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CHAPTER 1: INTRODUCTION

During the last decades the scope of mental health has broadened, and increasing numbers of stakeholders are entering the mental health arena. As a consequence, the need for the exchange of knowledge and visions on 'good mental health care' among stakeholders has increased. Within this multi-stakeholder setting, the voices and visions of service users are considered to be of central importance. However, their involvement faces particular challenges and requires extra attention. Moreover, significant changes in mental health care systems are required if they are to better acknowledge and integrate service user knowledge. In this thesis, I explore the contribution of service users involvement to the realization of 'good mental health care' and investigate possible strategies for effectively integrating service user knowledge in mental health care.

Background

Developments in mental health care

Contemporary visions on mental health are well represented by the definitions of **mental health** and **mental health care** provided by World Health Organization (WHO, 2001): *“a state of wellbeing in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.”* Mental health care is: *“related to the promotion of wellbeing, the prevention of mental disorders, and the treatment and rehabilitation of people affected by mental disorders”* and *“requires multi-sectoral action, involving a number of government sectors and non-governmental or community-based organizations.”*

Over the past century, visions on mental health have significantly broadened under the influence of four major developments.

A first development involves an increased emphasis on **community-based care** (Goodwin, 1997; Thornicroft et al., 2010). Although the community has always provided care to people with mental illnesses, it has recently become more incorporated in the regular care system. This was a particular consequence of the deinstitutionalization movement which replaced long-stay psychiatric hospitals with more open community-based services, mainly to address the poor living conditions of service users in psychiatric hospitals. Deinstitutionalization became prominent in the 1950s with the discovery of the first antipsychotic drugs. By incorporating community based-services in regular care, mental health care stretched its borders beyond the institution into the community.

A second important development is the increased attention for **recovery, rehabilitation** and related models from the 1990s onwards (Amering & Schmolke, 2009; Anthony 1993; Corrigan et al., 2007). These concepts and models focus more on the external spaces of everyday life and management of mental health in communities, and attribute great value to individual user’s rights and voices. Important underlying principles of these approaches are that they are service user and demand driven, health focused, holistic and based on individual strengths. Scholars often introduce models focusing on recovery, strengths and resilience as new paradigms, challenging the biomedical model which tends to be more professional and supply driven, illness focused, mechanistic and deficit based, emphasizing the vulnerability of people with a mental illness. The biomedical model explains mental health problems in terms of specific causal mechanisms located in the body, a vision which especially shaped mental health services during the second half of the 20th century and which remains highly influential (Double, 2002; Engel, 1977; Rosenberg, 2002). Although practice may not always be as polarized as is sometimes suggested by scholars, there are clear signs of a trend in which there is more attention for positive, recovery-

oriented and holistic views on mental health, additional to the biological and physical aspects.

Fourth, mental health care (and health care in general) has, over the past decades, been marked by a shift from supply-based care to more **demand-based and service user-centred care** in which care is increasingly shaped by needs and preferences of service users. This is partly a consequence of the push for restructuring health systems due to policy failures, perpetual crisis and tight budgets (Tomes, 2006). Increasing attention for democracy and the disability rights movement have also stimulated this trend (Gostin & Gable, 2004; WHO, 2001). In mental health care, this shift was specifically enhanced by the emergence of the psychiatric consumer and survivor movement in the early 1970s in the USA and Europe, promoting the rights and autonomy of people with mental illnesses.

The developments described above all illustrate the broadening scope of mental health and mental health care, affecting concepts, actors, practices and domains of mental health. Concepts and definitions of mental health appear more health-oriented, holistic and inclusive, and the number of actors involved has expanded, thereby changing the roles of many people and organizations involved. Mental health care practices now include a wider range of services as mental health care is expanding beyond the borders of traditional psychiatry, paying more attention to society, communities and the external spaces of everyday life of people with mental illnesses. As a consequence, increasing numbers of stakeholders are being involved and knowledge is being gathered from different disciplines and sectors. However, these developments also bring with them a range of challenges which will be discussed in the next section.

Challenges in of mental health care

Despite the advances and developments of the past century, the field of mental health still faces many challenges. An important challenge lies in the **limited understanding of the precise aetiology of mental health problems** (Herrman et al., 2005). Mental illnesses are generally considered to be determined by multiple and interacting biological, social and psychological factors. However, the mechanisms leading to mental illness are not yet well understood and remain an important topic of research and debate. In addition, diagnosis of mental illness is often problematic. There is little evidence that mental illnesses currently described in the Diagnostic and Statistical Manual of Mental Disorders (DSM) are separated by clear boundaries and, as a consequence, researchers are questioning the validity of classifications (Kendell & Jablenski, 2005; Stein et al., 2010). The recently published fifth edition of the DSM stimulates further debate on the ties between mental health care and pharmaceutical industries and the ‘overmedicalization’ of normal human behaviour as a consequence of the increase in the number of mental illness included in the DSM (Double, 2002; Watts, 2012).

The **global context of mental health** is increasingly acknowledged, drawing attention to the enormous burden of disease caused by mental health problems (Patel et al., 2006; Patel, 2010; WHO, 2004). The emerging understanding that mental health problems account for a much larger share of the total burden of disease worldwide than previously assumed, demonstrates the enormous **treatment gap between mental health care needs and the services available**, especially in low- and middle-income countries (LMICs) (Patel et al., 2006; WHO, 2001). However, addressing this treatment gap is often difficult due to a lack of priority given to mental health care, limited resources, differences between regions, and culture-specific aspects of mental health and illness. Another problem is the small number of studies on mental health related topics from LMICs (Herrman et al. 2005). Western approaches are often transferred to other countries without evidence of their local effectiveness and appropriateness. In addition, Western concepts are generally used, despite the fact that concepts and definitions of mental health and mental illnesses vary between situations and cultures (Herrman et al., 2005). Cultural aspects of mental illnesses also gain limited attention in the dominant DSM classification system and the responsiveness of services to cultural issues appears limited (Alarcon et al., 2009; Wolffers & van der Kwaak, 2013).

Defining what constitutes ‘good care’ is a central challenge which is strongly related to the limited understanding of mental health and cultural and situation-specific notions. What is defined as ‘good care’ depends very much on the personal perspective and, as with beauty, ‘good care’ is very much in the eye of the beholder. Given the widening scope of mental health, there is an increasing number of stakeholders, all with different knowledge, needs and visions on ‘good care’. Communication and negotiation between practitioners, researchers and service users is necessary to define and realize ‘good care’ jointly (Abma et al., 2009; Hisschemöller & Hoppe, 1996; Widdershoven et al., 2009a). A fundamental question in such negotiations is: what is ‘good care’? Obtaining a shared understanding on ‘good care’ poses particular challenges, as visions and ideas of stakeholders vary widely and can even conflict with each other. This is even more challenging in a multi-cultural context in which an even wider range of notions on mental health, illness and ‘good care’ can be found (Kleinman, 2001; Ryder et al., 2008; Waxler, 1977). Furthermore, the dominant visions and ideas of care, such as reflected in the diagnosis of mental illness as described in the DSM, are often resistant to change. They leave limited room for views of diverse stakeholders or give less priority to these perspectives, thereby hampering a discussion of ‘good care’ based on equality and democracy. This is especially evident in the involvement of service users who, traditionally, have had a much weaker voice than mental health professionals and researchers (Thornicroft & Tansella, 2005).

