countries to implement (Hall & Taylor, 2003; Rifkin & Walt, 1986). Critics argued that comprehensive primary health care would not work in countries with high levels of corruption, wars or in non-democratic contexts. A lack of political will and continuing financial policies that favored hospital and not community-based care all contributed to the failure to implement the principles of the Alma-Ata declaration (Lawn et al, 2008; Hall & Taylor, 2003).

A year after the declaration, a paper by Walsh & Warren (1979) proposed a simpler approach to primary health care that would allow countries with limited resources to provide care. In selective primary health care (SPHC) a set of specific and highly cost-effective interventions would be implemented in a top-down approach. This revised PHC approach proved more attractive to donor countries because it was easier to provide support, management and supervision of vertical programs than to the comprehensive strategies originally called for in the Alma-Ata declaration (Lawn et al, 2008; Hall & Taylor,
Selective primary health care originally focused on a small core of interventions known as GOBI (growth monitoring, oral rehydration, breastfeeding and immunization) and later expanded to include family planning, food supplements, female education, eradication of smallpox and guinea worm, vitamin A distribution, iodation of salt and elimination of tetanus (Lawn et al, 2003).

The interventions contained within the SPHC packages were usually delivered through vertical programs run from donor agencies or the central level of the country’s Ministry of Health (MoH). This approach was considered successful because interventions reached coverage levels quickly and the SPHC experience provided many lessons on how consistent leadership at the global and national levels can drive action and obtain health results. However, by focusing more on results than on systemic change and by continuing the use of vertical programs, health policies did not focus on the importance of equity or health promotion and shied away from multisectorality. Social participation in SPHC did not involve any decision-making from communities and most participatory experiences in these programs where meant to offset costs and not to empower local populations, as in the spirit of comprehensive primary health care (de Vos et al, 2009; Lawn et al, 2008).

1.1.2 A call-back to Alma-Ata: the return to the original principles of primary health care

In 2008, the WHO decided to highlight the role that primary health care can play when it comes to strengthening health systems and improving access to care (Gillam, 2008; Hall & Taylor, 2003). Through PHC, health systems can become more responsive and better able to deal with the changing needs of their population. The WHO’s 2008 World Health Report notes that more countries need to start balancing the growing burden of chronic non-contagious diseases that coexists with infectious diseases, malnutrition and challenges in reproductive health. This, plus the high levels of inequity that still exist called for a rethinking of traditional health systems and presented an opportunity for comprehensive primary health care to make a ‘come back’ (Gillam, 2008; WHO, 2008; CSDH 2008).

The return to the principles of the Alma Ata declaration comes with a set of reforms that aim to make primary health care context-specific in order to adapt to each country’s needs (Gillam, 2008). The first set of reforms deals with universal coverage, and aims to make pro-equity and pro-social justice health policies with a goal of reducing the levels of social exclusion in order to move towards universal coverage and social health protection. Service delivery reforms are aimed at improving the way health services respond to local needs in a socially relevant way. Multisectoral approach reforms make the health system more capable of collaboration with other sectors so that countries have comprehensive strategies that deal with the social determinants of health. Finally,
the last set of reforms deal with leadership and citizen participation, and highlight the importance of placing decision-making power in the hands of the people who know and can prioritize their needs and those of their communities (CSDH, 2008; WHO, 2008).

1.2 Social participation

The term ‘participation’ and how we understand and use it has changed since the signing of the Alma-Ata declaration thirty years ago. Over time, terms such as ‘community’, ‘stakeholder’, ‘user/patient’ and ‘citizen’ participation have been used either interchangeably or as a way to specify certain actions expected from stakeholders that belong to one of these groups. However different these terms might seem, the basic idea is the same: participation is the process through which individuals or communities interact with the health system (Flores & Ruano, 2009; Welschhoff, 2006; Rifkin et al, 1988). According to the Alma-Ata declaration of 1978, participation is the process through which individuals and communities are entitled to play a role in the planning and implementation of the policies that affect them and their families’ lives (WHO/UNICEF, 1978). However, there is a wide spectrum of definitions for participation that ranges from people/users passively receiving the benefits of a program or policy to actively engaging the population in decision-making processes about programs, policies and activities (Rifkin, 1990). For this thesis, the use of ‘social participation’ is meant to encompass all the kinds of participation presented here, and it is defined as a social process that is carried out at the local level and focuses on the identification of needs, decision-making and the establishment of mechanisms to meet these needs (Rifkin et al, 1988).

Arnstein’s ladder of citizen participation (1969) organizes the different conceptions and understandings of what participation is based on the role played by the participants in a policy cycle. The first group of steps in the ladder is known as ‘non participation’ and includes ‘manipulation’ and ‘therapy’. In this stage participation is about educating the public about what policies or projects will work for them and includes no feedback, so power is centralized in authorities or planners (Litva et al, 2002; Zakus, 1998). The second group of steps involves token participation. Here, participants receive information and may have the opportunity to provide their opinions through a process of consultation but there is no re-distribution of power, so participants do not have the means to ensure that they will be heard. The highest level of the ladder is called ‘citizen power’. People are empowered by their role as citizens and they use the rights and responsibilities that come with that role. This enables them to shape the policies that affect their lives directly. Citizen participation becomes a group of actions that contributes to creating a relationship of mutual obligation between citizens and their governments and the development of a process based on dialogue and that fosters the creation of agency (Mahmud, 2004; Gaventa, 2003; Morgan, 2001).
International financial organizations like the World Bank and other major funding agencies also took an interest in social participation in the 1980s and 1990s because of the perceived benefit of having ‘participation’ in their projects (World Bank, 1996). Today the World Bank recognizes that there are several stages of participation that can be placed along a continuum that goes from information sharing and consultation through collaboration and finally empowerment. However, previous projects placed more focus on participation in the first stages of the spectrum and emphasis was put on collaborating with local communities to off-set economic costs in the form of volunteer community work (Aycrigg, 1998). The economic argument for the use of social participation policies is that mobilizing all the available resources that a community has can contribute to the success of the program by cutting costs and by neutralizing possible resistance to the implementation of projects (de Vos et al, 2009; Aycrigg, 1998; Rifkin, 1990).

The Alma-Ata declaration, the World Bank’s participation continuum and Arnstein’s ladder highlight the transformative role that participation can have in a society (Aycrigg, 1998; WHO/UNICEF, 1978; Arnstein, 1969). According to the human rights perspective on participation, this can only happen in the framework of a specific set of civil and political rights that make social participation active, free, meaningful and is conducive to empowerment (United Nations, 1986). In this framework, the state plays a central role in ensuring that these rights are upheld through clear mechanisms that guarantee accessible, fair,
transparent, continuous and accountable processes of participation that allow people to be able to determine their own destiny (de Vos et al, 2009; Yamín, 2009). Social participation is the expression of agency and the instrument that leads to self-determination, two key principles also found in primary health care (Yamín, 2009; WHO/UNICEF 1978).

1.2.1 Participation in primary health care

According to the Alma-Ata declaration, community participation is the key to transforming the health system. By basing the organization of health service provision and the health priorities of a country on the needs the population identifies and prioritizes, health systems become more responsive and people centered (Litsios, 2002). In primary health care participation is organized around the concept of community, a term meant to encompass everything from small, isolated rural villages to neighborhoods in sprawling urban centers. By participating, individuals and families assume responsibility for the health and welfare of themselves and their community and through this process they become agents of development instead of passive recipients of aid (WHO/UNICEF, 1978).

The primary health care approach advocates two main channels of participation: the first one is to join community primary health committees and the second is to become a volunteer health worker (WHO/UNICEF, 1978). The committees are places where community leaders and representatives from the health system meet to discuss and set priorities, plan the implementation of policies and evaluate programs. In places where western-trained doctors and nurses were not available, the declaration for primary health care sought to have village health workers trained and integrated into the health care system. In this way the volunteers, later known as community health care workers (CHW), became a central feature of the PHC approach. Participation through community committees and CHW programs are still recognized as key ways to participate and interact with the health system today (Daniels et al, 2005; Hall & Taylor, 2003; WHO/UNICEF, 1978).

1.2.2 Social participation in Latin America

The drastic reforms to the health system that the Alma-Ata declaration called for were hard to implement in most countries around the world, and Latin America was no exception. Historically, the region has been characterized by having economically dependent states, highly stratified societies and high levels of social exclusion (Almeida, 2002). When the Alma-Ata declaration was signed, 14 out of the 18 Latin American countries had dictators as heads of state. By the 1980s, ten countries still did not have democratically elected governments (Flores & Ruano, 2009).

Dictatorships in Latin America during this period were characterized by high levels of political repression and violence that focused on the elimination of any form of participation within the state (Lehoucq, 2008; Rosenberg, 1995). The cold war and the fight against
INTRODUCTION

communism influenced political life in the region and it was in this context that torture, forced disappearances and other forms of politically motivated violence and repression contributed to creating apathetic citizens that shied away from a participatory process that local states saw was subversive and pro-communist (Lehoucq, 2008; Briceño-León, 1998; Rosenberg, 1995).

The economic crisis of the 1980s provided the backdrop for the region’s return to democracy. However, these newly elected democratic governments also struggled. In order to deal with the economic situation, many states implemented structural adjustment programs aimed at stabilizing the public sector through a reduction in the size of the state and by implementing drastic budget cuts mainly aimed at social spending (Stahl, 1994). These policies did not provide the expected relief and economic growth and failed to contain the growing poverty and inequality levels. Today, they are linked to diminishing the success of democracy and they did not contribute to improving social participation levels (Flores & Ruano, 2009; Briceño-León, 1998).

During the 1990s and by the turn of the century, most Latin American countries had improved politically and economically. By this point, many of the countries could boast concurrent democratically elect governments and most of the constitutions in the region recognized health as a human right that should be provided by the state. However, the visions set in these new constitutions were hard to carry out because of the weak states that resulted from the structural adjustment policies, the years of internal war and strife and the economic climate. As a result of this, Latin American states are now smaller and less capable of providing adequate healthcare for their populations (Homedes & Ugalde, 2005; PNUD, 2004; Almeida, 2002).

1.2.3 Social participation in health in Latin America

During the 20th century, Latin American participation policies ranged from ones meant to empower local populations and improve the health system’s coverage levels, to health programs that saw participation in economic or financial terms to policies that wanted to completely exclude all forms of participation (Ruano & Flores, 2009; Homedes & Ugalde, 2005). In the 1950s and 1960s countries like Cuba and Panama had implemented policies to make their health systems more responsive to local needs, and this seemed to be the trend for other countries as well (Vázquez et al, 2002). However, changes in the social context over the 1970s and 1980s, and elevated levels of political violence translated into a return to hospital-centered care and the demise of once progressive participation policies (Flores & Ruano, 2009).

Partly because of the return to democracy that many countries experienced in the 1980s, and partly as a response to structural adjustment programs that called for decentralization and state downsizing policies, social participation became important once again. González Block et al (1997) mention that by the 1990s, eleven out of twenty one health
system reforms in Latin America included a participation component. However, the emphasis was on participation as consumption of health services, not as active agents of change (Bonfmann & Gleizer, 1994; Ugalde, 1985). As economic efficiency became a central value of the health system, participation was more about offsetting costs and less about redistribution of decision-making power (Fores & Ruano, 2009).

