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**Connecting visions and voices: Involving service users in realizing 'good mental health care'**

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# CONCLUSIONS & DISCUSSION

# CHAPTER 13

The studies presented in Part 1 and 2 contribute to answering the following research question:

> *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 chapter, I discuss the insights obtained from the different studies according to the four research sub-questions:

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

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

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

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

After addressing each of these questions, issues regarding the validity of the research are discussed. The chapter concludes with recommendations for future research and some final remarks.

# What is 'good mental health care' according to service users?

In this paragraph, I provide insights into service users' perspectives of 'good mental health care' in order to address sub-question 1. First, I describe service users' views on 'good care'. Next, I indicate the extent to which service users' ideas about 'good care' are different or similar to those of other stakeholders.

The findings show that service users have a need for approaches which pay attention to the different roles and ambitions of service users in society, taking both their individual strengths and weaknesses into account. Although illness and related symptoms also play a role, they are merely one aspect of service users' lives. Service users in the participatory video case study stressed the importance of listening to individual service users' dreams and hopes, and believing in the capacity of service users to fulfil their ambitions despite their illness. The importance of considering clinical care in the context of other aspects of service users' lives, such as work, family, relationships and alternative or informal ways of dealing with mental illness, is well illustrated in the guideline development case study which emphasized the need for individually tailored approaches. Guideline recommendations included for example the careful assessment of the strengths and weaknesses of individual service users in specific employment situations. The crisis card case study also demonstrates the importance of respecting service users' wishes, preferences and autonomy in the event of a crisis. The instructions formulated by service users on crisis cards often involved their own social and care network (including family, friends, neighbours and care providers) and stressed arrangements needed (such as taking care of pets) if the person is admitted to a mental institution. By providing such information, the crisis card appeared to contribute to the quality of care from the perspective of service users. Service users' peprspectives highlighted broader societal issues, such as the negative impact of stigma on the lives of people with mental illnesses, which is evident in all of the case studies. The impact of stigma on employment was most evident in the guideline development case study, while the participatory video case study showed how stigma was related to negative stereotypes of service users in long-term care. In the crisis card case study, stigma possibly stopped some service users from drawing up crisis cards because the card would identify them as crisis-prone users of care.

In addition to discussing their strengths, dreams and the social and societal context of their illness, service users also wanted to discuss their illness and symptoms. In the guideline development case study, many service users experienced difficulties at work due to symptoms of severe mental illnesses. Indeed, these symptoms largely determined the type of support they needed. The crisis card appeared to play an important role in giving service users insight into their illness, related symptoms and crisis situations, facilitating self-management. Illness-related aspects were less prominent in the participatory video case study. Instead, issues related to organization of care and services and service user-provider

relationship were more apparent. Service users were dissatisfied with some of the activities provided and their inability to influence them. Such issues were also evident in the guideline development case study. Service users, for example, indicated that there was not enough communication between psychiatrists and social security services, and that services were insufficiently responsive to their strengths and weaknesses. Medication received limited attention in the case studies.

Service users are able to provide unique insights into experiences with care processes from an insider's perspective, giving others a richer understanding of what it is like to cope with mental illness. The uniqueness of service user input seems to be determined, to a large extent, by the attention and weight that is given to particular issues, as well as the way issues are formulated. Service users and professionals often address similar issues but they do this from their own point of view, using their own language and experiences to signify their perspectives. The type of contribution of service users to care processes can be illustrated by the guideline development case study. The case studies and focus group discussions provided few new insights when compared to the scientific literature and the knowledge of professionals. However, participants suggested that service user input helped to keep the process close to the lived reality of service user, thereby increasing its practical relevance. It also functioned as a way of triangulating different types of knowledge, establishing a firmer evidence-base. Service user representatives in guideline development groups had a more distinctive input because they helped to emphasize topics and literature of most relevance to the service user perspective. Findings from the crisis card study suggested that the fact that service users formulated their illness from their own perspective rather than from a professional perspective, helped care providers and families to gain better insights into the illness of the service user. In the participatory video, the narratives of service users helped health care providers to see the familiar stories of service users in a different light.