Service user involvement in mental health care

Growing service user involvement is a central trend in mental health care developments described above, especially visible in the emergence of recovery and rehabilitation models, and the shift towards demand driven and service user-centred care. Several arguments for service user involvement have been put forward. First, involvement of service users in health care service planning and evaluation is thought to increase the quality of care. Users are experts on their own illness and need for care, and their perspectives often differ from those of professionals (Borrill, 2000; Lindow, 1999; Thornicroft & Tansella, 2005). User involvement might especially complement the current limited understanding of mental illness and contribute to the development of alternative approaches to mental health and illness (Faulkner & Layzell, 2000; May, 2001). Second, service user involvement is thought to increase democracy in mental health care. From this perspective, service users have the right to be involved in different aspects of care because they are the end-users and primary stakeholders (Beresford & Croft, 1993; Fiorino 1990). A third reason for actively involving service users is that it can enhance the acceptance and legitimacy of decision-making and services provided (Rowe and Frewer 2000; Whitstock 2003). Fourth, user involvement may be directly beneficial to the user by being therapeutic and by promoting social inclusion (Hickie & Kipping, 1998; Sayce & Morris, 1999).

Service user involvement is also central to many challenges that mental health care is currently facing, especially in defining 'good care' in a multi-stakeholder setting. An important barrier is that many researchers and practitioners attribute great value to objectivity and evidence-based practices, engendering resistance to subjective, experiential knowledge (Telford & Faulker, 2004). In addition, there is the notion among some professionals that mental health service users are unable to make valid statements about therapy and treatment because of their 'impaired cognitive state' (Rose, 2003; Beresford, 2002; Rush, 2004). Stigma also appears to influence service user involvement in mental health because it can lead to exclusion of users from participation (Corrigan, 2004; Littlewood et al., 2007). Other, more general concerns about user involvement in health care relate to the representativeness of service users as the 'wrong' perspectives might be given too much weight, the lack of scientific evidence supporting the views of users and the financial and time costs of user involvement (Boote et al., 2002; Caron-Flinterman et al., 2007; Tait & Lester, 2005; Telford & Faulkner, 2004). In addition, some service users do not want to take part in the decision-making process (van de Bovenkamp, 2009; Waterworth & Luker, 1990) which can be seen as a challenge if the wish not to participate is rooted in the stigma surrounding mental illnesses or low self-esteem.

Currently, service user involvement in mental health care predominantly takes place in high-income countries such as the USA, Australia, the UK and the Netherlands. These are countries with strong, more developed mental health care systems (Peck et al., 2002; Simpson and House, 2002). In contrast, there is a dearth of studies focusing on service

user involvement in LMICs. However, service user involvement is gaining ground globally (Herrman, 2010; Wallcraft, 2011; WHO, 2001). Some scholars have specifically proposed service user involvement as a way of strengthening the relatively weaker mental health care systems in LMICs, because it would stimulate these systems to become more needs-based and responsive (Saraceno et al., 2007; Underhill, 2002). Differences between mental health care in high-income countries and LMICs elicit particular challenges and opportunities for service user involvement. In high-income countries, service user involvement and knowledge is often appreciated to some extent and regulated by policy and legislation. The predominant challenge in these settings is finding the most effective strategies for integrating service user knowledge more fully into mental health care systems. These settings require research focused on exploring ways to optimize processes and outcomes of service user involvement. In many LMICs however, service user involvement initiatives often occur on a small scale, at the grassroots level and in research. In LMICs, these initiatives often have a predominantly explorative character, investigating the potential of service user involvement in developing and strengthening mental health care systems.

Aim of the research

In the dynamic context of mental health, the role of service user involvement is increasingly valued in defining and improving mental health care. However, for service user involvement to be able to contribute optimally to ‘good care’ which is more responsive to the needs of different stakeholders, changes are required in current mental health care systems. Service user needs and knowledge need to be acknowledged and integrated into mental health care systems. Little is yet known about how these changes in the role of service user involvement in mental health care systems can be brought about. Therefore, this thesis aims to:

gain insights into the contribution of service user involvement to realising good mental health care, by investigating the nature of service user knowledge and by identifying possible strategies for both its integration with other stakeholders’ knowledge and for embedding service user involvement in mental health care systems.

Outline of the thesis

This chapter (**Chapter 1**) provides an introduction to the central topic of this thesis: service user involvement in mental health care. The next chapter (**Chapter 2**) elaborates on theory and concepts related to knowledge integration in mental health care, service user involvement and Transition Theory. **Chapter 3** gives an overview of the main objective and research questions, the research approach and methodologies of the different studies, the validity checks applied, and the composition of the research teams.

Chapters 4 to 12 present the findings of this thesis. Together, these nine chapters describe six different studies, all exploring service user involvement in mental health care. The chapters are divided into two parts to distinguish between service user involvement in countries with strong mental health care systems and countries with weaker mental health care systems. The different chapters have either been published or are under review for publication and have been slightly adapted to ensure consistency in terminology, reference style and lay-out.

Part 1 (Chapters 4 to 8) investigates service user involvement in different initiatives (case studies) carried out in the Netherlands, a country with a strong mental health care system. **Chapters 4 and 5** address the role of service users in the development of the crisis card, a tool for documenting individual care preferences in advance of potential crises. The chapters focus respectively on the perceived effects of the crisis card and the implementation of the crisis card by a local mental health care institution. **Chapter 6** describes a study that actively involved service users investigating perceived effects of the making and screening of a video about service users' perspectives on long-term mental health care, and subsequent discussions. **Chapters 7 and 8** both focus on the involvement of service users in clinical guideline development in mental health care. While Chapter 7 provides an overview of service user involvement in the development of multidisciplinary clinical practice guidelines developed in the Netherlands since the year 2003, Chapter 8 focuses on service user involvement in a specific guideline, namely the Guideline on Employment and Severe Mental Illness.

Part 2 (Chapters 9 to 12) explores service user involvement in LMICs with weak mental health care systems. **Chapter 9** involves a literature study of role of service user knowledge in LMICs from the perspective of Transition Theory. Chapters 10 to 12 present further explorations of important aspects related to the role of service user involvement in specific LMICs, Vietnam and the Philippines. **Chapter 10** focuses on perceptions of mental health and illness, and their link to health-seeking behaviour in Vietnam. **Chapters 11 and 12** present findings from a study carried out in the Philippines, reporting respectively on stress and coping of migrant domestic workers, and the resilience of migrant domestic workers.

Finally, the main research question and related sub-questions are revisited in **Chapter 13**. The chapter first presents the main conclusions and discusses the findings presented in this thesis. Next, issues concerning validity of the findings are discussed. The chapter concludes with recommendations for future research.

CHAPTER 2: THEORETICAL BACKGROUND

In this section, the main concepts and theories used are discussed. I start by setting the stage for stakeholder involvement by elaborating on the dynamics of the mental health field in terms of the increasing complexity and growing attention for integration of knowledge. The chapter continues with a discussion of the concept of service user involvement which plays a crucial role in current trends in mental health care. In the final section, service user involvement is approached from a systems perspective, arguing that service user involvement requires a transition in current mental health care systems.

Knowledge integration in mental health care

Given that stakeholders have different opinions, experiences and needs regarding mental health care, an exchange and integration of their perspectives and knowledge is needed in order to establish a shared understanding of what constitutes ‘good mental health care’. As the scope of mental health care becomes broader and the number of stakeholders grows, the complexity of mental health care increases (Plsek & Greenhalgh, 2001). As a result, the need for knowledge integration becomes more urgent while, at the same time the process of integrating knowledge from different stakeholders becomes more complex and challenging. To visualise this situation a typology of the complexity of knowledge integration in mental health care is developed (see Figure 2.1). This typology will be used to further discuss knowledge integration in mental health care in this section. I first describe the two dimensions depicted in the figure: the scope and number of stakeholders. Next, I elaborate on the four different areas depicted in the figure.