Today, many countries still highlight the importance of participation in decentralization and in health care. There are experiences with local-level health committees where many stakeholders come together to discuss health issues (Vázquez, 2002; Bronfman & Gleizer, 1994). In many cases this process is meant to take roles and responsibilities away from a weakened state. The Nicaraguan example shows that community participation in health could be used as a means to have community members voluntarily render health services (Briceño-León, 1998; Ugalde, 1985). In countries like Colombia and Guatemala, comprehensive but sometimes vague legal frameworks were set in place but economic and social determinants might contribute to hindering the way the frameworks are implemented or carried out. In Brazil, policies led to the creation of spaces for collective and individual participation, and although they are not perfect they represent an example for other countries in the region (Vázquez, 2002; Mosquera et al, 2001).
CHAPTER 2

Study Justification

The aim of this chapter is to situate the thesis into the current research trends in social participation in health while also showing how the findings and discussions presented here contribute to improve the understanding and the study of social participation in health. The first part of the chapter, entitled ‘Previous and ongoing research approaches to participation’ presents the research trends in social participation in health and how they have changed over the years. It also distinguishes two approaches to analyzing participation and links them to this study. The second part of the chapter is the ‘Study justification’ and delineates a clear gap in the knowledge that exists regarding social participation in health. Both of these sections contribute to framing the chapter that presents the aims and research questions of this thesis.

2.1 Previous and ongoing research approaches to participation

In the Alma-Ata declaration for primary health care, social participation was seen as a way to give individuals responsibility for their own health and as a means to create active collaborations between the health sector and the community (Flores & Ruano, 2009). During the first years of implementation, in the late 1970s and early 1980s, research focused mainly on measuring participation from a quantitative perspective, focusing on the number of community members or local stakeholders involved in a particular policy or program (Morgan, 2001). This changed thanks to Rifkin’s seminal work on how to monitor and evaluate social participation in health. Her research, mostly carried out in the 1980s, provided a multi-dimensional and non-linear perspective based on the use of qualitative methods that placed a value on case studies and the way specific programs integrated social participation components, building on previous work done on citizen participation by Arnstein (1969) and others (Rifkin, 1986, 1990; Rifkin et al, 1988).

Today there are two distinct lines in research regarding social participation in health, both of which can be traced back to the original definition put forward by the WHO and UNICEF in 1978. The first of these is related to the responsibility that individuals have to participate in the health system, and focuses on seeing participation as a product that can help to promote the sustainability of policies or programs through the use of community members as either a cost-cutting method or as a way to provide services that the state is not able to render effectively (Morgan, 2001). Through this view of participation, states and international donors have been able to install accountability mechanisms into policies and programs. However, this approach has been criticized for presenting a stripped-down perspective of participation that values cost offsetting over the transformative power that participation can have in a community (Barnes & Schattan, 2009; Aycrigg, 1998; Bronfman & Gleizer, 1994).
Besides stressing the role that individual responsibility can play, the declaration also highlighted the importance of creating agency through the collaboration between community and health sector stakeholders. By emphasizing that participation in health is a social process, this perspective brings into the discussion the role that cultural, social and political factors can play when it comes to hindering or promoting participation (Homedes & Ugalde, 2005). It is through this perspective that studies on how power influences the participation process can be carried out, even when these fall outside of traditional political systems or institutional structures. However, studying participation in this way is more time consuming, and the outcomes of the research can be harder to generalize to different settings, something that has been perceived as a major limitation in some studies (Morgan, 2001).

By following this second line of research on participation, the thesis focuses on the process of participation in one municipality in Guatemala, and tries to capture the complexity of this process while still focusing on pragmatic outcomes that can benefit policy makers and communities alike. While it does not follow a case study methodology, the study is in the same line as those carried out by Zakus (1998), Muller (1991) or Ugalde (1985) because it presents the value that exists in exploring and examining participation and translates those findings into policy recommendations that can be useful for other contexts.

2.2 Study justification

Social participation in health is enjoying a period of renewed interest because of the WHO's callback to the principles of the Alma-Ata declaration and to the primary health care approach (WHO, 2008). In Latin America, social participation policies have been part of the mainstream discourse on health, and most countries in the region recognize the role that participation can have in health and in society as a whole: it is through it that people can identify their health needs, that social inclusion levels can improve and that more pro-equity policies can be implemented and monitored (Almeida, 2002). In Guatemala, social participation is a key component of the on-going decentralization process and an essential part of the health system. The country has a legal framework that promotes inclusive participation in place, and a participation scheme that goes from the community to the national level. However, little attention has been paid to the process of social participation in health and how it occurs at the municipal and community level, and to how the experiences of community members influence and shape the process of social participation in health at the municipal level.
CHAPTER 3

Aims

3.1 General objective
To explore the role that social participation has in a municipal-level health system in Guatemala in order to inform future policies and programs.

3.2 Specific objectives
1. To analyze the social and historical context where the different processes of social participation in health occur in Guatemala.
2. To explore how the social participation process works in one municipal-level health commission.
3. To explore the meaning of community participation in the context of implementing and running a water project in rural Guatemala.
4. To explore how community health workers’ personal characteristics and interactions with the health system relate to community participation and leadership in health.

3.3 Research questions
What is the social and historical context in which the process of social participation in health occurs in Guatemala?
What does the process of participation in a municipal-level health commission look like?
How do community members define and use participation in health in their local settings?
How do the personal characteristics and work of community health workers influence community participation and leadership in health?
In what way do community health worker programs influence life at the community level?
How is participation in health put into practice in community settings?
The Conceptual Framework

Social participation in health is a dynamic process that brings together different stakeholders to discuss, implement, evaluate and make decisions on health policy. This chapter presents the conceptual framework for the study, which served as a means to explain and organize the key factors, concepts and stakeholders of the process. Through it, a more complete analysis of the relationships and the process were possible (Miles & Huberman, 1994). Walt and Gilson’s health policy triangle (1994) was used to guide and structure the fieldwork and the overall analysis of the data. The four components of the triangle also provide the frame for the findings (see chapter 7). The second section presents information about the process and the content, including the three levels where participation takes place, social participation in health as defined in legislation, and how the people in Palencia interpret that definition according to their role and the resources available to them. Finally, the third one groups data regarding the actors to present the personal meaning that the people in Palencia found in their own process.

The second section of this chapter presents the overall organization of the thesis and explains the way that each sub-study reflects a different side or experience of participation, while still showing how all the studies come together to present a more complete picture of participation in health. The last part of this section presents the rationale behind the structure of the findings chapter.

4.1 The health policy triangle

This study used the framework developed by Walt and Gilson (1994, taken from Buse et al, 2007) to explore the process of social participation in the municipality of Palencia, Guatemala. The health policy triangle shown on figure 3 (see below) shows that there are several components that go into any health policy: the context, the content, the process and the actors. All of these come together to show how policies contribute to, and are shaped by, the context, the use of power through influence or resources and by internal or external factors that might seem unrelated to the policy process itself.

The context of policies is shaped by situational, structural, cultural and even international factors that contribute to build a unique setting where different actors or stakeholders meet and work together in the process of developing and implementing policies. The use of this framework is reflected in the themes presented in the findings (see chapter 7). The first of these themes presents the social, historical and political context in which the legal framework for social participation was developed and corresponds to the context section of the framework. The second theme presents information about the process and the content by presenting data about the three different levels where participation
takes place and about the way that social participation in health is presented in the legislation and how the people in Palencia interpret that definition according to their role, to the space in which they participate and to the resources that are available to them. Finally, the third theme groups data regarding the actors to present the personal meaning that the people in Palencia awarded their own process.

**Figure 3:** The health policy triangle

![Health Policy Triangle](source: Gil & Walt from Buse et al, 2007)

### 4.2 The structure of the thesis

Social participation in health is a complex process that is framed in a specific social and political context, and that is shaped by policies and institutions just as much as by people and their on-going discussions and actions. In order to capture a fuller picture of the process of social participation in health, the main objective in this study was broken down into four specific objectives (see chapter 3), each one reflected by a sub-study presented in paper form in appendixes I-IV. This focus allowed for a deeper look at the social, policy and human components of participation in health.

The figure below shows how looking at participation as a process that has many ‘sides’ allowed for it to be studied as a multifaceted and intricate social activity. Each side represents a specific objective for this study. The first sub-study examined the social and historical context in which social participation in health takes place, and provides the setting for the development of the national framework on participation. This legal framework influences the way that participation happens at the municipal and community level. The second sub-study looks at the process of participation in Palencia’s municipal-
level health commission. This is the place where representatives from the local government, from the central and district levels of the MoH, and local leaders come together to discuss how to shape national policies to fit their specific needs and decide how to use the resources they have available. By following and analyzing this process we show how this legal framework and the power each stakeholder has contributes to shaping the process itself.

The third and the fourth sub-studies focused on participation at the community level, and examined the situated practices of participation as outlined in the Alma-Ata declaration. Sub-study number three focused on community participation and water, a key determinant of health. Through the story of the community leaders in El Triunfo the importance of perseverance, support from other stakeholders and how a shared identity can play a key role in improving the life of people in rural villages was shown. The last sub-study, number four, looked at individual participation through the experience of being a community health worker in Palencia’s health extension program. This showed how community and individual values contribute to shaping participation and also how the experience of participating has impacted the CHWs’ lives.

**Figure 4:** The structure of the sub-studies

All of the sub-studies contributed to the overall study aim by presenting deep and rich information regarding the historical and political context where social participation in health takes place, and by analyzing three situated practices of participation at the municipal, community and individual level. When the data from these sub-studies is analyzed together, a more complete and holistic representation of the process of participation in health can be presented. Because of this, the findings and discussion chapters (see chapters 7 and 8) of this thesis present and discuss the data as a whole as opposed to referring to the specific findings of each sub-study, in the way figure 4 (above) exemplifies.
CHAPTER 5

Background

In this chapter, specific information about Guatemala is presented as a way to provide a deeper understanding of the underlying social issues that are a part of the process of social participation in health in one municipality. The chapter is divided into four sections, and each of these presents specific information about the national context. The first one presents general information about Guatemala, including demographic data and political distribution. The second part presents an overview of the country’s health system, including the public system and the national social security structure. Afterwards, the private profit and non-for-profit systems are presented in order to show a fragmented and unequal structure that allocates more resources to the metropolitan, urban population.

The third section of this chapter presents the social and political context of the study and consists of a general overview of the major historical and political milestones of the country in the course of the 20th century. It deals with information regarding the armed civil conflict and finishes with the peace accords of 1996. The final section is entitled ‘Decentralization and the legal framework’. Here, more specific information about the return to democracy and the decentralization process are presented through a policy perspective. Finally, this section provides an overview of the social development council structure.

5.1 Guatemala

This Central American country has 14 million inhabitants, a poverty rate of 52% and a rural population that makes up about 75% of the total population (World Bank, 2006; Flores & McCoy, 2004; INE, 2003; INE, 2003a). However, this is changing thanks to growing urbanization rates and rural to urban migration (INE, 2003). Guatemala’s Gini index of 53.7 shows that there are high levels of inequality in terms of income concentration and distribution, and poverty levels are routinely higher in rural areas than they are in urban ones (World Bank, 2006; INE, 2003a).

Guatemala is an ethnically diverse country, with 23 indigenous groups making up 45% of the total population. The other 55% is composed of non-indigenous groups mostly of mixed European and Amerindian descent. Although the official language is Spanish, 40% of the population uses it as a second language and are native speakers of one of the indigenous languages that exist in the country. Life expectancy at birth for Guatemalans is 70 years, which breaks down to 72 years for females and 69 for males. The birth rate is 27 live births/1000 population and population growth is 1.9%. Currently, the
average age in Guatemala is 20 years old: 19.4 for males and 20.7 for females, the lowest median age in the Western Hemisphere (INE, 2003).