The perspectives of service users in this thesis are strongly linked to the principles of recovery-based approaches and the strengths model, emphasizing demand-driven, health-focused, holistic and strength-based approaches to care (Anthony 1993; Leamy, 2011; Saleebey, 1996). In the case studies, this did not generally imply a rejection of biomedical approaches, something often proposed in this literature. The findings rather suggest that recovery-based approaches are closer to service users' ideas and views of 'good care'. Service users' perspectives tend to be more holistic and more focused on non-medical aspects of care; these issues generally receive less attention from professionals. These findings are consistent with the literature on service user perspectives on 'good care' (Attree, 2001; Cooper-Patrick, 1997; Schröder et al., 2006; Telford & Faulkner, 2004; van Schaik et al., 2004 van Wersch & van den Akker, 2005). In a study by Attree (2001, p.456), good quality care was characterized by service users and their relatives as: "*individualized, patient focused and related to need; it was provided humanistically, through the presence of a caring relationship by staff who demonstrated involvement, commitment and*

*concern*." Care was described as 'not so good' when it was experienced to be a routine, unrelated to need and delivered in an impersonal way. Recent literature particularly emphasizes the relationship between service users and health care professionals – or the helping alliance – as an important aspect of the experience of 'good care' (Johanssen & Ecklund, 2003; Larrabee & Bolden, 2005; Nolan & Badger, 2005). Although service users and professionals might not be equal, in the sense that one is the provider and the other the receiver of help, an alliance in which the knowledge and expertise of both parties is valued and used to make decisions appears preferable.

In sum, the findings presented in this thesis indicate that care packages that only focus on medical and clinical aspects of care are likely to be insufficient because they treat problems in isolation. Complementing or integrating medical approaches with recovery-focused approaches could be a promising strategy for realizing 'good care' which takes service users' perspectives into account. Furthermore, specific attention should be paid to the service user-professional relationship, and how the exchange and integration of their perspectives may contribute to the development of 'good care'. As a consequence, evaluation of the quality of care should be based on both technical, clinical measures and service users' ideas on 'good care' (Attree, 2001; Perkins, 2001).

## How to involve service users effectively in mental health care?

This section addresses sub-question 2 and provides insights into processes of involving service users effectively in different areas of mental health care. First, methods of service user involvement are discussed in terms of the level and degree of involvement, as well as the outcomes of service user involvement. Next, I discuss the main lessons of case studies for enhancing service user involvement.

### Determining the level and degree of service user involvement

The degree of involvement (information, consultation, partnership, control) of service users is an important factor to consider when discussing service user involvement. It provides insights into the power balance between service users and other stakeholders and service users' opportunities to influence decisions. The degree of involvement in each of the case studies is presented in Figure 13.2 and discussed below.

| Degree of involvement | Case studies (level of involvement) | | |
| --- | --- | --- | --- |
| | Case study 1: crisis card (Micro/Meso-level) | Case study 2: participatory video (Meso-level) | Case study 3: guideline development (Macro-level) |
| *Information* | | | |
| *Consultation* | | X | X |
| *Partnership* | X | X | X |
| *Control* | X | | |

*Figure 13.2: Degree of service user involvement, and level of involvement, in the three case studies*

In case study 1, the degree of service user involvement in crisis cards can be characterized as both partnership and control. Service users were in control because they developed their own crisis card, determining its content with an experiential expert. The involvement of experiential experts in services can also be characterized as a partnership because the experiential experts were part of the team of service providers. In case study 2, service user involvement in the participatory video project occurred predominantly as a partnership. The content of the film was jointly determined by service users and professional filmmakers, and the discussions that were held after the screenings of the video were facilitated collaboratively by professionals and service users. To some extent, the participatory video project can also be described as a form of consultation as the local care provider used the video to consult service users on its policy on long-term care. In case study 3, involving service user involvement in guideline development, the degree of involvement was mainly a form of consultation but resulted, in some cases, in partnership. A number of service users were consulted in  focus group discussions, case studies and questionnaires. Some service users were representatives in guideline development groups, with the aim to form a partnership with professionals in the development of the guideline. However, in many guideline development processes, this took the form of consultation because service users' input did not influence final decisions.

Figure 13.2 shows that when the level of involvement in case studies was higher, the degree of involvement was lower. In other words, when the level of involvement rose from

the micro-level to the meso- and macro-level, the degree of involvement dropped from control to partnership and consultation. It seems plausible to suggest that more opportunities for service user involvement arise at the micro-level because the focus of involvement is their own care and because there are fewer stakeholders and, consequently, fewer barriers to involvement. As the level of involvement increases, care is discussed at an increasingly abstract level and the representativeness of the service users becomes an increasing matter of concern as service users are expected to represent the perspectives of other service users. As a consequence, consultation methods are more likely to be applied, thereby allowing for a greater number of service users to be involved which increases likelihood of adequate representation.