Number of stakeholders	Scope	
	Narrow	Broad
Low	1. Low complexity of knowledge integration	2. Medium complexity of knowledge integration
High	3. Medium complexity of knowledge integration	4. High complexity of knowledge integration

Figure 2.1: Typology of the complexity of knowledge integration in mental health care

The scope of mental health care and complexity

The scope of mental health care may be either narrow or broad. A broad scope refers to a holistic approach to mental health issues which emphasizes the interrelatedness of different aspects of mental health. Such views are increasingly influencing mental health care but little is known, as yet, about how different aspects interact with each other. As a consequence, there is uncertainty about the approaches required when taking a broad perspective on mental health. Plsek and Greenhalgh (2001) indicate that complexity increases with the degree of uncertainty about the required approaches. A narrow scope

involves a focus on particular aspects of mental health. Such a focus can be necessary or preferred in some cases, especially when there is a high degree of certainty on these specific aspects.

The dynamics described above can be illustrated by the difference between illness focused approaches which are narrower, and health focused approaches which are generally broader and more holistic. For a long period, mental health care focused predominantly on illness and absence of illness. As Keyes states (2005, p.546): “*under this assumption, if society can effectively treat mental illness, then more individuals will become mentally healthy.*” However, there is increasing evidence that mental health and mental illness are separate unipolar dimensions, This means that mental health is much more than the absence of mental illness and that many other factors have to be considered when addressing mental health. As a result, there is an increased focus on positive aspects of health and wellbeing and their relation to illness. Mental health services are subsequently starting to orientate themselves towards promoting wellbeing as well as treating illness (Slade, 2010). However, the mechanisms underlying mental illnesses are not yet fully understood, and there is even more uncertainty about the mechanisms influencing mental health which can thus be characterized as an issue of high complexity.

Another example of how the scope of mental health is related to complexity involves the increasing attention for societal aspects of mental health. With the growing evidence of the social determinants of mental health and the promotion of community-based care, mental health care expands its focus into the realms of the community and wider society. Although care directed at the individual level (pharmacotherapy and psychological therapy) remains the standard, a growing number of interventions are situated in societal settings, such as forms of supported living and care farms (Iancu et al., 2013). The focus on social determinants also involves relational aspects of mental health with, for instance, the role of social networks and social support being widely discussed in literature (Kawachi & Berkman, 2001; Thoits, 1995). Researchers are starting to connect the different types of knowledge by investigating individual determinants in the context of environmental and societal determinants (Rutter, 2006; Meaney, 2010) but this research is still in its infancy. According to Rose (2011, p 6), the merging of these different types of knowledge creates a new territory in mental health care: “*where a focus on the external space of everyday life and of the expert management of mental health ‘in the community’ meets a focus on the internal space of the brain and the ambitions of the experts of the neuromolecular gaze.*”

Number of stakeholders and complexity

Complexity is also influenced by the *number of stakeholders* that are involved in care. Although collaboration with other stakeholders may not always be required or preferred, initiatives in which different stakeholders collaborate in providing mental health care are increasing. As the number of stakeholders increases and different stakeholders become involved in the discussion on ‘good care’, the risk of disagreement among stakeholders

increases. Plsek and Greenhalgh (2001) indicate that care becomes more complex when the degree of disagreement is higher.

The increase in stakeholders is particularly related to the rise of community-based initiatives and the establishment of stronger links between mental health care, other health sectors and social services. Trends of growing attention for service user involvement also play a role. As a result, the single practitioner has a less prominent role and user-provider relationships are more often situated in a multidisciplinary team. An example of this is Assertive Community Treatment (ACT) in which a multi-disciplinary team, including social workers, nurses and psychiatrists, cares for a certain group of service users and shares responsibility for individual service users (Marshall & Lockwood, 2002). Another example is the growing number of service users who are working as experiential experts (or expert users) providing mental health services in collaboration with other practitioners (Repper & Breeze, 2007; Stevens & Tanner, 2006). However, integrating knowledge and experiences of different actors often creates tensions because of changing roles. Some practitioners may object to changing roles and tasks as they hang onto traditional specialisms, pointing to the negative effects of role strain and role confusion (Brown et al., 2008). Other tensions may arise because of the challenge of defining 'good care' in a multi-stakeholder setting as different stakeholders are likely to have different perceptions, visions and needs. For example, service users may have a more holistic and social approach (e.g. practical issues of care, issues in daily living) than researchers and practitioners who more often focus on particular aspects of mental health problems (e.g. diagnosis, drug treatment) (Telford & Faulkner, 2004). If different stakeholders are to work together and make shared decisions, a negotiation of different types of knowledge, visions and needs of the stakeholders is required.

Typology of knowledge integration

Different levels of knowledge integration may be appropriate for different situations in mental health care. Below I describe the typology presented in Figure 2.1 to indicate that the complexity of knowledge integration can be low, medium or high. Current trends in mental health care are increasingly characterized by situations in which knowledge integration is highly complex. Shifts in knowledge integration may occur as a result of an increase in the number of stakeholders involved or a broader scope of mental health.

Examples of care situations that require a relatively low complexity of knowledge integration include a psychiatrist prescribing an antipsychotic to a person suffering from schizophrenia, or a person receiving cognitive behavioural therapy (CBT) from a psychologist for acrophobia (fear of heights). The complexity of knowledge integration is low because these situations revolve around specific topics (e.g. prescribing drugs or CBT) and few stakeholders are involved. Often the professional is the only decision-maker in such situations. However, the level of knowledge integration may increase when service users become more involved in decision-making in the treatment process. A situation in

which different types of knowledge co-exist without interfering might sometimes be preferred, for pragmatic reasons or, for example, because knowledge can become more articulated without interference from other types of knowledge.

There are also care aspects which require a medium level of knowledge integration. This is the case when there is a broad scope of mental health and few stakeholders involved. For example, when a general practitioner meets a person with depressive symptoms, recognizes that the complaints could be related to marital problems, problems at work and a recent diagnosis of diabetes. A broad scope is likely to elicit the involvement of other stakeholders (in the example, other specialists, family or employers may become involved) and, subsequently, the complexity of knowledge integration increases.

Medium complexity may also apply to situations in which there is a narrow scope of mental health but a high number of involved stakeholders. This is, for example, the case when a multidisciplinary team of practitioners sits together to discuss the aggressive behaviour of a person with a psychotic disorder. However, when there are many stakeholders involved, it is more likely that knowledge about different aspects is introduced (in the example, the psychiatrist links the aggressive behaviour to medication, while a nurse connects it to visits from the service user's family) which increases the complexity of knowledge integration.

An increasing number of aspects of mental health, however, are characterized by a high level of knowledge integration as a result of both the broadening scope of mental health and growing number of stakeholders. A clear example of this is Individual Placement and Support (IPS), a type of employment support which assists people in their efforts to achieve steady employment in mainstream jobs. IPS takes the interests and motivations of a service user as a starting point and integrates employment services with psychiatric services.

Service user involvement in mental health care

“More emphasis on the person's own goals and strengths will be needed, with integration of interventions which promote wellbeing into routine clinical practice” (Slade, 2010, p1). This statement illustrates that care is increasingly centred on a positive image of service users and all aspects of their daily life, and is increasingly shaped by the user's views, needs and knowledge. This is indicative of the central role of service users in knowledge integration in mental health care. In this section, I elaborate on the concept of service user involvement. First, a brief introduction to service user involvement in mental health care is provided. Next, the notion of service user involvement in mental health care is conceptualized by elaborating on its central concepts: service user (who is the service user?) and involvement (at which level and to what extent are users involved?)

Service user involvement in mental health care

The active involvement of end-users of health care in decision-making processes is increasingly accepted (Amering & Schmolke, 2009; WHO, 2001). This development is linked to several social, political, scientific and economic changes in the past fifty years. The emergence of anti-psychiatry and survivor movements in the early 1970s in the USA and Europe has been particularly influential (Peck et al., 2002; Tait & Lester, 2005; Tomes, 2006). These movements emphasized a positive image of people in distress, portraying them as individuals who had the strength to 'survive' the psychiatric institutions. They also involved a rejection of forms of professionally led initiatives and information from professionals. Another equally important development has been the shift from supply-based care to more demand-based and service user-centred care, taking place since the 1990s as consequence of the need for restructuring of the mental health system due to policy failures, perpetual crisis and tight budgets (Tomes, 2006). More recently, the World Health Organization (WHO, 2001) became an important proponent of service user involvement because the seminal World Health Report *Mental health: New Understanding, New Hope* recommends involvement of communities, families and consumers in development and decision-making regarding mental health policies, programmes and services.