Politically, Guatemala is divided into 22 regions that are subdivided into 333 municipalities. Municipalities act as the organizational and administrative unit of government and it is at this level where citizen participation is mainly promoted (Congreso de la República de Guatemala, 2002).

**Figure 5:** Location of Guatemala (in black) in Central America

---

### 5.2 The Guatemalan health system

The Guatemalan health system is highly fragmented and unequal. This translates into low and unequally distributed numbers of human resources for health, inefficient services and high concentration of resources in the central, metropolitan area leading to very low access to services and higher out of pocket expenditure for the poorest population (Flores, 2007). The system is mainly financed through out of pocket payments and only around 11% of the population is covered by either public or private insurance. In Guatemala, there are private, public and social security systems that subdivide and have different schemes for different populations. This leads to inefficiencies and a duplication of labor. There are no functional links or separations between each subsystem and each one has a population to which they render these differentiated services. Most of the health system's resources are concentrated in the metropolitan area, where only about 25% of the total population lives. Another important characteristic of the health system is that users seek care in all the subsystems interchangeably depending on their need, economic capacity or the availability of services (Flores, 2007; PAHO, 2007a).

The public health system is made up of the Ministry of Health, the Ministry of Defense, local municipalities, social funds and the social security system, and represents about
half of the country’s total health expenditure. Most of the funds in this system are channeled through the MoH (Flores, 2007; PAHO, 2007a). Investment in the public health sector declined from 8% to 7.3% of the national budget between 1998 and 2003, and public spending decreased by almost 50% in the same period (Flores, 2007; Flores, 2007a; PAHO, 2007a). Resource allocation for this system is based on historical budgets that do not necessarily take the needs or demands of the population into account. Finally, the MoH also allocates funds to NGOs that are outsourced to provide specific health care packages to rural populations through the ‘extension of care’ program (Verdugo Urrejola, 2000). The services provided by the public health system are divided into three levels of care: the first one provides primary care through health centers, health post and the outsourced NGOs. The second has institutionalized services at health centers and maternal clinics and the third level is provided by the district, regional and national-level reference hospitals (Flores, 2007a; PAHO, 2007a).

The Guatemalan Social Security Institute accounts for the other 54% of the public health expenditure, and this is spent insuring all formal workers. This system is financed through state-appointed funds and premiums that are co-paid by the employer and the employees (IGSS, 2008; PAHO, 2007a; Mesa-Lagos et al, 1997). This insurance scheme covers around 11% of the total population mainly because formal employment is not widespread throughout the country (PNUD, 2005). The social security institute has specialized programs to treat trauma, disease, maternity and specific care for retirees. It also provides preventive and curative health services for the children of the affiliates that are younger than five. As with the other subsystems, most of the physical infrastructure and human resources are located in the metropolitan area (Flores, 2007; PAHO, 2007a; Mesa-Lagos et al, 1997).

The private health system is composed of private hospitals, clinics and health providers, and accounts for 60% for the country’s total health expenditure. About 90% of the this expenditure is out of pocket payments made by private homes, private insurance account for 6% of the disbursement and NGOs for about 4% (PAHO, 2007a). This subsystem is divided into profit and a nonprofit sectors that either provide western medical services or traditional indigenous medicine. While the for-profit sector is made up of private providers, the nonprofit is comprised mainly of NGOs (Flores, 2007).

5.3 The social and historical context of the study

During the last century, Guatemala underwent profound social and political changes as a result of going from a liberal dictatorship to a democracy and then being plunged into a 36 yearlong internal war that ended in 1996. Until the 1940s, the country had a series of dictators that concentrated power in the central level of the government through the use of political repression, forced disappearances and torture. A coup d’état in 1944 started the decade of the revolution and a new constitution banned forced labor and
idle land. For the first time, Guatemalans had the right to state-provided health services and health, the right to work and freedom to take part in political life. During those ten years, around 500 peasant unions and 300 peasant leagues were formed (Booth et al, 2006). It was during this period that the concept of municipal autonomy was first implemented, although the state remained heavily centralized. By 1955, another coup had toppled the government and started a series of events that would lead the country into a period of armed conflict (Luján Muñoz, 2004; CEH, 1999).

For the remainder of the century, Guatemala would have a politically unstable climate characterized by high levels of political repression and violence. In the years between 1955 and 1985, the government abolished all worker’s unions and political organizations because they were perceived as dangerous. The extremely restrictive and violent policies set in place by the military governments of this period combined with the cold war and the pro-communist movements in the region provided grounds for the development of guerrilla groups. Through rural and urban confrontations, the military and the guerrilla tallied about 200,000 victims of murder, kidnapping, rape and torture (Luján Muñoz, 2004; CEH, 1999).

Several different political and social changes led to the 1986 elections, the first free ones to be held since the onset of the war. Although the internal armed conflict had not ended, the newly elected Christian Democrat government promoted civil participation through social development councils. These new policies received major support from international donors and the return to democracy led to a temporary decline in the violence and repression levels (Flores & Ruano, 2009). However, by the end of the 1980s, violence levels had peaked again.

After several years of negotiations, peace was finally declared on December 29, 1996. According to the peace agreements signed by the state and the guerrilla leaders, peace could only be achieved through the equitable social and economic development of all the population. Decentralization was to become the country’s main policy, and community participation was to be the basis for decentralization. The state committed itself to facilitate full and organized participation in decision-making process and mobilize the necessary resources for this to happen (Booth et al, 2007; MINUGUA, 2004; Luján Muñoz, 2004).

5.4 The decentralization process and the legal framework

The decentralization process can be traced back to specific constitutional reforms from 1985, but it was not until the 1996 peace accords that decentralization was linked to social justice, equality, development and participation (Brink-Halloran, 2009; MINUGUA 2004). Guatemala’s 1985 constitution defined decentralization as an administrative and economic reform that should be based on citizen participation. It also called for the
creation of national, regional and community-level development councils but it did not include an organizational framework for them (Congreso de la República de Guatemala, 2007a; Amaro, 2000).

From 1985, Guatemalan municipalities have had the right to 10% of the government’s revenues and were awarded authority over the provision of social services. The goal of this was to strengthen the political and administrative capacities of the municipality so that they could receive more power, responsibilities and resources in the coming years (Congreso de la República de Guatemala, 2007a). In 1987, the first law for the national system of urban and rural development councils passed. Through it, the importance of participation in the development process was enshrined thanks to the councils’ capacity to implement and administer projects. By 1988 there were over 1500 community-level councils in place and this represented the first real opportunity for community participation in over 30 years (Brink-Halloran, 2009; Amaro, 2000). This first attempt at the development council system failed due to a lack of organization and because emphasis was put on the planning of development, at the expense of the execution of projects. Over time, political will waivered, funding was cut and participation levels fell, which led to the councils’ dismantling. A revised version of the municipal code was passed in 1988. It gave municipalities more power through a clearer definition of their roles and responsibilities in areas of government, finance and the administration and implementation of public services (Puente Alcaraz & Linares López, 2004).

The 2002 legal framework for participation included revised versions of the municipal code, a new social development council system and the decentralization act. Through this set of laws, powers and responsibilities were transferred to municipalities and other branches of the executive branch (Puente Alcaraz & Linares López, 2004). According to Brink-Halloran (2009), the underlying principles of the framework are municipal autonomy, elimination of discrimination, social inclusion, reduction of poverty and citizen participation. The legislation aimed to improve the efficiency and effectiveness of public services and to facilitate social auditing processes. This is summarized in table 2 (see below).

Table 2: Events and legislation in the decentralization process

<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
<th>Legislation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1985/1987</td>
<td>Return to democracy</td>
<td>New constitution</td>
</tr>
<tr>
<td></td>
<td></td>
<td>First development council law</td>
</tr>
<tr>
<td>1988</td>
<td>Removal of the first development council law</td>
<td>First revised municipal code</td>
</tr>
<tr>
<td>1996</td>
<td>Internal armed conflict ends</td>
<td>Peace accords</td>
</tr>
<tr>
<td>2002</td>
<td>New decentralization reforms</td>
<td>Decentralization act</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Second revised municipal code</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Second social development council law</td>
</tr>
</tbody>
</table>

Adapted from Brink-Halloran, 2009
According to the decentralization act of 2002, participation is the involvement of communities and organizations in the planning, execution and control of the municipal, regional and national level government. Organized communities have the right and the responsibility to audit the projects or programs that affect their lives (Congreso de la República de Guatemala, 2002b). The revised municipal code defines the structure and role of the municipality and highlights the right of citizens to be informed of all the inner workings of the municipal government and to participate in the creation and audit of the municipal budget. It also deals more specifically with the municipal-level development council (Congreso de la República de Guatemala, 2002).

The last law in the legal framework for participation is a revised version of the urban and rural social development council law. This version expands from the previous version from 1987 by adding a community and a municipal-level council and by connecting all levels in a comprehensive structure that goes from the community to the national level (Congreso de la República de Guatemala, 2002a).

5.4.1 Social development council system

Guatemala’s social development council system is a bottom-up structure that constitutes the only officially recognized way to participate in the decentralization process. The scheme is based on the social development council law of 2002 and their objective is ‘to organize and coordinate public administration through the formulation of policies of development, budgeted plans and programs and the promotion of inter-institutional cooperation’ (article 3, Congreso de la República de Guatemala, 2002a). As shown on figure 6, the system starts at the community level, goes through the municipal and regional level all the way up to the national-level social development council. This scheme creates spaces to plan, coordinate and implement social development policies and according to article 2, promotes the process of participatory democracy in conditions of equity and equality (Brink-Halloran, 2009; Congreso de la República de Guatemala, 2002a).

The national and regional levels of the council offer spaces where civil society and government elected officials and representatives meet to discuss national-level policies, while the municipal and community levels focus on local issues and priorities. Community-level councils are made up of community representatives. Their mandate is to be actively involved in identifying, prioritizing and solving problems and issues in their own community and municipality. They do this by prioritizing projects and submitting them to the municipal government, who then evaluates and gives a budgetary decision. The law specifies that council members are to make decisions in the process of formulating, implementing and evaluating programs, policies and projects, as well as receive regular updates regarding the municipal budget (Congreso de la República de Guatemala, 2002a). This level of the scheme became so popular that by 2007, twelve thousand out
of the seventeen thousand recognized communities in Guatemala had formed a council of their own (Brink-Halloran, 2009).

The president of each community-level council has the right to participate in the municipal-level council, whose mandate is to support the work the community-level councils do, promote inter-institutional cooperation and participate in the formulation and monitoring of the budget. Other participants include the municipal mayor, who heads the council, local civil society organizations and NGOs, as well as governmental organizations that work in the municipality (Congreso de la República de Guatemala, 2002a). This level's meetings act as a place for the dissemination of information and they emulate the recommendations from the 1988 municipal code (Fernández, 2008). According to article 36 of the municipal code, the municipal council needs to create specialized committees in education, infrastructure, finances, economic development and health. Although it is not specified in the social development council law, the committees from the council scheme mimic this structure and they are often considered a part of the council scheme. These committees design plans, policies and projects, and oversee and evaluate their implementation. A fully working municipal-level council allows for participation from a wide array of stakeholders. However, there are no mechanisms to ensure that the council system works, and the law does not specify structure, functions, meeting times or the way specialized committees are supposed to work (Brink-Halloran, 2009).