## Outcomes of service user involvement

In all case studies, service user involvement had an impact on outcomes. However, the size of this impact varied while actual effects on care practices were less evident. Below, I discuss the impact of service user involvement in the different case studies in relation the degree of involvement.

In the guideline development case study, the influence of service users on the final guideline text was not always visible. In some cases, service users' input was not specified, making it hard to determine whether service users influenced the outcomes or not. In other guidelines, service user input was included in separate sections in the text. Although their input is identifiable in these guidelines, it is not integrated with other types of knowledge from scientific literature and professionals, and it can be more easily disregarded. It seems crucial to specify service user input, while also integrating it with other input. In the guideline development case study, the guideline developers were committed to doing this, and they accordingly formulated a strategy for reconciling service user input obtained through consultation methods with professionals' peprspectives and evidence from scientific literature. This indicates that although service user involvement using consultation methods could be effective, its impact is highly dependent on commitment from the ones in power (usually professionals or researchers) who need to integrate input from service users into decisions (Hickie & Kipping, 1998).

In the participatory video case study, the involvement of service users played a crucial role in strengthening the impact of the video, bringing forward their perspectives, and facilitating discussion of their issues (Abma, 2005). The focus on service users appears to have contributed to the empowerment of service users (Bery, 2003) and, in particular, the service users who participated in the video. The participatory video project, furthermore, helped to raise awareness of the service users' needs and desires, causing some health care providers to change their way of thinking about service users. In addition, it emphasized the importance of dialogue and collaboration between service users and health care providers and, as a result, service users and health care providers appear increasingly involved with each other and collaborate better. However, the impact of service user

involvement should be viewed in the context of a larger project in the institution which aimed to generate innovation in the quality and organization of long-term care. The larger project seemed to create an enabling environment for service user involvement to have an impact on care. In other words, service user involvement served as a catalyst for change. These findings suggest that partnership and dialogue, and their embedding in larger projects and institutions, enhance the impact of service user involvement. However, empowerment of service users is needed as well, to ensure that service users' voices are articulated and heard.

In the crisis card case study, the crisis card stimulated the empowerment of service users but its impact on concrete care processes was limited by lack of involvement and lack of commitment from professionals. This suggests that user-controlled initiatives can contribute to effective involvement by enhancing empowerment of service users, an important condition for them to articulate their voice (Beresford, 2002). However, user-controlled initiatives might require additional strategies directed at implementation and professional involvement if they are to have a wider impact on mental health care. Such strategies might, for example, entail the embedding of user controlled initiatives into larger projects as in the participatory video case study.

## Lessons for enhancing service user involvement

The case studies indicate that two elements are crucial for effective service user involvement: the articulation of service users' voices and the development of dialogue and partnership.

### *Articulation of service users' voices*

The findings of this thesis, confirmed by the literature, emphasize that the position of service users requires specific attention because they have a weaker voice than other stakeholders (Perkins, 1996; Thornicroft & Tansella, 2005). The crisis card care study and the participatory video case study both show that empowerment, improved self-esteem and overcoming stigma are necessary if service users are to be confident in speaking up. The guideline development case study additionally showed that input from service users is generally attributed a lower value than scientific evidence or input from professionals, an issue also recognized in the literature on service user involvement (Telford & Faulkner, 2004; van Wersch & van den Akker, 2005). This is not consistent with the ideal scenario for evidence-based care, proposed by Sackett et al. (1996), which considers that optimal care can be realized by integrating service users' values and expectations, individual clinical expertise and the best available clinical evidence. The lower values accorded to service user inputs might prevent an equal dialogue from taking place. Additional support, capacity building and training might be needed to enhance involvement of service users and the articulation of their voice.

Cognitive impairments are often assumed to prevent service users from being involved in mental health care (Rose, 2003a; Beresford, 2002; Rush, 2004). In the guideline on employment and severe mental illness, cognitive impairment only played a minor role in involvement. Some service user members of guideline development group did experience some difficulties in contributing because of their symptoms. However, this did not seem to have much effect on their involvement, possibly because it was feasible to adapt the process of guideline development to the needs and characteristics of service users. The guideline development case study was less able to adapt to service users in comparison with the other case studies in this thesis, possibly because it took place at the macro-level. Service users were required to represent the views of many other service users which can be assumed to be more difficult than discussing aspects of personal treatment. This suggests that cognitive impairments are not necessarily a barrier to service user involvement if processes of involvement take into account the needs and capacity of service users.