In the early 1990, service user involvement was characterized by a *consumerist approach* due to the introduction of an internal market in health care (Barnes et al., 2000; Rush, 2004). Service users were increasingly regarded as consumers who should be able to exercise choice in the services they used. Professionals and care providers were expected to provide information that would enable these consumers to make informed decisions. From the mid-1990s, the concept of *empowerment* became more influential, addressing the imbalance of power between those who provide services and those who use them. When service users gain more access to information and become more in control of their situation, they will start claiming influence on decisions affecting their care. More recently, service user involvement is discussed in terms of *stakeholding* and *partnership*, providing the opportunity for all those with a stake to participate as partners, thereby placing service user involvement in a multi-stakeholder context (Barnes, 2000).

The service user

The language that is used to describe service users in mental health varies widely. Users may be referred to as patients, consumers, survivors or service users (Telford & Faulker, 2004). It appears difficult to find an acceptable terminology to describe people with mental illnesses in the context of mental health care. People are, for example, uncomfortable with the term consumer because it suggests a marketplace and free choice, while mental health services often provide limited choice or no choice at all. The term patient, on the other hand, may be rejected because it determines people in terms of their

illness as “*objects of the clinical gaze of mental health professionals.*” (Tait & Lester, 2005, p. 168). The notion of users as survivors is strongly related to the survivor movement and anti-psychiatry ideology from the 1990s. Currently, the most popular terms in the mental health field are service user and user. However, this implies that an individual with a mental illness has an understanding of his illness and already decided to seek mental health care. As a consequence, persons not seeking or using mental health care are excluded.

In this thesis, I will refer to service users when referring to persons using mental health care services. In other cases, I will more generally refer to ‘people with mental illnesses’ or indicate why other terminology has been chosen.

Involvement

Service users can be involved in various aspects of mental health care. Roughly five areas can be distinguished: *individual treatment, service delivery and evaluation, research, education and policy.* Service user involvement is most frequently described in the context of provision and evaluation of mental health services (e.g. Crawford et al., 2003; Happel, 2008; Robert et al., 2002; Rutter et al., 2004; Simpson & House, 2002) and in education (e.g. Barnes et al., 2000; Forrest et al., 2000; Wood & Wilson-Barnett, 1999; Terry, 2012), while studies on user involvement in individual treatment (e.g. Loh et al, 2006; Storm & Davidson, 2010; Tee et al., 2007), research (e.g. Rose et al., 2010; Telford & Faulker, 2004; Thornicroft et al., 2002; Trivedi & Wykes, 2002) and policy are less common (e.g. Kayiira, 2010). Service user involvement can have many different forms and intensities. Below, the concept of service user involvement is further explored by characterizing involvement in terms of the degree of involvement and the level of involvement. Next, a matrix combining these terms is presented.

Degree of involvement

To distinguish between different levels of service user involvement, different models have been developed (Arnstein, 1969; Hickey & Kipping, 1998; Oliver et al., 2008). Hickey & Kipping (1998) propose a model which describes user involvement in mental health care along a continuum of participation. They distinguish four degrees of involvement: information, consultation, partnership and user-control. Below, a brief description of the four levels is given:

Information: The user is provided with information but is not included in the decision-making process. This is done, for instance, through websites and information leaflets, and by verbal information provision by professionals.

Consultation: Service providers seek the views and opinions of the service user but use their own discretion in deciding whether or not these are considered in the decision-making process. Examples of consultations methods include surveys, interviews and focus groups but also professionals asking for service users’ preferences when making a decision on treatment.

Partnership: Power is redistributed following negotiations between the user and service providers so that decisions can be made jointly. This is done, for example, in cases of shared decision-making, committees and panels, and dialogue sessions.

User control: Power is redistributed so that the user makes the decision. The user decides whether or not to involve other people in the decision-making process. This is the case in user-run initiatives.

Area and level of involvement

Peck et al. (2002) describe the level of involvement in terms of the type of interaction in which the service user is engaged. At the *micro-level*, service users are involved in interactions with other service users and professionals. Interaction between service users usually takes place in the context of service user organizations and self-help groups, while interactions between service users and professionals generally take place in a treatment setting with the relationship being between an individual service user and a professional. At the *meso-level*, service users engage in local services, referring to the organizational level of a mental health care provider, including the planning, delivery and evaluation of services. At the *macro level*, service users participate in the organization of overall services, involving general service and care planning, often at the regional or national level in a policy context, such as regulations or clinical practice guidelines.

Matrix of service user involvement

The two frameworks of the level of involvement and the degree of involvement are combined to construct a matrix of service user involvement (see Figure 2.2). Recognizing that there may be some overlap between the boxes in the matrix, user involvement activities in mental health care can be located in the matrix, and each box provides an example of service user involvement. Activities in which service users interact with other service users are not included in the matrix because this thesis focuses on service user involvement in the context of multi-stakeholder settings.

Degree of involvement	Level of involvement		
	<i>Micro</i> (Individual treatment)	<i>Meso</i> (Local services)	<i>Macro</i> (Overall services)
Information	Professional decides on care plan	Service user receives information about services	Service user reads a clinical practice guideline
Consultation	Professional decides on care plan after inquiry with service user	Client council in mental hospital	Service user consultation in development of clinical practice guidelines
Partnership	Professional and service user co-decide on care plan	Service users are part of a team providing services	Service users participating in guideline development group
Control	Service user develops care plan	Service user run mental health services	Service users initiating and financing development of clinical practice guideline

Figure 2.2: Matrix of service user involvement, including level of involvement and the scale of involvement (based on Peck et al., 2002).

A systems perspective on service user involvement

In the previous section, it became clear that service user involvement is promoted throughout mental health care, a trend which is strongly related to the shift in mental health care systems towards more needs-based and service user-centred care. The system-wide implications of service user involvement emphasize the relevance of a systems perspective to service user involvement. Such a perspective provides insights into the role of service user involvement in mental health care systems and in system change, and more specifically in the embedding of service user involvement at different levels of mental health care systems. This section explores service user involvement from a mental health systems perspective by applying concepts and theories from System Innovation and Transition Theory as conceptual frameworks.

Health systems are defined by the World Health Organization (2000, p24) as: “*All the activities whose primary purpose is to promote, restore, improve or maintain health, protect people against the impoverishing effects of illness and ensure that those who need care are treated with dignity and respect.*” The mental health care system is a subsystem of the health care system but can also be considered as a system in itself which is composed of a range of sub-systems involving, for instance, different types, settings and doctrines within mental health

care. This section commences by elaborating on the need for change in mental health care because of persistent problems. Subsequently, the concept of mental health care systems is further described by characterizing systems in terms of culture, structure and practice. Next, the idea of systems change is introduced by describing important notions from System Innovation and Transition Theory, including the multi-level perspective and the multi-phase concept. The section concludes with a brief discussion of how initiatives involving service users - so called niche experiments - can be scaled-up using a transdisciplinary approach.

Persistent problems and need for change in mental health care

In the introduction of this thesis, some of the main challenges in current mental health care systems were mentioned, including are the enormous burden of mental illnesses and the limited understanding of mental health and mental illness. Other important problems are the expanding costs of care and, mainly in LMICs, a lack of resources and access to care. Such problems can be considered *persistent problems*, a term to signify problems that are enduring and systemic in nature as they are deeply rooted in existing institutions and routines, therefore requiring a systems perspective (Loorbach, 2007). Persistent problems are characterized by limited success in addressing the problem, despite the fact that many different stakeholders are involved (Broerse & Bunders, 2010). In addition, fruitful collaboration between these stakeholders is difficult to bring about, partly because different stakeholders approach the problem from their own perspective and role, and partly because adequate knowledge integration does not take place. This highlights the need for integrating knowledge of different stakeholders when addressing persistent problems in systems.