Figure 6: Special commissions within the council structure
CHAPTER 6

Methods

This chapter presents the methodology used for this study and for all the sub-studies that can be found in appendixes I-IV. The first part of this chapter presents the municipality of Palencia by giving specific information regarding its population and the main demographic indicators, the municipal health system and the municipal-level health commission. It also presents data regarding the social development council system. The next section of the methods chapter deals with the overall methodological approach to the study. It shows how the applied ethnographic approach was used and how it influenced both the process of data collection and data analysis. The third section of the chapter presents a detail account of the process of data collection. The data analysis section follows, where the different methods used for the different sub-studies and for the overall analysis of the data presented in the findings (see chapter 7) is presented. Finally, we discuss the ethical issues encountered in this work.

6.1 Setting: The municipality of Palencia

Palencia is a municipality located in the region of Guatemala, and has a population of 55,410 inhabitants of whom 70.3% live in rural areas and 38% are poor (INE, 2003). Of the total population, around 70% have regular access to safe drinking water and to electricity, and about 20% have access to sanitation. The poverty rate hovers around 50%. The main economic activity for the people of Palencia is subsistence farming and small-scale coffee plantations (Municipalidad de Palencia, 2009; INE, 2003a). When it comes to the municipality’s social development council scheme, there are 49 community-level councils and one municipal-level council (Municipalidad de Palencia, 2009).

For the MoH, Palencia is one of seven districts in the Northeastern health area of the Guatemalan region. In regards to infrastructure, the MoH has one health center, seven health posts and one oral health clinic. The closest hospitals are the two national referral hospitals located in Guatemala City, about 30 km from the urban center of Palencia. The district also has one NGO that outsources care through the ‘extension of care’ program. They have seventeen mini-clinics to provide care through local community health workers and ambulatory staff that visits each post about once a month. The municipal government funds one medical and one dental health clinic, as well as keeping a nutritionist on staff. There are also two private laboratories and one private physician.

In Palencia, both the municipal and the community-level social development councils have a health commission. The goal of both these commissions is to bring the health sector together with the council scheme and to provide a space for social participation that deals with specific health issues (Congreso de la República de Guatemala, 2002a).
The municipal-level health commission is in charge of tailoring national policies to the specific needs of the municipality, and should be the coordinating body for all health-related work in the municipality. At the community level, the health commission is responsible for keeping the community’s environment healthy, providing information about disease outbreaks and establishing emergency plans for transporting the sick. They also provide feedback and information for the municipal-level health commission (Congreso de la República de Guatemala, 2007; Congreso de la República de Guatemala, 2002a).

The municipal-level health commission started working in the municipality in 2009, and focused on implementing a health promotion plan that aims to coordinate the work of the municipality, the health center and the NGO. The plan focuses on reproductive health, a healthy schools initiative, implementation of safe drinking water projects, and prevention of contagious diseases. As a way to test-run the plan, two community-level health commissions that had applied for a project within these main themes were invited to attend the municipal-level health commission meetings.

**Figure 7:** The province of Guatemala with Palencia
6.2 Applied ethnographic approach

Applied ethnography is a method that allows researchers to study complex social phenomena through the use of praxis-based tools that lets the researcher become actively involved in the participating community (Robson, 2002). The ethnographic method helped us to develop a deeper understanding of the processes, meanings and stakeholders that are involved in social participation in health in the municipality of Palencia. Through the use of a combined emic-etic\(^1\) perspective, a complex and rich narrative that reflects the study participant’s social world, and the constructs and structures that constitute the process of participation can be analyzed and presented in a way that can be useful for policy makers (Maginn, 2007; Mulhall, 2003; LeCompte & Goetz, 1982).

The goal of applied ethnographic research is to be able to analyze social phenomena through the use of a holistic perspective that can show cultural and social nuances in a way that traditional qualitative or quantitative research cannot. According to Whitehead (2004), ethnography is based on specific ontological and epistemological principals that allow the researcher to be flexible and creative, and that permit an open research design that is meant to address the changing nature of social processes and phenomena (Agar, 1997).

While applied ethnography can employ qualitative and quantitative methods of data collection, this project focused solely on qualitative methods as they were seen as the most appropriate means of capturing the experience of what it is like to participate in health in Palencia. The main method used for data collection was participant observation, as this was deemed the most appropriate tool for achieving familiarity with the environment in Palencia as well as a means to establish rapport with the individuals that participate at different levels of the health system in Palencia (Mulhall, 2003). Through the act of participating as an active observer, I was able to take part in meetings and informal conversations that helped to guide the development of interview guides for in-depth interviews, group discussion and workshops. During the fieldwork I also collected information through the use of a camera and a field journal, which provided a way to gather data and track the research process and the local culture through my own perspective (Whitehead, 2004).

Because the value of research findings partially depend on its credibility, ethnographic studies rely on comparability and translatability of research findings instead of the traditional positivistic concepts of generalizability and validity. Together, these ethnographic

\(^1\) An emic approach refers to analyzing the components of the cultural system from the perspective of the group that is being studied, while an etic approach is the analysis of the cultural system using the researchers’ own paradigms. A combined emic-etic approach presents a reconstruction of the group’s social world based on the experiences of the researcher and on the interpretations of the subjects (Whitehead, 2004).
METHODS

notions contribute to the generalization of the research. In order to secure comparability, the characteristics of the group being studied were clearly outlined, whether it was CHWs, members of the health commission or El Triunfo’s social development council so that comparisons with similar or different groups could be undertaken later. Translatability assumes that the methods and categories used, as well as the characteristics of the phenomena, are explicitly identified so that this comparison can be carried out. The goal of comparison is to clarify, refine and validate constructs and concepts, and this can be carried out in single or multi-sited ethnographic research projects (Maguinn, 2007; LeCompte & Goetz, 1982).

6.3 Data collection

The fieldwork for this study was carried out over eight months and three field visits that were conducted in three research visits between early January of 2009 and late March of 2010. It was during this time that I collected data for papers II, III and IV of this thesis (see appendices II-IV). The data collection necessary for paper I was conducted during the months of July to September of 2008 (see appendix I) and occurred before any of the fieldwork in Palencia had started.

Over the course of the fieldwork in Palencia a total of 38 in-depth interviews with provincial health authorities, municipal authorities, district health authorities, community representatives and community health workers were conducted. A semi-structured interview guide design to gather rich information regarding the participant’s experience and perspectives on the process of social participation in health was tailored to each stakeholder group according to the level at which they participated (be it municipal, community or individual-level) and to the role they played in that particular process (either as an institutional stakeholder, a community stakeholder or as a community health worker). The use of semi-structured guides allowed me to retain the capacity to explore interesting topics as they presented themselves while still giving enough structure so that the data collected from the interviews could be valuable during analysis. In addition to the in-depth interviews, four group discussions that also followed a semi-structured interview guide were conducted with the members of the community-level social development council of El Triunfo. Most of the interviews were tape-recorded after approval from the interviewees was gained and then transcribed by me on the same day. For the ones that were not tape recorded, notes were taken and later used in the same manner as the transcriptions. All of the informal conversations and informal interviews were completely unstructured and were documented in the field journal through the keeping of extensive field notes written every evening after the end of the workday. As advised by Mulhall (2003), I only kept one diary that collected both my personal experiences and the field notes. This was done in order to be able to analyze the complete field experience later.
METHODS

The first of the field visits lasted from January to March of 2009, and included meetings of the municipal-level health commission, smaller informal meetings called to discuss specific cooperation topics between specific groups of stakeholders and field visits to meet many of the CHWs in Palencia’s extension of care program. During this time 13 in-depth interviews with members of the municipal-level health commission were carried out. Informal meetings and interviews with community health workers were also carried out in order to establish rapport with the CHW and as a way to familiarize myself with the study setting. A detailed field journal and photos of meetings and visits helped me to provide a richer context for the interviews. This first field visit resulted in the data that was analyzed for paper II of this study (see appendix II).

Image 3: Group picture after the last group discussion with the council members of El Triunfo. In the picture (from left to right): Don Miguel, Don José A, Ana Lorena Ruano, Don Octavio, Don José, Don Roberto and Christie DeRussy

The second field visit started in early June and ended in late August of 2009, and focused mainly on the members of El Triunfo’s community-level social development council. During this time, I still continued to be an active participant of the municipal-level health commission and was a regular visitor in Palencia’s health center. I also conducted a few visits to the far-away communities where the CHWs of the extension of care program were working. During this time, I was supported by Christie DeRussy, who was working with me as part of the practicum requisite for an MPH degree. She also kept a field journal and provided support by taking notes during group discussions. In this field visit, I conducted the four group discussions with the members of El Triunfo’s community-level social development council. As with the semi-structured interviews from the previous research visit, these provided a structure for the discussion while still allowing for freedom to explore interesting topics. In addition to this, Christie DeRussy and I developed and
implemented two workshops about the legal framework on social participation, one
designed for the members of Palencia’s municipal-level health commission and one for
the community-level social development council from El Triunfo. As with the previous
round of fieldwork, a field journal and photographic documentation were kept. This field
visit, and the data obtained from it resulted in the third study of this thesis (see appendix
III).

**Image 4: Participant observation during the third field visit in February of 2010**

The third and last field visit was conducted between early January and late March of
2010, and mainly consisted of daily visits to the communities that are part of the program
to extend care’s catchment area within the municipality of Palencia. However, I still vis-
ited the health center and the municipal-level health commission regularly and visited
the members of El Triunfo’s social development council. During these weeks I visited
each of the 17 communities in the program to extend care twice. I participated in two
of the monthly training sessions for CHWs that are held in Palencia’s health center.
Through the community visits I conducted 18 in-depth interviews, two of them with
members of the ambulatory health team and sixteen in-depth interviews with community
health workers. During this time I also had several informal interviews with the health
team members and with the CHWs. I followed the same methodology for data collection
as I did in the two previous visits and gathered photographic documentation and also
kept a detailed field journal. This field visit, and the data obtained from it, resulted in the
fourth study in this thesis (see appendix IV).
6.4 Data analysis
For this study there were two rounds of data analysis. The first was aimed to address the specific objectives and research questions, and resulted in each of the four sub-studies. A second round looked at all the data as a whole in order to analyze it as a total picture of the process of social participation in health in the municipality of Palencia. While the first round of analysis used a specific methods tailored to each research question, the second round focused solely on the use of thematic analysis. This section presents information regarding the specific methods for analyses used in each of the sub-studies (see appendixes I-IV): documentary analysis was used for sub-study I, role-ordered matrices were used for sub-study II, narrative analysis for sub-study III and thematic analysis, that was also used for sub-study IV.

6.4.1 Documentary analysis
Documentary analysis aims at analyzing written records of accounts through the use of categorized analysis in order to find the key content or main discourse within them and then presenting these findings in light of larger social or political contexts (Robson, 2002). This method was used for sub-study I (see appendix I) as a way to cohesively and congruently present data regarding the social, political and historical context of social participation in Guatemala during the 20th century. The first step in this process was to identify sources of information: this was done by reviewing historical documents, personal accounts and previous work done regarding the Guatemalan armed civil conflict. Special focus was put on identifying the impact that the violence levels of this period had on the social fabric of the country as a whole. The data was grouped into four categories: power relations and social participation, repression and social leadership, political violence and its effect on social participation and the effects of impunity on the population’s trust of the state.

6.4.2 Role-ordered matrices
The analysis of qualitative data via matrices provides a systematic organization of research findings in a way that allows for deep analysis and comparison to be carried out. Through the crossing of two or more variables, matrix analysis creates a space where the active interaction of rich information can result in holistic analysis (Miles & Huberman, 1994). For sub study I, role ordered matrices were used because we were interested in understanding how the process of social participation occurred from the perspective of the participants, who all participated because of they represented a specific stakeholder group. By organizing our data by roles we were able to compare different categories of stakeholders: we could easily find how representatives from the municipal government in Palencia felt about one issue and compare it to the perspectives from community representatives or municipal-level health authorities (Robson, 2002; Miles & Huberman, 1994).
The first step in the analysis consisted in identifying the role categories to be used as one of the two axes in the matrix. The categories for the second axis were both a priori categories that had been included in the semi-structured interview guide and emerging categories that resulted from the interviews and from the informal discussions that were part of the participant observation. The second step involved careful reading and coding of the interviews and the third step was organizing the information according to the axes. We used Microsoft Excel to help us keep track and provide a clear and organized visual display of this process. Once the meaning units had been placed on their respective place in the matrix we proceed to conduct comparisons and to group similar perspectives into larger stakeholders groups. As a result, two major stakeholders groups with clearly defined perspectives and ways of approaching social participation emerged: community-level stakeholders and institutional stakeholders. This became the means by which we classified and presented our results (see appendix II).

6.4.3 Narrative analysis

Narrative analysis is a qualitative method that allows researchers to analyze the experiences of individuals within their social framework through the telling of stories that have clear subjects and that present relationships between characters, events and consequences our outcomes (Jonas, 2005). Narrative analysis can refer to an entire life story or focus on a particular event or process. Through the use of this method, a researcher can find the socially constructed truth behind the personal experiences of the tellers, which come in the form of a sequenced series of events that are selected, organized, connected and presented as meaningful for the hearer (Riessman, 2008; 2003).

The kind of interviewing that produces meaningful narratives occurs through the establishment of rapport between the teller and the listener. This allows the tellers the freedom to talk and explore experiences and award them with meaning (Riessman, 2003). The gathering of the narrative of the experience of participation from the members of El Triunfo’s community-level social development council happened through a series of four interviews. Because of this, the first step in the analysis process was to organize the narrative following the chronological occurrence of specific milestones mentioned during the interviews. This required careful reading in order to find and organize these events sequentially and then careful and respectful editing of the interviews so that the narrative could take shape. We did this by following Riessman’s (2008) advice and methodology because narratives that result from a series of interviews are rarely organized chronologically. The resulting narrative told a story of community organization and focused specifically on the experiences of the members of this council, so our third step was to mark the group’s major milestones. We also included my field notes and perspective because as the target audience for the narratives, my role could not be extricated from the narrative itself (Riessman, 2003). Finally I analyzed how each section of the narrative
brought meaning to the work that the council was carrying out through the use of narrative thematic analysis, as recommended by Elliot (2005).

6.4.4 Thematic analysis

Thematic analysis is a qualitative method used to search through data in order to find recurrent patterns that can be grouped into themes through the use of discursive interpretation (Cresswell, 2007; Fereday & Muir-Cochrane, 2006). To do this, the data is organized systematically by the identification of topics that link together from codes into categories, and later into meaningful and mutually exclusive themes (Fereday & Muir-Cochrane, 2006). This was the chosen method to use both for sub-study IV (see appendix IV) and for the overall analysis of the entire fieldwork as presented in chapter 7 (see below).

For the analysis carried-out for sub-study IV, the first step involved the careful reading of the interview transcripts by all the members of the research team. During this process, notes and memos were taken in order to mark possible organizing patterns, codes or categories. This first step provided a deeper sense of the various topics that are embedded in the data. The second step in the analysis was to code the data through the identification of meaning units and then to label them. Once this had been done, a third step was to sort these codes into categories. We used a priori categories that we had previously established during the development of the interview guides as well as emerging categories that were the result of the coding process. Both types of categories were used because it was already established that the purpose of the analysis was to study the process of social participation. However, all the themes that resulted from the organizing of the categories (step four) were inducted from the text. Once these themes were identified they were organized and contextualized and presented in the findings with a detailed description and illustration from the meaning units used to construct each theme (Fereday & Muir-Cochrane, 2006; Crabtree-Miller, 1999).

When it came to analyzing all the information collected during the fieldwork to present the findings in this cover story, we also used thematic analysis. The first step in this second level of analysis was also to read through the findings presented in all of the sub-studies, unused data and field notes. This resulted in memos that later helped to organize the data. For this analysis we already had a priori themes that reflected the conceptual framework (see chapter 4), so the second step was to code and find categories that reflected these themes. However, following the flexibility that the use of an ethnographic approach allows, we retained the capacity to add complexity and richness to the themes through emerging categories. In the same manner as with the analysis carried out for sub-study IV, the last step was to organize and contextualize the themes with a detailed description of the findings (Fereday & Muir-Cochrane, 2006; Crabtree-Miller, 1999).
6.5 Ethical considerations

In Guatemala, it is only necessary to ask for ethical clearance when conducting clinical trials or human testing. However, achieving ethical clearance was of utmost importance for this study. During each of the field visits, a detailed plan of activities was presented to municipal and health authorities, as well as to community members that were to be directly or indirectly involved in the fieldwork and data collection. We obtained verbal informed consent from all the interviewees and informed them that they could withdraw at any time without any consequences. We asked permission to tape record the interviews or to take notes, and offered anonymity to the participants. This request was taken by all of the participants except for the members of the community-level social development council of El Triunfo. In this particular case, the council members felt that it was important to them to tell their story and to ‘stand-up’ for the values they were trying to put across with their narrative. Because of that, we used the real name of the community and the real first names of all the council members, although we did not add their last names.

After all of the sub-studies that make-up this thesis, I made one final field visit to Palencia. I then presented the major findings of each study and gave a copy to the municipal and health authorities. I also visited the village of El Triunfo and informed them about what I had done with the interviews. Finally, I presented the results of the sub-study on community health workers to health authorities, the members of the ambulatory health team and to the community health workers that attended the monthly training session.
CHAPTER 7

Findings

This chapter presents the findings of the study as organized by the conceptual framework of the study, (see chapter 4) and not as they are shown in the sub-studies that can be found in appendixes I-IV. The four themes that are a part of this chapter reflect the overall process of data analysis as detailed in chapter 6 (see section 6.4). The first theme, ‘Guatemala: war, peace and participation’ presents the historical, political and social context that has contributed to shaping the participation policies and practices in Guatemala as a whole. The second theme, ‘Framing development through participation’ takes a deeper look at these policies and how they have been received in the municipality of Palencia. The third theme is entitled ‘Organizing participation at the local level’ and presents data regarding three situated practices of participation, each occurring at a different level: the municipal, the community and finally the individual level. Finally, the theme ‘Reflections on a process’ presents reflections on what it means to participate to the people that were a part of this study.

7.1 Guatemala: war, peace and participation

For many decades, Guatemalan citizens were banned from participating in civil society either due to a lack of spaces or because of the danger that leading a public life could mean. After the signing of the peace accords, social participation was seen as the main policy behind the decentralization and the social development process. In this section I present the social, political and historical events that contribute to explain why the Guatemalan state sees social participation as an integral part of their social development policy today, and how this context continues to shape how participation occurs today.

During the second half of the twentieth century, the cold war and the fight against communism provided the context for Guatemala’s armed civil struggle. Locally, the late 1950s was a time of growing social, political and ethnic inequalities and the lowest social spending levels in the region. By the mid 1960s, on-going confrontations between leftist guerrilla groups and the right-wing Guatemalan army had escalated to the point where civil society organizations like workers and student unions, community organizations and church groups were considered dangerous to national security (CEH, 1999; ODHAG, 1999).

By the time the peace accords were signed in December of 1996, an estimated 200,000 people had been murdered or were forcibly disappeared, 150,000 children were left orphaned and about 1.5 million people of all ethnic groups had been geographically displaced. In total, about 25% of the total population of Guatemala were direct victims
of the escalated violence levels (ODHAG, 1999). When broken down by age, Figure 8 shows that most of the victims were people between the ages of 16-45.

**Figure 8:** Total number of murder victims by age group 1965-1995

According to Kobrak (1999), many of the victims were community leaders, students and academics. The targeting of students in a country with already low levels of university enrollment meant that graduation rates remained low. Local community leaders in health were also the focus of high levels of repression and violence. The state saw health promoters working in rural areas as subversive and the Behrhorst foundation reported that between 1980 and 1984 anywhere from 30 to 40 health promoters were either executed, forcibly disappeared or displaced (CEH 1999; Kobrak, 1999).

It was during this period of Guatemalan history that already weak community-level structures broke down. Obligatory mechanisms for participation replaced organic community organizations or groups. This impacted traditional systems of authority, the dynamics of community relations and basic elements Guatemalan of identity (Suárez, 2002).

Today, Guatemala is a post-war society that is trying to foster social participation in a context full of challenges for both the population and the institutions that promote it. The negative consequences of the internal conflict are still felt in the country. Victims of the internal war report intense and generalized feelings of fear, despair, mistrust and insecurity (Beristain, 2001). Recent surveys of citizen participation reveal that overall levels of participation and of trust of political and social institutions are low (Brett & Rodas, 2008; Torres-Rivas & Rodas, 2007). Public arenas and participatory spaces are seen as apolitical, and participation is thought of as an administrative, not a political process (del Valle, 2004).
The process of reconstructing the country’s social fabric started with the signing of the peace agreements of 1996 and continued with the passing of the 2002 legal framework designed to promote decentralization through inclusive participation. Two years later, the research center ASIES (2006) found that the levels of perceived freedom of association, demonstration and meetings were on the rise. The survey also found that people trusted elections more and felt better represented. The work of the social development council scheme has also opened up participation opportunities and spaces where different groups can meet and work together in a way that can help to reestablish trust.

7.2 Framing development through participation

According to the legal framework, participation is the process through which institutions and organized communities take control of public programs in the hopes of empowering stakeholders to achieve local ownership of them. Social participation in health can occur through health commissions that work at the municipal or community level and through the work of individuals who volunteer their time to provide basic health services in their villages or towns (Congreso de la República de Guatemala, 2007; 2002a). The possibility to participate has changed things for the people in Palencia, as don José explained:

‘I think the policies were wrong before... it used to be that people in the city or from the municipality solved problems and then they would come and do projects. It was just them and now with the decentralization we can have communities decide what their priorities are... Now we know that if a road gets paved it’s because we asked for that, that the pavement is there for our reasons. It is the community who decides, not outsiders’.

The goal of the legal framework is to create open and structured spaces for participation where different stakeholders can meet and discuss current issues, and where municipal and community-level stakeholders can be empowered to be a part of every stage of the policy cycle. A community-level stakeholder from the municipal-level health commission said:

‘I think the policies are here to empower the people. It starts with the municipality and then down to us. You could say we’re the smallest link in the chain but because of the laws we have the chance to make decisions and ask for solutions to our problems’.

For the municipality of Palencia, social participation is an empowering process that is meant to improve the quality of life of everyone through the building of infrastructure, the implementation of programs and policies and building a better relationship between

---

2 In Spanish, ‘don’ is a term that is equivalent to ‘mister’ in English. It is often used as a respectful way to refer to older men. The female form, doña, applies to older women and is used in the same way.
the state and its inhabitants. Communities are seen as active participants of the process and its goal is to get all the stakeholders involved in order to integrate different views, priorities and perspectives into policies. However, this changes when it comes to participation in health. One stakeholder from the municipality said:

‘[Social participation is a way to]... try to get people to not be afraid of going to the doctor, because even when institutions want to work with the communities, our own idiosyncrasies and culture restrict us from accepting care from the physician. The first step in participating is to be open to a medical examination... so that they are aware of their needs’.