Persistent problems form an important force for change. Currently mental health care is responding to persistent problems by trying to shift from demand-based care to care which is more needs-based and service user-centred. Part of this trend is a broadening of scope of mental health care and an increase in stakeholder involvement and collaboration. Within the context of these developments, the growing involvement of service users plays a central role as people with mental health problems bring a wealth of previously unheard knowledge and experiences to the discussion table. However, integration of their knowledge with other types of knowledge poses particular challenges. Therefore, when aiming for mental health care which is needs-based and service user-centred, special attention should be devoted to finding ways of optimizing and embedding service user involvement in mental health care systems. This requires structural system change. To describe such fundamental changes in mental health care systems more thoroughly, it can be helpful to consider them to be transitions. Rotmans et al. (2000, p19) define a transition as: *“A gradual process of social change in which society or an important subsystem of society structurally change.”* Transitions are generally long-term processes, covering one or more generations. Transition Theory has been applied to a wide range of phenomena,

such as agriculture and economies and has, more recently, been used to describe transitions in health care (van den Bosch 2010; Broerse & Bunders, 2010).

Culture, structure and practice in mental health care systems

Within Transition Theory, systems are often characterized in terms of structure, practice and culture. The cluster of these three aspects is also referred to as a constellation. Van Raak (2010, p52) proposes the following definition of a constellation: *“A set of interrelated practices and relevant interrelated structuring elements that together both define and fulfil a function in a larger societal system in a specific way.”* The mental health care system is composed of multiple constellations of structure, culture and practice:

Structure involves how people organize the things they do, either physically, institutionally or financially, for instance through mental health legislation, policy, regulations and guidelines. A concrete example is the organization of mental health care through mental health institutions or community-based modes of care. Structures steer the actions of actors and play both a constraining and a facilitating role.

Culture refers to ways of thinking, mental models and perceptions. Culture can reflect notions about the structures, practices and social function of the system, and different actors can have different perceptions and opinions on this. Within the field of mental health, culture involves, for example, stigma, paternalistic attitudes of professionals towards service users, explanatory models of mental illnesses, the biomedical model and recovery thinking.

Practice involves the actual actions within constellations, thus what people actually do, how they work and behave. This mainly refers to the user-professional relationship but can also relate to the interaction between professionals and managers or government officials. The prescription of anti-depressants or provision of psychotherapy, experienced power differentials between service users and psychiatrists are examples of practices in the context of mental health care.

Within a constellation, structure and culture are the elements which may enable or constrain the practices of actors involved in the constellation (Giddens, 1984). The actors are individuals or groups acting in unity who play an important role in relation to the constellation. Their actions make up the practices in the constellation, and their choices are influenced by the structure and culture within the constellation, but they also influence these aspects to some extent themselves. The constellation as a whole determines the societal role of the constellation: it produces goods, but also determines the meaning of those goods within the system at large and in society. A transition within the system implies a fundamental change of structure, culture and practice (Rotmans & Loorbach, 2010).

Understanding transition: multi-level and multi-phase

Two concepts that are considered important for understanding transitions in social systems are the multi-level perspective and the multi-stage concept. Below, I briefly introduce both concepts.

Multi-level perspective

The multi-level perspective provides the setting for transitions by describing the dynamics between different levels in the system: landscapes, regimes and niches (see Figure 2.3).

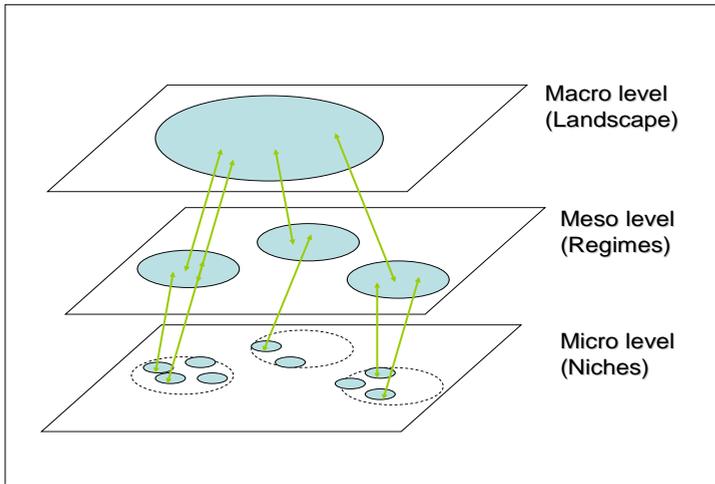


Figure 2.3 The multi-level model (based on Broerse & Bunders, 2010)

The *landscape* level refers to the broader societal context of transitions. It involves, for example, demographics, culture, and values. Changes at the landscape level can stimulate or hinder changes at other levels within the system. Examples are the shift towards demand-based mental health care and empowerment of service users.

The *regime* level encompasses the dominant structure, culture and practices through which actors interact. The regime has a stabilizing function by guiding the actions and ways of thinking within the system. It involves the dominant care models and routines in provision of mental health care, for example the prescription of lithium for bipolar disorder and the diagnosis of mental illnesses according to the DSM.

At the *niche* level, actors experiment with innovations in the systems. Experiments may be initiated when current regimes prove insufficient solutions for problems experienced by the actors in the systems. As solution pathways at regime level are resistant to change, initiatives take place at the niche level where there is room for testing new ideas and practices. Niche experiments do not necessarily affect the regime and landscape level in systems. Successful niche experiments which are able to spread, expand or multiply can impact the current regime, and may ultimately become part of this regime. Landscape

trends may hinder or facilitate this process. Initiatives of service user involvement, the central focus of this thesis, represent typical niche experiments.

Multi-phase concept

The multi-phase concept describes the process of transition as it develops in time, distinguishing four phases, namely: pre-development, take-off, acceleration and stabilization. These phases are represented by an S-shape (see Figure 2.4) (Loorbach, 2007; Rotmans et al., 2000).

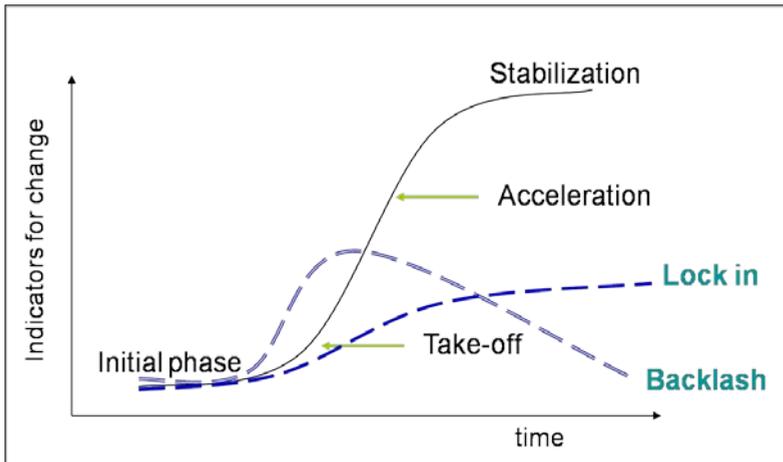


Figure 2.4 Four phases of a transition process (based on Broerse & Bunders, 2010)

The four phases are:

Pre-development: In this phase significant change is not visible, and a status quo is maintained. Although experiments may take place at the niche level, there is limited impact at the regime level. If change does take place, it is incremental and mainly meant to optimize existing structures and practices.

Take-off: This is where change is slowly becoming visible. It often involves initiatives emerging from the niche level that are being scaled up. This becomes possible when the push for such an innovation is stronger than the constraints.