Community members see participation in health and in the decentralization as two activities that belong to the same process. Don José defined participation as:

‘Grouping together and supporting each other when it comes to health, education and community development. We all have to work together as a team to know where there are faults and what we could do to mend that’.

7.3 Organizing participation at the local level: the case of Palencia

There are three different spaces in which social participation in health takes place in the municipality of Palencia: in the municipal-level health commission, in the community-level social development councils and in the community health worker program. Each of these spaces has a set of participants, and they all have specific roles to play in these processes. In this section, we present the actors and the process in each of these identified spaces.

7.3.1 Organizing participation in health at the municipal level

There are two types of stakeholders in Palencia’s municipal-level health commission: the institutional and the community stakeholders. Institutional stakeholders are representatives from the municipal government, NGOs or from the MoH (either at the district of the provincial level). They are the most educated group of participants, and the majority holds university degrees in social work or medicine. The second group of stakeholders is made up of representatives from the community-level social development councils. They have little formal education and balance out their work with the commission with their jobs as subsistence farmers.

According to several institutional-level stakeholders, the participants from the municipality and the health center are the two leaders in the municipal-level health commission. The health district coordinator acts as the head of the commission and the municipality uses its convening power to attract and engage stakeholders in this participation pro-
cess. According to the institutional stakeholders, this power comes from the friendly, open and ‘go-getter’ approach that the mayor has. As one institutional stakeholder said:

‘…the municipality has great convening power. When they organize or are part of an activity people come, leaders come. They have good people working and I’ve seen that the mayor is humble and accessible. He gives this process priority and solves problems quickly. He is that way with us and he is that way with the people from the community. That’s why he has such pull here’.

Community stakeholders see this commission as an opportunity to present their priorities and get solutions to their health-related problems. However, in practice community stakeholders have very little power:

‘It’s them [the institutional stakeholders] that decide what we’re going to do because they only ask our opinion but don’t necessarily follow it. They tell us when the project is happening and they decide everything and just inform us and they never ask us’. (Community stakeholder)

This is because institutional stakeholders see and use the municipal-level health commission as a place to coordinate with other institutions. One institutional stakeholder said:

‘The unrealistic financing that we get doesn’t meet the needs of this district. What we have to do is work together with other institutions and gain support from them so that they can help us with health promotion or with our finances’.

Institutional stakeholders have more power resources and this allows them to play a bigger role in the way policies are shaped and put into practice in Palencia. However, they also face barriers that have implications for the continuity of the participatory process and for the collaboration between them. One of these is the unstable condition of their jobs with the institutions. One institutional stakeholder said:

‘We have a high employee turnover rate. A lot of people only have short-term contracts and then new people come and all our programing is ruined. Another problem is that we have a lot of pressure from different institutions at the same time. Everyone needs to get their results, but no one has enough resources’.

Palencia’s municipal-level health commission is seen as space that will help the institutions that work in the health sector reach their target coverage levels for immunization, ante-natal care, environmental health and other important indicators.

‘We all have a relationship, we are not an association, we are a health commission and we came to an agreement that as institutions, we needed to solve the health problems in the communities… so we all work together and include
community members, so we can find solutions to all the problems’. (Institutional stakeholder)

The legal framework lacks clear and precise instructions on how to go about implementing this participatory process. As a result, institutional stakeholders know the importance of community participation and empowerment, but seem to be unsure on how to go about achieving or facilitating it. When asked about the process of participation and the roles that each kind of stakeholder has, one institutional stakeholder reflected:

‘Well, we have them [the community stakeholders] come so they can be informed, know what is happening. They’re meant to listen and well, they have a chance to also voice their opinions and tell us if they agree with what we’re doing because we are working in their community and they should also get to decide’.

7.3.2 Continuity in community participation

For the villagers of the small farming community of El Triunfo, community participation has been a local tradition. Through community organization they have managed to carry out large-scale projects like the building of a school, a health post and three piped water projects. Currently, the community-level social development council, a group made up of five middle-aged men, is implementing these projects. The council members have been in different community committees and projects together for over thirty years. The support they receive from each other and the shared experience of participation has contributed to the constancy of their work. As don José said:

‘We have all gone through this [process of participation], we have all been deputy mayors, council members. The people ask us to do it, they come to look for us and who are we to say no? So instead of saying no, we say yes… and we sacrifice because it is hard work. It is work we do after we come home from our jobs. We go to meetings, report on them and act on projects and we do it at our expense. Not everyone can do it and we can’t do it all the time but we stay… we don’t shy away from our responsibility’.

Personal values and beliefs play an important role in the way these council members see their participation in community issues. As don Miguel reflects:

‘I never really had a chance to go to school and then I took a three-year theology degree in the dioceses and I was around so many people with degrees and they were so smart… and I felt bad about myself until I realized that studies are important but your ethics, your morals, and your spirituality are even more important because it is through them that we come to know what is essential: a life of service to others’.
The group first got together as a community committee because of the need to rebuild the village after a 7.5 Richter scale earthquake devastated most of El Triunfo in early 1976. After the earthquake, the state organized reconstruction committees and international charities donated building supplies and food. Don Miguel, don José, don Roberto, don Octavio and don José A started to work together cleaning debris, rebuilding homes, and managed to get enough funds and supplies to build a road from the square in their village to the main road that lead to the town of Palencia:

‘Roberto and me knew how important it was to have a proper road. We needed buses to be able to come all the way here but it was so rocky that the tires would fall apart… With Roberto we organized a plan to get building supplies, some water pipes, and some food so that people here could give up Mondays and instead of going to their fields come work on the road. We used the pipes to take water from the high part of the village to the low part and after many years of work we finished the road and the people that live over there got water!’ (Don José)

Over the next two decades, the council members planned and implemented two major projects: the building of a health post and a piped water project. As with the reconstruction committee, the projects were carried-out with support from outside stakeholders. The municipality, the health center and foreign donors all collaborated with the group. In the course of their career as a committee, they have helped their community by volunteering their time and resources. However, the members know that they cannot continue with the council forever. Don José:

‘Some people don’t know how hard this job is, they think it is easy to serve the community, but just because the outcome seems easy, it doesn’t mean they don’t come from our hard work. We have managed to overcome obstacles but I think our time is coming to an end. We continue because we have projects underway, projects we started and for which we are responsible. If a new council started today all our planning would be lost because people would have to start from scratch… so we will work until someone wants to take over for us’.

The council has tried to involve younger villagers by asking them to participate in specific projects or programs. This has proved difficult because community members with little education and land migrate seasonally to different parts of the country to pick fruit in larger plantations. Young people that finished high school find white-collar jobs in the town of Palencia, so they are not available on a consistent basis either. Another barrier to participation is the lack of economic support for the members of the council. Don Miguel says:
‘People here like to get involved but then they see the expense and say ‘I am poor. I can’t go to the meetings in Palencia. Who will pay for my transport? What about my fields?’ if people don’t have the means, they can’t do it… we put money out of our pockets but it is hard, so it’s easy to understand why they don’t want to stay in the council’.

Don Roberto mentioned how hard it was to keep people involved in the process, especially when it came to expenses and time that should be spent working. New people are scared to make mistakes, he says. The best bet is to start early and teach children how important it is to get involved:

‘People think that if you make a mistake everyone will laugh at you but you just have to learn from that and keep going. It is tough to go to a meeting and not know anything but you pick up things along the way and that helps… José thinks you have to get everyone involved and you can see, his [two-year-old] grandson is always here. He sees everything that we do and learns… so it’s only a matter of time until he starts doing this here, too!

7.3.3 Being a community health worker

The program to extend care provides an opportunity for participation in health at the individual level, and gives villagers the chance to learn new skills and to work closely with their neighbors and with doctors and nurses from the health team. The doctor that leads this team said:

‘Their [the CHW’s] work is very important; it helps me as a doctor so that I can have information [about the people in the community] there when I need it. The CHWs are definitely important because if they are not here, if they are not leaders, then all of our work comes out short. Their main role is to be leaders and to help, so we all work together’.

Through their work as CHWs, villagers have more access to learning and many of them reported this activity as the means to finishing grammar school or health promoter classes. Before starting to work as a community health worker, Esmeralda had only basic reading skills and was forced out of school at a very early age. Her work with the extension of care program provided her with the opportunity to learn new skills. She said:

‘I like this job because we learn new things, we learn them in a clear way so that stuff that used to be blurry, things we only used to hear others talk about, we understand now… it makes me happy to know these things and to work with them’.
Participation seems to be a family tradition in the municipality of Palencia, and many CHWs reported having active parents, siblings or spouses. Shared values that make community service and volunteerism help to encourage people to participate and allows other villagers to value the work that these volunteers do. Doña Irma, the CHW from El Hatillo reflected on the importance of service in her community:

‘... It is my responsibility to do a good job because if you want what’s best for your family, for your children, you also want what’s best for your community. That is my goal in life; to see my children grow and learn more and I tell them that participating is the way to do it. That is my purpose in life and I have served since 2004. It’s just nice to help and teach others so that everyone knows what to do and how to help.’

The position of community health worker provides a space where villagers can put these values into practice. When this is combined with the support they feel from the health system and with the improvements they perceive in their communities, it creates a sense of commitment that lets them deal with the negative aspects of their work. As Doña Aura said:

‘You feel the responsibility to serve because it starts like something you volunteer for and then you see it as something ‘you have to do’. It’s like a duty and you just have to do it. That motivates you, to see it like a responsibility so that when you come home from your normal work and are tired you keep going. It’s the sense of responsibility that keeps you going.’

7.4 Reflections on a process

The people in Palencia participate at different levels of the health system and while their roles and responsibilities might differ, they are committed to improving the quality of life of their neighbors through their actions. In this section we present reflections on what is it to participate and what that means to the people that were a part of this study.

Don José from El Triunfo reflects on the role that participation can have in his community:

‘Do you know what we do? All this delinquency and psychologically ill young people. Some even have educated and well-to-do families but they don’t have peace in their lives or hearts so they think that the solution is to jump off a bridge. They go around killing people left and right, and they are organized. Well, if they are organized to do evil, why can’t we do it to help people get off that bad road so that they can have a life that respects and praises God and that is in harmony with your neighbor... but if my neighbor is an extortionist, a truant, I’d be afraid of him killing me. There’s no need for that.’
Don Miguel from El Triunfo talks about the sense of importance and urgency that characterizes the way he and his fellow council members participate and how focusing on what he needed to do helped him deal with the hardships of the job:

‘There is no time to lose. First you have your family and then your community. This is true at the social as well as at the religious level... for the most part our motivation comes from our needs and the enthusiasm and interest we have in improving our family and everyone else’s lives. And when people say ‘let’s do it’, we feel good, like when neighbors help each other. The motivation is our community. If no one else stands up, you have to... when you stop paying attention to the community’s lack of support, you start improving your community.’

The community health workers in the village of San Guayabá are a married couple that have been involved with the extension of care program for several years. They have worked together and supported each other in their work. To them, being a CHW is about working with the people, as Mario said:

‘What I like is to go out and see how people live. I like knowing about the needs people have, working with them. That is what really made me want to be a CHW: I like people. I have always liked to serve the community in many different ways and to collaborate with people.’

As time passes and community health workers gain more experience, they start to be recognized as local leaders. This means that the municipality and other institutions that work in Palencia contact them to ask or share information. Doña María, a CHW from Manantial said:

‘People look up to me because once they saw me as a leader they always try to get me involved in everything. I give the community information and I help in any way that I can. No problem for us to do it, to help a little.’

The people in Palencia see the importance of promoting participation in health, even if at times they are unsure of how to do it. One stakeholder from the health center said:

‘Like everywhere, there are some people that participate and some people that do not. What we need is more communication about what we are doing, what we hope to do and what we need to do it.’
Discussion

8.1 The role of the Guatemalan context in shaping participation

In order to analyze the process and experience of participation in health we must first examine how the historical, social and economic context has contributed to shape what participation is and how it is carried out today. Guatemala is a post-conflict society that has historically been characterized by high levels of political repression, violence and non-democratic governments (Luján Muñoz, 2004). Violence has permeated the public and private spheres of life and has influenced the way people interact with institutions at the national and community level (del Valle, 2004). Today, the Guatemalan state recognizes the role that democracy and strong institutions can play in the process of obtaining fair and equitable social and economic development, and that participation is at the center of attaining this goal (MINUGUA, 2004). As a result, the state’s perception on social participation has changed from a negative to a positive one. In this section, we discuss the factors leading to this change and that helped to shape the process of participation in the country in general, and specifically we will focus on how the context has impacted social participation in Palencia.

In Guatemala, the violence levels that came as a result of the armed internal conflict hit their peak in the years directly after the signing of the Alma-Ata declaration. The violence was directly linked to the Guatemalan state’s policies on restricting participation and systematically eliminating community leaders (CEH, 1999). Members of the opposition, high school and university students, as well as community leaders were the target of kidnappings, torture, forced disappearances and assassinations. This, and the structural poverty and exclusion that many rural or ethnic population groups faced, contributed to keeping university enrollment and graduation levels low when compared to regional standards (Kobrak, 1999). In addition, the constant threat of violence and the breakdown of the structures of organization ripped the social fabric and made the public and political life to be perceived as a dangerous activity with few benefits (Duque, 2007). The villagers in Palencia saw very little of this violence when compared to other areas of the country, but the geographical isolation that protected them also limited their growth opportunities. The Palencian countryside was not a place where insurgent groups could hide and carry out their work, and so the geographical location of the municipality protected its people from the violence. However, this also created the disadvantageous position of isolation, and throughout the 20th century there were very few chances for economic growth and social development.

It has been more than fifteen years since the peace accords were signed and the internal armed conflict officially ended, but the negative consequences of it are visible in Gua-
temalan society today. Public spaces are still perceived by citizens as administrative and apolitical, and although participation levels have gone up (Brett & Rodas, 2008; Torres-Rivas & Rodas, 2007). Duque (2007) argues that government representatives still perceive community participation as a threat to the processes they need in order to carry out their own jobs. Despite this, social participation is the main policy for the country’s decentralization process and participation is now being promoted as a way to reduce levels of social and political exclusion, a means to achieve higher equity levels among population groups and a tool for healing the social fabric that was badly damaged during the violent 20th century.

The legal framework that has been in place since 2002 highlights the role that communities have in the social and economic development process with the aim to improve the overall quality of life and life opportunities for all Guatemalans (Congreso de la República de Guatemala, 2002a), and according to Brink-Halloran (2009), Guatemala has entered a new period of democracy where basic political rights exist and are respected. Community empowerment, democratic decision-making, and the achievement of consensus between government authorities and civil society representatives are at the core of the legislation. However, the return to democracy and the end of the war were processes promoted by Guatemalan elites that sought to take power from both the guerrilla and the army, and not necessarily the result of organic, grassroots movements (Robinson, 2001). As a result, and despite the legal framework, the country continues to have weak institutions with a thin institutional culture that is unable to consistently disperse power among the different stakeholders (Barnes, 2005).

For countries like Bolivia and Mexico, decentralization was the result of the efforts of a political party or coalition that sought to strengthen the legitimacy of institutions as well as their own popularity. However, in Guatemala the decentralization process that started in the 1980s and that coincided with the return to democracy was mainly perceived as an administrative process that aimed to take power away from a weakened central state and not necessarily a means to empower local populations (Fernández, 2008). Values like equity and social justice, and even social and economic development were not part of the discourse on decentralization until the drafting of the peace accords in 1996. This helps to explain why, despite the importance that the legislation places on involving local communities in all steps of the policy processes, it lacks accurate directions for the implementation of participatory schemes and why there are no regulatory systems in place that would help to guarantee a more balanced participation from all levels of civil society and from the government (Brink-Halloran, 2009; Johnson, 2001).

In contrast to the Guatemalan case, Brazil’s experience with social participation in health shows that regulations that have clear benefits and penalties can contribute to improving participation levels (Atkinson & Haran, 2004). The lack of concrete guidelines as to how to implement participation processes and foment the involvement of community stake-
DISCUSSIONS

holders hinder the Guatemalan process while the Brazilian schemes have an easy to follow structure with specific federal funds that serve as a way to encourage the involvement of many sectors of civil society. This contributes to create a system where the policies provide a way to balance out the personal interests of more powerful stakeholders (Barnes & Schattan, 2009; Elias & Cohn, 2003). Because the Guatemalan legal framework is vague and open for interpretation, participants interpret it based on their abilities, agendas and on the resources they have. This leaves each municipality free to have their own version of what participation in health means.

8.2 The process of participation in Palencia

The people of Palencia can participate at three different levels within the health system, and each of these reflects different stages of the policy cycle. Participation at the municipal-level health commission is aimed at shaping national policies to local needs and at setting priorities so that the available resources are used in the most appropriate way. At the village level, community-level social development councils help to identify needs, provide feedback and implement projects. Finally, individuals can participate in the health system by volunteering as community health workers. In this section we discuss the process behind the work of the municipal-level health commission, of the council in El Triunfo and of the CHWs and the role that power, values and group work play.

8.2.1 Starting from scratch: institutionalizing participation in health at the municipal level

The municipal-level health commission did not begin meeting until late 2008, when the institutional stakeholders developed a health promotion plan that called for an improvement in the coordination levels between institutions that included a pilot project in two villages. The institutional participants where chosen depending on their capacity to bring resources for coordination to the table, and the community-level stakeholders were presented with the opportunity to have a priority project implemented in their villages in exchange for the pilot experience. Historically, these spaces have only existed to facilitate institutional coordination. The community-level stakeholders lack the power resources necessary to be a part of this established collaboration. However, the view of these community-level stakeholders reflects the spirit of inclusion and dispersion of decision-making power that is at the heart of the policies (Barnes, 2005), a view that is not directly in conflict with that of the institutional stakeholders, who are also coping with the social, political and policy-related changes that are impacting the ‘traditional’ way of working.

Unbalanced power relationships between stakeholder groups can lead to a concentration of decision-making power that favors the better educated and better funded institutional stakeholders, something that can make community-level stakeholders feel
Disenchanted with the participation process (Boschker, 2009). However, both stakeholder groups in Palencia report feeling positive about the process and like everyone is participating to the extent of their time and financial capacities. For the institutional stakeholders, the duty to participate has come as an extra responsibility in an otherwise full workweek. They lack the time, the tools and the incentives to be a part of the commission, and it is only because of the possibility to use their already scarce resources better that they keep attending the meetings. Community-level stakeholders can only attend some of the meetings, since they do not have the economic capacity to travel and miss work. It is clear that the results obtained from the effort put into attending the meetings outweighs negative feelings over decision-making power. Starting the kind of democratic, inclusive participation process that the Guatemalan legal framework calls for requires time, continued support and clear guidelines that can help participants while they learn the skills needed to be a part of this process.

8.2.2 Building on what we already have: community and individual participation

The social participation processes that occur at the community level in Palencia, both through village councils or individual participation, have a longer trajectory and are better established than that of the municipal-level health council. This is because unlike participation at the municipal level, there have been previous experiences of implementing community-level committees as well as projects aimed at training community members as health promoters in the recent past. These processes have benefited from the geographical isolation that protected Palencia’s villages from the destructive effect that the armed internal conflict had in other areas of the country (Flores & Ruano, 2009). This allowed for community practices, values and institutions to continue with little or no interruption to their respective processes. In this section we will discuss the community-level council in the village council in El Triunfo, a group that has had a decades-long experience, and how the work that long-time CHWs carry out is influenced by their family lives and the role that agency and personal and group values play in these processes.

The community-level social development council from El Triunfo has been able to achieve a participation process that spans over thirty years in length thanks to contextual and personal elements that provide the background to this participation process. Solidarity and a desire to serve are at the core of the work that these council members do. The deep bond that exists between these men and their village comes from having a tight-knit community where the inhabitants feel connected to each other through the similarities in their work, values, family bonds and religious beliefs (Durkheim, 2008). The group has developed an identity that is based on their desire to improve the quality of life for themselves, their families and their neighbors, and that is grounded in the deep friendship that these men have built through the shared experience of participation and
accomplishing long-standing goals (Giddens, 2005). The council’s successful experiences and achievements have contributed to highlighting the role that social participation can play in improving community life.

The community health workers in Palencia have developed a tight social network that allows them to link their communities and the health system together through their work in a way that provides a deep feeling of personal satisfaction (Ramírez-Valles, 1998). This happens through recognizing the role that volunteerism and serving the community plays in improving community life. The experience of having close family members that have active community lives provides them with adequate support, guidance and motivation from people that recognize the importance of the work they are carrying out (Daniels et al, 2005). At the institutional level, the relationships that exists between the CHWs and the health team are based on mutual respect and teamwork, and the bonds that exist between all the participants of this process have been developed organically and come from the uniqueness of the context, the interaction of their personalities and shared values. This also contributes to the feelings of satisfaction and creates opportunities for personal growth, which also plays a role in keeping the CHWs engaged in their every day work.

8.3 Values and social participation in health

The experience of participating in the health system is felt and understood at the individual and at the group or community level through the building of common meanings, the sharing of values and by the interpretation that individuals award to their actions and motivations to participate (Herman-Kinney & Reynolds, 2003; Hill et al, 1996). To fully understand the role that social participation plays in Palencia’s health system we must look at how the people that are involved in the process define and explain it in the context of their work and their everyday lives. In this final section of the discussion, we will consider how values and new skills are put into practice, and we will use them as a way to look at the participation process from the perspective of the participants themselves.

People in Palencia see participation as a process that has allowed them to make decisions on health policy, implement projects and improve the overall quality of life of the community. The participants have been able to establish processes based on self-reliance, equity, social justice and community protection, values that are also central to the primary health care approach (WHO/UNICEF, 1978; WHO, 2010). Because these participants share the same values as those enshrined in the Alma-Ata declaration, their actions have deeper meaning and provide a different level of personal satisfaction. As a result, the people in Palencia see their work as a tool that helps them to stay involved in what they view as a larger process of community development. From this perspective, the embodied experience of participation provides them with an intrinsic satisfaction that can be shared with family and neighbors, and that enriches their lives in a meaningful way (Csordas,
2002). This could help to explain why many of the community members have continued to be involved in their community’s health commission or working as CHWs over long periods of time.

This process of participation has provided more than just a platform for community members to express their values through tangible actions in their villages, it has also given them the opportunity to learn skills that can be put to use in other areas of their lives. Through their experiences with the health system, the community health workers and the council members from El Triunfo have gotten involved in other projects, be they personal or community-oriented. Overall, the experience of participation and the results the villagers have obtained have contributed to provide satisfaction when circumstances like lack recognition, payment or severe resource constraints could have deterred continued participation.