Acceleration: In this phase, change is accelerated and change becomes clearly visible in the system at regime level. Changes at the landscape level can function as catalysts for change.

Stabilization: The pace of changes decreases and a new status quo is reached in the stabilization phase of transition. This means that new structures, cultures and practices have become embedded in the system.

Not all transitions, however, follow the 'S-curve' of the multi-phase model. Sometimes acceleration of changes only takes place to a limited extent and the transition does not

reach its full potential. This situation is called ‘lock in’. A ‘back-lash’ may also occur when initiated changes are reversed, returning to the situation of the pre-development phase.

Service user involvement as a system innovation appears to be near the take-off phase. New initiatives and experiments have emerged at the niche level, and some changes are being scaled up. However, service user involvement is not yet embedded in dominant structures, culture and practices. There are important differences between weaker mental health care systems, mainly found in LMICs, and more developed health care systems in high-income countries. In weaker mental health care systems, service user involvement is generally in the pre-development phase and sometimes in an early take-off phase, while in more developed mental health care systems it is often in the take-off phase and seems, in some cases, to be heading towards acceleration. This results in different challenges and opportunities for the embedding of service user involvement in mental health care systems. In weaker mental health care systems, it might be easier to influence culture, structure and practice at the regime level because they are less firmly embedded in systems. The more developed, mature health care systems are considered to be more rigid (van Raak, 2010).

Transition management: fostering niche experiments

Although a transition cannot be controlled or directed, it might be possible to influence its speed and course. *Transition management* (Rotmans, 2005) is the term given to efforts to influence transitions, focusing on both processes and outcomes of transitions. Processes focus on the joint learning processes of diverse actors while outcomes focus on sustainable and responsible development as outcomes. Transition management proposes that experiments at the niche level can be facilitated by drawing more actors and more problems into the so-called transition arena. By drawing more problems into transition arenas, the applicability of niche experiments increases, providing more opportunities to connect to the regime level. By involving more actors, niche experiments enlarge their impact and actors have the opportunity to transfer knowledge from niche experiments to other contexts. The involvement of regime actors can enhance the niche experiments. In addition, involving more actors provides the opportunity to integrate knowledge from an increasing number of stakeholders which stimulates the ability of niche experiments to address persistent problems.

Experiments in which different societal actors from various disciplines are engaging in sharing knowledge and experiences require a *transdisciplinary approach*. Transdisciplinarity is defined by Thomson Klein (2001, p7) as: “*A new form of learning and problem solving involving co-operation between different parts of society in order to meet complex challenges of society.*” Transdisciplinary approaches appear to be highly applicable to managing transitions in mental health care systems because they acknowledge complexity and emphasize knowledge integration through stakeholder involvement. More specifically, experiments on service user involvement are most likely to lead to changes in mental health systems when they take place in transdisciplinary settings where different types of

knowledge and diverse actors are brought together. In a transdisciplinary setting, actors learn about what changes are needed in terms of structure and competences in order to facilitate transitions in the mental health care systems. Structural change is needed in incentives and procedures related to service user involvement. In terms of competences, professionals, service users and other actors need to learn about each other and develop the knowledge, skills and attitudes needed for the proposed transition (Broerse et al., 2010).

CHAPTER 3: RESEARCH DESIGN

This thesis explores the role of service user involvement in shaping mental health care. This topic is addressed through a number of studies. In this chapter, the objectives, main research questions and the sub-research questions are first presented. This is followed by a description of the research approach used to answer the main questions, including an overview of the different studies that form the building blocks of this thesis. Thereafter, research teams involved in the different studies are listed. Finally, issues related to validity are addressed.

Research questions

The increasing complexity of mental health and the need for appropriate approaches to knowledge integration of a multitude of stakeholders were considered in the previous chapter. Service users can play a central role in this process but, to date, there are limited insights into the role of service user involvement in mental health care systems. Therefore this research aims to: gain insights into the contribution of service user involvement to realising good mental health care by investigating the nature of service user knowledge and by identifying possible strategies for its integration with other stakeholders' knowledge and for embedding service user involvement in mental health care systems.

The main research question that guides this thesis is:

What is the contribution of service user involvement to realising 'good mental health care', and how can service user knowledge be integrated effectively in mental health care?

In this thesis, the concept of 'good mental health care' refers to the notion that 'good care' can only be defined in a dialogue between stakeholders. As stakeholders have different opinions, experiences and needs regarding mental health care, an exchange of their perspectives and integration of knowledge is needed to establish a shared understanding of what constitutes 'good mental health care'

Based on the main research question the following four research sub-questions are formulated:

1. *What is 'good mental health' care according to service users?*

This sub-question focuses on providing insights into the voice of service users. The involvement of service users brings in new types of knowledge and experiences, as people with mental illnesses have needs, values and opinions that are often different from those of other types of stakeholders. Inclusion of service users' voices affects definitions of 'good care' and integration of their input in decisions has implications for mental health care. To gain insights into the type of knowledge that service users bring to the discussion table, a case study approach is applied in which the contributions of service users are investigated and described. Potential implications for mental health care are assessed.

2. *How can service users be involved effectively in mental health care?*

Although the number of initiatives involving service users in mental health care is increasing, little is known about how this can be brought about effectively. There is limited knowledge on the process and outcomes of service user involvement, the potential barriers and facilitators to service user involvement, and appropriate methods. To gain insights into these aspects of service user involvement, a case study approach is applied in which real-world examples of processes of service user involvement are assessed.

3. *How can service user involvement be embedded in mental health care systems?*

For service user knowledge to be able to contribute to a more needs-based and more responsive mental health care system, significant changes in mental health care are required, affecting the way things are structured as well as ways of working and thinking. This implies that initiatives of service user involvement have to be scaled-up to become more firmly embedded in mental health care systems and related constellations of culture, structure and practice. This sub-question is addressed by a case study approach, studying the lessons of the case studies from the perspective of Transition Theory.

4. *What is the potential of service user involvement in countries with weak mental health systems?*

As discussed in Chapter 2.3, opportunities for service user involvement may be different for weak and strong mental health care systems. Current knowledge predominantly provides insights into service user involvement in strong mental health care systems, found in high-income countries such as the Netherlands. Given that service user involvement is increasingly promoted worldwide as a strategy for a more needs-based, responsive mental health care it is increasingly important to gain insight into the global context of service user involvement in mental health care. Specifically, more knowledge is needed on the factors potentially influencing service user involvement in countries with relatively undeveloped, weaker mental health systems. This fourth research question explores the potential of service user involvement in the context of weak health systems in LMICs. This section discusses the findings with respect to the potential of service user involvement in the context of weak mental health care, for each of the previous 3 sub-questions.

Research approach

This thesis consists of two parts. The first part includes three case studies about service user involvement in the field of mental health in a country with a strong mental health care system, the Netherlands. The first part addresses sub-questions 1, 2 and 3. The second part addresses sub-question 4. It comprises one literature study and two exploratory studies relating to the potential of service user involvement in LMICs. In this section, I first elaborate on the design of the first part (the case studies) and then continue with the design of the second part (the exploratory studies).

Part 1: Case studies on service user involvement

The case study approach is used to study and gain insights into certain phenomena in a real-life setting (Yin, 2003). Thomas (2011, p513) defines case studies as:

“... analyses of persons, events, decisions, periods, projects, policies, institutions, or other systems that are studied holistically by one or more methods. The case that is the subject of the inquiry

will be an instance of a class of phenomena that provides an analytical frame - an object - within which the study is conducted and which the case illuminates and explicates.”