In order to understand the impact that social participation in health has on community life we must analyze the outcome of the process alongside how participating has influenced the lives of the participants. From the outsider perspective, Palencia shows a wide range of types of participation that can go from simple information provision or cost offsetting to ones where community members are partners with more powerful stakeholders (Arnstein, 1969). However, the stories of participation presented here reflect a deeper experience than one that can be analyzed only by its outward results. If community participation is seen as a manifestation of personal and shared values then the outcomes of the process go beyond implementing a policy (Csordas, 2002). Through the experiences presented here we see how participation in the community, even with what is considered utilitarian or token community involvement, has lead to personal growth and that the work that the people in Palencia carry out on a daily basis provides deep satisfaction and personal gratification (Arnstein, 1969; World Bank, 1996).
Conclusion

In Guatemala, social participation is recognized as the main policy in the on-going decentralization process, and is backed up by a legal framework and by a social development council scheme that aims at creating open spaces for participation. It is in these spaces that stakeholders come together to discuss and implement actions. This process of participation is illustrated in figure 9 (see below). The model shows how the different roles and power resources that each stakeholder has had a bearing on the activities and level of involvement they can have in the process.

Figure 9: Participation, power and health policy: a model for understanding stakeholders’ roles and collaborations in public health policy

One of the key activities within the council scheme is the identification of needs at the local level, an action that is carried out by community and institutional stakeholders that are working ‘on the ground’ and that have a deep involvement in the everyday lives of the community. These needs travel up the participation structure and are discussed at the community, district and national levels. The discussions serve to inform policy makers, who are institutional stakeholders that plan and prepare national-level health policies. As these policies come down from the national to the district and the community level, they are shaped to fit the specificities of the context. The model shows how these activities are intrinsically linked to two different kinds of power, which are power to formulate policy and power to implement it.
Because these two types of power are complementary but dependent to the amount and the kind of resources available at each level of the participation structure, in the model they are represented by a set of complementing triangles. Stakeholders that have high levels of power to formulate policy will have better access to financial, human and material resources and information, while stakeholders that have higher levels of power to implement policy will have resources like community legitimacy, knowledge of local culture, values and mores, and a deep understanding of local social processes.

This helps to balance the structure of participation and can act as a reminder of abilities that lie outside of the scope of one individual stakeholder, making the role of collaboration more important. The lines in the model indicate the places where we can locate stakeholders from the MoH, health district and from the community. In these three examples we can see how the power to formulate policies becomes smaller as we reach the base of the model and how the power to implement policies increases as we get closer to ‘the ground’. This shows that in this kind of participation processes, no stakeholder is truly powerless.

In Palencia’s municipal-level health commission, the institutional stakeholders saw their role as decision-makers, while they allocated basic implementation roles to the community-level stakeholders. The commission was seen as a space for collaboration and coordination of scarce resources that are needed to reach coverage levels. Because they are mostly stakeholders that work at the district level, they have power to formulate and to implement policies. However, the lack of inclusion of community-level stakeholders when it comes to truly discussing and making decisions on health issues means that the commission is not using all the available resources. The coordination of financial, human and material resources is just as important as the legitimacy that comes from having community leaders involved in more steps of this process. This can only be truly obtained through meaningful partnerships with community leaders and other stakeholders that are working on the ground.

When it comes to participation at the community level, the council members of the village of El Triunfo present an example of how meaningful participation can result in achieving long-standing community goals. This group of men has been able to maintain a participation process for over three decades, a process emerging from the community level and that has engaged district, national and international-level stakeholders. The foundations of this process are the deep bonds of friendship they share and the individual beliefs that through their work, the lives of the people of their village can improve. In this way, these community stakeholders have managed to use their low levels of policy formulation power to plan social development projects through the development of collaborations with more powerful stakeholders while using their high levels of policy implementation power to ensure that these projects are carried out and sustained over long periods of time.
CONCLUSION

At the individual level, the community health workers of Palencia have also managed to establish deep and meaningful bonds with their communities; bonds that are based on shared values with their neighbors, co-workers and with the people from the health center. Their participation process has allowed them to learn new skills and build capacities that have put to use in their work. Stakeholders like Doña Maria and Don Mario have channeled their leadership skills and the recognition they have from their communities into their work, bringing higher levels of legitimacy to the program and strengthening the relationship between the communities and the health system.

This thesis has shown that social participation in health is a complex process that can provide enriching experiences that can lead to personal growth, to the fulfillment of long-standing community goals and to the improvement of collaboration between stakeholders. In order for these processes to be successful, they need clear frameworks and policies that reward the involvement of stakeholders from the national, district and community levels. Community participation processes need strategic support from outside stakeholders and enough time for them to produce strong and legitimate institutions like the council from El Triunfo, which has earned trust from community and from municipal-level stakeholders. It has also showed that when it comes to individual participation, a combination of intrinsic motivation based on personal and shared values and beliefs combined with encouragement from external stakeholders can empower community members to learn new skills and to stay involved in health issues at the community level. What is needed now is more structured support for these processes in the form of policies, funds that facilitate community participation in policy formulation and capacity building at all levels in the skills needed to develop collaborative relationships and mobilize people and resources to address their own needs.
Images from Palencia

Image 5: Palencia’s landscape

Image 6: Palencia’s health center

Image 7: Central office at Palencia’s Health Center
Image 8: ALR with the staff at Palencia’s health center.

Image 9: ALR with the director of Palencia’s health district

Image 10: Fixing the car
Image 11 & 12: The entrance to El Triunfo announcing the construction of the extension of the water project

Image 13: The council members from El Triunfo and Don Roberto’s son and grandson near one of their water sources. From left to right: Don Maynor and his son (Don Roberto’s family), Don Octavio, Don Miguel, Don Mario and Don José A. Sitting down: Don José
Image 14: The doctor from the PEC in consult in a community in Palencia

Image 15: The health team giving a lift to kids on their way from school

Image 16: Community clinic built with the CHW's stipend

Image 17: Don Mario, working with the children in his community
Acknowledgements

One’s life has value so long as one attributes value to the life of others by means of love, friendship, indignation and compassion.

Simone de Beauvoir

‘My time as a PhD student has been an adventure, an opportunity to learn from the world around me and from the people that were kind enough to share their work, their thoughts and their lives with me during this journey. My life during these four years would not have been as rich, as fun or as interesting without the family and the many friends I made as a doctoral student. For that, I am eternally grateful. I would like to begin by thanking the Umeå Center for Global Health Research and the Swedish Council for Working Life and Social Research for providing the funds for my doctoral education. I am also grateful for the generous donation from the Swedish Center Party. Finally, I would like to thank the Swedish Research School for Global Health for the opportunities and the funding. It was thanks to these institutions that I was able to take learning opportunities that helped me have a more rounded and practical doctoral education.’

I realize how lucky I am to have Miguel San Sebastián, Anna-Karin Hurtig and Kjerstin Dahlblom as my supervisors. Thank you for always being available, for your support and friendship, for the comments and discussions. I have learned so much from all of you, and I am grateful for the things I learned outside of the world of academia too. Kjerstin, thank you for teaching me how to knit socks, and make prinsesstårta and chocolate balls; you have made my family, my friends and me happier, warmer in winter and maybe a little wider around the waist. Anna-Karin, thank you for always having your door open to me when I was confused, nervous, or when I just needed someone to talk to. I will always remember your kindness and our laughs. Finally, Miguel: thank you for this opportunity, for all your advice, your honesty and for all your help during this time. Thank you for always being available as a supervisor and as a friend. I am particularly thankful for those weekly trips to Mercadona during my time in Granada, it really is very fun to go to the supermarket with your supervisor!

When I came to Umeå, I never expected that I would make so many new friends. Gerd, thank you for always helping me find my way home, for fixing my bike, for our late night walks in the forest in search of flowers, and for all the jokes we have shared in these years here. Alison, thank you for opening the door to your house, for always making me feel at home and for sharing your family with me. Thank you for all the deep conversations, for all the light ones, for bread making and for reminding that sometimes, we don’t really need to have recipes. Katrina, thank you for your friendship. You are a wonderful
ACKNOWLEDGEMENTS

and special friend. Thank you for the fikas, the excursions downtown, for the encouragement and for being like a sister to me. I am looking forward to that purple house. Paola, thank you for always being there, no matter how busy life is, for listening and for all your advice but most of all, for learning a few new words every time we have a conversation. You are well on your way to becoming a linguist with me as a friend. I hope I can pay all your kindness back with more than cookies. Isabel, thank you for all those laughs, for your advice, and mostly, for always taking the time to have vegetarian Spanish food at your table. Anna-Britt, thank you for all your advice and help, for being my opponent in all my seminars and for our shared love of baked goods and pop culture. Finally, to Mariano and Claudia, thank you for being the only ones that haven’t needed me to translate my ‘Guatemalan’ into Spanish! Thank you Cynthia, Angélica, Kristina L, Anna Rosén, Anna Myleus, Mojgan, Ann Sörlin, Gasto, Rose, Stephen, Haile, Tesfaye, Kidanto, Ari, Barnabas, Yien Ling, Kristina E, Fredinah, Laia, Fredik, Curt, Raman and Lucia. I would like to thank everyone at Epi for the fikas and explanations about ‘Sweden’, but I would specially like to thank Birgitta, who is always in the middle of so many things but still found the time to make me feel at home.

To my friends from Guatemala, thank you for never letting distance and time zones get in the way of our friendship. My special thanks to Alejandro, for staying up late at night to talk and laugh, and for reading all my drafts, even when they made very little sense. Thor, thank you for all the adventures and the laughs. We should start talking about that branch office soon. Finally, thank you Julio for the support, friendship, help and all the good music. Thank you Ana Isabel, Héctor, Marielos, Hugo, Christie, Fernando, Andrea, Anita, and Liby and Rosalinda. Roz, you are a special and wonderful friend. Thank you for our walks and for our escapades together. No one makes better cupcakes than you!

To the Phé Funchal family, my special gratitude for teaching me the value of perseverance: Denise, thank you for being my writing partner; Marcelo thank you for always pushing me to follow my chosen path, even when the road was dark and unclear, my love to both of you.

My special gratitude goes to Walter Flores and Fidel Arévalo, who introduced me to public health. You have been wonderful teachers. I value and appreciate everything I learned from both of you.

I would like to thank my big, wonderful family for all their support and love. I am grateful for my parents’ long explanations about the world, for sharing all their books even when I was not very careful with them, and for teaching me how important it is to follow your dreams. I love you, mami and papi, and you are always in my heart. Lelo and Mamachita, you are the best grandparents in the world, and the funniest ones by far. To Rodolfo, Guillermo, Manuel, Cristina and my little Javier, my life is better because I am part of our team. Thank you for always making me laugh and for never letting me feel like I am far away from you. I am proud to be your big sister.
Finally, to the person that has walked this road with me, I would like to extend my deepest gratitude for all the love, support and companionship during this time. Magnus, thank you for always being there for me, for your comments and contributions, for all the things that you have taught me and for all those things that we are still to explore. Thank you for all our evenings on the blue couch and for never being far away, even when we have been oceans apart.
References


Flores W & McCoy D. 2004. ‘Making progress –slow, but with grounds for some optimism. Maternal and child health and equity in Guatemala: an analysis of the clinical, health system and underlying reasons, with recommendations for national and international stakeholders’. Background paper for the MDG taskforce on maternal and child health.


Maginn PJ. 2007. ‘Towards more effective community participation in urban regeneration: the potential of collaborative planning and applied ethnography’. Qualitative research 7: 25-43.


REFERENCES