This definition highlights several important aspects of case studies which demonstrate the relevance of a case study approach to this thesis. The holistic approach of case studies allows for studying a broad range of elements of a certain phenomenon in a real-life context. In our case, the phenomenon refers broadly to service user involvement in mental health care. A holistic approach implies an attempt to take the complexity of the field of mental health into account, and acknowledges the importance of various elements such as the different actors that are involved, the events that take place, the decisions that are made and other specific characteristics of the initiatives of service user involvement. In addition, the definition shows that within a case study, different methods may be applied. In this thesis, this mainly involved a range of qualitative methods including document analysis, interviews, focus groups and dialogue sessions which were often used in combination. Furthermore, the case study provides a unique type of analysis in which the case illuminates and explains certain phenomena. In this thesis, the collection of case studies together forms the frame for analysis. However, the different case studies also stand alone as unique studies addressing specific situations.

According to Stake (1995), the selection of cases offers the opportunity to maximize what can be learned, knowing that time is limited. It is therefore justifiable to use convenience selection for the cases and information oriented selection (Flyvbjerg 2006; Yin 2003). We selected cases that addressed our research question, and were open and accessible for investigation. We thereby used the following criteria:

- The case should be situated in mental health care.
- The case should concern an initiative of service user involvement.
- The case should address the role of service user involvement in mental health care systems.
- The case should be accessible for in-depth investigation.
- The case should provide opportunities for answering the scientific questions posed in this study.
- The selected cases should be sufficiently diverse in context and characteristics (e.g. levels of involvement) in order to obtain new insights.

Selected cases

Three cases have been selected to answer the first three sub-questions. Table 3.1 provides an overview of the three cases and characteristics of the setting of the cases. The cases are all situated in the Netherlands, a country with a relatively developed, mature mental health system. There is diversity in the topics of the cases: development of psychiatric advanced directives (crisis card), the use of participatory video in a psychiatric hospital, and guideline development in mental health care. The table below provides an overview of the three cases and indicates the level of involvement of each case according to the matrix

presented in Figure 2.2. The level of involvement is not indicated in this table because it is dependent on the process and outcomes of the cases. This will be further discussed in the results and discussion session in this dissertation. Below, I describe each of the cases in more detail.

Table 3.1: Over view of case study topics and level of involvement

Case study	Level of involvement	Chapter
1 The effects and implementation of the crisis card	User-professional interactions (micro level)/ Organization of local services (meso level)	4 & 5
2 Participatory video as a tool for stimulating service user involvement and dialogue	Organization of local services (meso level)	6
3 Service user involvement in mental health guidelines	Organization of overall services (macro level)	7 & 8

Case study 1: The impact and implementation of the crisis card

This case focuses on the benefits and concerns surrounding implementation of the crisis card (Chapter 4 and 5). The crisis card is a small document - the size of a bank card - containing practical information about preferences for future crisis care and a contact person nominated by the user. The crisis card has its origins in the consumer movement in the UK and emphasizes user involvement in the process. The study describes the findings of an evaluation of the perceived effects and implementation of the crisis card in a local psychiatric hospital. Chapter 4 focuses on perceived effects of the crisis card, while Chapter 5 specifically addresses issues concerning implementation of the crisis card. Data were collected through interviews with participants from six stakeholder groups, including service users, care professionals and crisis card counsellors with personal experience of mental illness (for more details on methodology see Chapters 4 and 5).

In this case, service user involvement takes place both at the micro-level and the meso level. The micro-level - the interactions between users and professionals - involves service users developing and using the crisis card. The meso-level - the organization of local services - refers to the implementation of the crisis card in the psychiatric hospital. The case contributes to answering sub-question 1 by providing insights into the needs, visions and opinions of service users regarding 'good mental care'. In addition, the case helps to answer sub-question 2 by exploring service user involvement in the development and implementation of crisis cards. The case study also addresses sub-question 3 by providing insights into factors influencing the embedding of the crisis card in the structure, culture and practice of local services.

Case study 2: Participatory video as a tool for stimulating service user involvement and user-provider dialogue

This case involved an assessment of a participatory video project involving service users from the long-term care facility of a psychiatric hospital (Chapter 6). This project was initiated by the psychiatric hospital with the aim of improving the quality and organization of long-term care facilities by stimulating the discussion of good care. It consisted of the making of a video representing service users' perspectives on long-term care, followed by a round of dialogue sessions during which health care providers and service users met to watch and discuss the video. The case study assesses the role of the video and accompanying discussion sessions in stimulating dialogue between service users and providers. Special attention was paid to the role of service users in this process. The video was assessed using a Responsive Evaluation approach which is described in more detail in Box 3.1. Data collection involved interviews, a focus group discussion and a dialogue session with care providers, service user, managers and one family member (for more details on methodology see Chapter 6).

In this case, the level of involvement takes place at the meso-level (the organization of local services), because the aim of the project was to improve the quality of 'good' long-term care facilities. However, issues relating to user-professional interactions are also addressed. The case provides insights that contribute to answering sub-questions 1, 2 and 3. It provides insights into: 1) the experiences and perceptions of service users concerning long-term mental health care, 2) the process and outcomes of service user involvement in the participatory video project and 3) the extent to which the project contributed to embedding of dialogue and service user involvement in the psychiatric hospital.

Box 3.1 Responsive Evaluation

In our study, we applied the Responsive Evaluation methodology to evaluate the role of participatory video as a tool to stimulate the discussion of 'good care'. According to Stake (1975), "*Responsive Evaluation is based on what people do naturally to evaluate things: they observe and react.*" Responsive evaluation is a process-oriented approach that focuses on the involvement of stakeholders, and criteria for evaluation are based on the dialogue between these stakeholders (Guba & Lincoln, 1989). The aim of this dialogue is to make explicit the issues of different stakeholders and to facilitate discussion of these issues. In practice, this means that the specific subject of evaluation develops during the dialogue and in agreement with the stakeholders. Over the years, different scientists have reframed and applied the theory to specific work fields including mental health care (e.g. Abma, 2005).

Case study 3: Service user involvement in clinical practice guideline development in mental health

This case involves service user involvement in multidisciplinary clinical guideline development in mental health care. Clinical practice guidelines are documents which aim to guide decisions and provide criteria for diagnosis, management, and treatment in health care in order to improve the quality of care. The study is covered by two studies. The first study describes an inventory of initiatives on service user participation in twelve mental

health guidelines in the Netherlands and an in-depth assessment of five specific mental health guidelines in order to identify facilitators and barriers (Chapter 7). The second study elaborates on one of the five mental health guidelines, the Multidisciplinary Guideline on Employment and Severe Mental Illness (Chapter 8). It entails an evaluation of both the process and outcomes of service user involvement in guideline development and provides insights into the needs and preferences of service users regarding employment and severe mental illness. Specific attention is paid to the use and potential of a dialogue-based approach in the reconciliation of preferences of service users and professionals in the guideline development process. To evaluate the process and outcomes of service user involvement, the reflexive monitoring and action approach was used (see Box 3.2) and a monitoring and evaluation framework was developed. Chapters 7 and 8 provide further details of the research methodology.

In this case, the level of involvement comprises the organization of overall services, at the macro-level as clinical practice guidelines are part of national policy. The case contributes to answering sub-questions 1, 2 and 3. It provides insights into: 1) the needs, opinions and preferences of service users regarding the content of clinical practice guidelines and the realization of ‘good care’, 2) the process and outcomes of service user involvement in clinical practice guideline development, 3) the extent to which service user involvement is embedded in the structure, culture and practice of clinical practice guideline development.

Box 3.2 Reflexive Monitoring in Action

Monitoring and evaluation in this study was a reflexive process, following principles of Reflexive Monitoring in Action (RMA) (Grin & Weterings, 2005; Regeer, 2010). RMA aims to stimulate learning processes in projects by enhancing reflection and dialogue between stakeholders concerning the process and outcomes. This is facilitated by a monitor, who observes the process and gathers related data, and reflects with stakeholders on the activities, enabling optimization of the process. An evaluation framework including criteria to assess the participation process and its outcomes is developed to evaluate service user involvement

Part 2: Service user involvement in weak mental health systems

To gain a better understanding of the potential of service user involvement in the context of weak mental health care systems in LMICs, more insights are needed into a range of aspects related to service user involvement in such contexts. To achieve this, Part 2 of this thesis explores this topic, based on one literature study (Chapter 9) and two exploratory studies describing important aspects of the role of service user involvement in weak mental health care systems (Chapters 10, 11 and 12) (see Table 3.2). Part 2 aims to answer sub-question 4. Below, I briefly describe the three studies. Details on research methods are provided in the respective chapters.

Table 3.2: Overview of case study topics and location.

Study		Location	Chapter
1	Integrating service user knowledge in the development of 'good mental health care' in LMICs	LMICs	9
2	Perceptions of mental health and health seeking behaviour	Vietnam	10
3	Mental health-related needs and resources of female migrant workers	Philippines	11 & 12

Study 1: Integrating service user knowledge in the development of 'good mental health care' in LMICs

In recent years, the importance of service user involvement has been increasingly recognized globally. Service user involvement has been specifically proposed as a way of strengthening mental health care systems in LMICs because of its potential to make these systems more needs-based and responsive. However, there are very few examples of service user involvement in LMICs to be found in the literature. In this literature study, the potential of service user involvement in developing 'good mental health care' in LMICs is explored, using a transition perspective (Chapter 9). Barriers and opportunities are described in terms of the dominant culture, structure and practice of the mental health care system and possible shifts towards integration of service user knowledge. This study first provides insights into current situations and factors hampering knowledge integration. Thereafter, the proposed changes are described, identifying facilitators and possible opportunities for change.

Study 2: Perceptions of mental health and health seeking behaviour in Vietnam

In study 1, the important role of local concepts and explanatory models of mental health is emphasized, and it is argued that these can provide useful starting points for change towards effective service user involvement. Despite the fact that this is a crucial first step in the involvement of stakeholders in improving quality of care, there is limited information on local concepts of mental health and illness. Study 2 focuses on these local concepts of mental health and illness by exploring perceptions of mental health and mental health care among community members, family members and health workers in urban Vietnam (Chapter 10). This study describes the perceptions of mental health of community members, family members of people with mental illness and health workers, and their ideas concerning appropriate help-seeking behaviour. The study included both quantitative (questionnaires) and qualitative methods (focus group discussions).

Study 3: Resilience of female migrant workers from the Philippines

Study 1 identified approaches with a broad focus on wellbeing and approaches which connect mental health care to livelihood issues, which can be considered to be

opportunities for integration of service user knowledge. Study 3 focuses on these livelihood issues in combination with wellbeing by investigating the mental health of female migrant domestic workers from the Philippines. These women face many migration-related stressors affecting their mental health. Currently, there is an emphasis on these women's problems and vulnerability, while there are few insights into strengths and resources of women and their communities that may reduce the risk of mental health problems. The study is covered by two chapters. Chapter 11 involves an assessment of stress and coping of female migrant domestic workers from the Philippines in different phases of the migration process: prior to migration, in the country of destination and upon return to the Philippines. Chapter 12 describes a range of factors that potentially contribute to the resilience of female domestic workers from the Philippines, exploring the way in which these factors affect stress and wellbeing in the context of livelihoods. The study combined quantitative (questionnaires) and qualitative methods (focus groups).

Validity

Multiple strategies have been used within this study to minimize the effects of researcher bias and to enhance the validity of the results and conclusions. The strategies comprise the use of:

Rich data: Throughout the research, primary data was extensively documented. Interviews and focus group discussions were audio taped and transcribed. Extensive notes were made of meetings including date, aim and participants, and other observations.

Triangulation: A variety of methods was used to collect data to reduce the limitations of a specific method and researcher bias. In setting up and conducting the research, more researchers were involved. Also in the analytical phases of the study, multiple researchers were involved. Coding and agreements on coding schemes was undertaken by at least two researchers.

Member checks: Member checks entail systematically asking for feedback on data and conclusions from the people who were involved. After focus group discussions and interviews, a draft summary report was sent to the participants in order to check if the researchers correctly interpreted the input and to confirm accuracy. In this way, mistakes and misunderstanding by the researchers was minimized.

Continuous reflection: During the research, continuous reflection with colleagues, peers and project participants was undertaken to reduce researcher bias.

Saturation: In the project, saturation of the data was sought as much as possible. Interviews and focus group discussions were generally conducted until no new issues arose.

Research teams

The studies presented in this thesis were carried out by research teams of varying composition. The author of this thesis was a member of these research teams, an overview of which is provided in Box 3.3.

Box 3.3 Composition of the research teams

Part 1

Crisis card (case study 1)

- Lia van der Ham (Researcher at Metamedica VU medical centre/ Athena Institute, VU University Amsterdam)
- Yolande Voskes (Researcher at Metamedica, VU medical centre)
- Nel van Kempen (Employee/crisis card counsellor at Pro Persona)
- Guy Widdershoven (Professor at Metamedica, VU medical centre)

Lia van der Ham was responsible for the execution of the research. Nel van Kempen provided organizational assistance. Yolande Voskes and Guy Widdershoven were responsible for the design of the research and were involved as advisors.

Participatory video (case study 2)

- Lia van der Ham (Researcher at Athena Institute, VU University Amsterdam)
- Adeë Bodewes (Former intern at Athena Institute, VU University Amsterdam)
- Frank Kupper (Researcher/ Lecturer at Athena Institute, VU University Amsterdam)
- Jacqueline Broerse (Professor at Athena Institute, VU University Amsterdam)

Lia van der Ham, Adeë Bodewes and Frank Kupper were responsible for executing the research, Frank Kupper was head of the research team. Jacqueline Broerse was involved as advisor.

Clinical guideline development (case study 3)

- Lia van der Ham (Researcher at Athena Institute, VU University Amsterdam)
- Carina Pittens (Researcher at Athena Institute, VU University Amsterdam)
- Saskia van Veen (Researcher at Athena Institute, VU University Amsterdam)
- Roddy van der Horst (Former master intern at Athena Institute, VU University Amsterdam)
- Jacqueline Broerse (Professor at Athena Institute, VU University Amsterdam)
- Maurits van Tulder (Professor at Health Sciences, VU University Amsterdam)

Lia van der Ham, Saskia van Veen, Carina Pittens and Roddy van der Horst were responsible for the execution of this research project. Maurits van Tulder provided advice and direction. Jacqueline Broerse was project leader and involved in the facilitation, analysis and reporting.

Part 2¹

Perceptions of mental health and illness in Vietnam (study 2)

- Lia van der Ham (Researcher at Athena Institute, VU University Amsterdam)
- Pamela Wright (Director of Medical Committee Netherlands-Vietnam)
- Jacqueline Broerse (Professor at Athena Institute, VU University Amsterdam)

Lia van der Ham was the main executive researcher in this research project. Pamela Wright facilitated the research project and provided advice throughout the project. Jacqueline Broerse was involved as advisor.

Mental health of migrant domestic workers from the Philippines (study 3)

- Lia van der Ham (Researcher at Metamedica VU medical centre/ Athena Institute, VU University Amsterdam)
- Raquel Ignacio (employee at Action for Health Initiatives [ACHIEVE], Inc. Philippines)
- Maria Theresa Ujano-Batangan (Associate Professor at University of the Philippines)
- Malu Marin (employee at Action for Health Initiatives [ACHIEVE], Inc. Philippines)
- Ivan Wolffers (Professor at Metamedica, VU medical centre)

Lia van der Ham was involved as research and advisor in this research project. Raquel Ignacio was responsible for organization and execution of the research. Maria Theresa Ujano Batangan, Malu Marin and Ivan Wolffers provided assistance and advice throughout the research project. Malu Marin was project leader.

¹ No research team is listed for study 1 (Part 2) as this involved a literature study.