The findings presented in this thesis show that service user representatives - often with personal experience of mental illness - play an important role in service user involvement processes, mainly as spokesperson providing input on behalf of other service users. These service user representatives can also help by establishing connections and communications between service users and professionals because they are often familiar with both perspectives and are more used to voicing their concerns. In all case studies, such persons fulfilled crucial roles. In the crisis card case study, the crisis card counsellors (experiential experts) facilitated the implementation of the crisis card. They provided service users with a safe environment to identify their preferences regarding the planning of care processes in potential future crises and also helped to embed the crisis card in the organizational structures of the local care provider. In the participatory video case study, experiential experts helped to stimulate discussions between service users and care professionals during dialogues sessions which were held after the screening of the video. In the guideline development case study, service user representatives advocated the service user perspective in guideline development groups. Although high levels of professionalization of service user representatives may be necessary in certain situations, it may also limit the articulation of the service user perspective by some service users who distance themselves from the perspectives of service users when adapting to professional language and thinking (Caron-Flinterman et al., 2007). Therefore, it is important that the service user representative maintains strong connections to the groups he or she represents by, for example, membership of organizations and associations or by conducting additional research. In addition, the service user representatives need a so-called 'helicopter view' which refers to the capability of representing the accumulated perspectives of other service users, rather than presenting personal opinions and desires.

Methods that are highly participatory in nature are more likely to bring about effective involvement of service users as this requires an active role from the end-users of research and interventions (Baum et al., 2006; Smith, 1993). The participatory video case study

provides an example of such an approach because making of the video empowered service users and helped them to tell their stories (White, 2003). The participatory character of this method, which enabled service users to share their stories, appeared to have contributed to this. Principles of Participatory Action Research (PAR) might be applied to enhance the involvement of service users in research and other interventions because it aims to empower users (McTaggert, 1991; Reason & Bradbury, 2001). In addition, involvement is situated in the context of the collaboration between researchers and the end-users of care who jointly undertake the research and learn from each other.

## Strategies for knowledge integration: establishing dialogue and partnership

Service user knowledge is mostly likely to become integrated in mental health care way if it occurs in a partnership. However, establishing partnerships in which the voice of service users receives a value equal to that of professionals, remains one of the main challenges due to the power imbalance between service users and professionals which is engrained in organizational structures and thinking of stakeholders (Hickie & Kipping, 1992; Rose, 2003b). Next, I will elaborate on the lessons from our case studies regarding partnerships and dialogue, and opportunities for enhancing service user involvement.

Partnership and dialogue played a role in all three case studies to a lesser or greater extent. In the guideline development case study, an innovative dialogue-based approach was used to reconcile the perspectives of service users and other stakeholders. In a facilitated dialogue session, stakeholders were able to hold a constructive discussion based on each other's concerns and to formulate shared recommendations for the guideline. The approach resembles the Dialogue Model for research agenda setting (Abma & Broerse, 2007; Abma & Broerse, 2010). Such approaches seem particularly useful in stimulating interaction in a multi-stakeholder setting and they might also help to increase support among different stakeholders. They are characterized by an emergent design so that activities can be adapted to the needs and wishes of the involved stakeholders. The Dialogue Model, or similar approaches, might be particularly suitable for initiatives at the meso- and macro-level as they allow for a larger number of stakeholders to be involved and could particularly facilitate integrating knowledge derived from consultation methods.

The findings from the participatory video case study indicate that dialogue could be stimulated by moral deliberation which explores different stakeholders' perceptions of 'good care'(Abma & Widdershoven, 2009; Molewijk et al., 2008). Moral deliberation takes place in dialogue sessions in which participating stakeholders share their experiences and notions of their practice, thereby building shared understanding. As deliberative strategies are closely connected to concrete care processes, they might be particularly applicable to individual treatment situations or the organization of care within institutions. The involvement of service users in moral deliberation is currently rare, and needs further exploration. The inclusion of service user narratives, for example using video, could

facilitate the involvement of service users in deliberative processes (Abma & Widdershoven, 2005; Deep et al., 2010; White, 2003). The case study further suggests that for dialogue to have a more sustainable impact, it should be shaped by recurrent sessions of deliberations. In the case study, this did not happen and, as a result, its direct effects were mainly temporary.

In the crisis card case study, collaboration was established between the crisis card counsellor and the mental health care institution. The crisis card counsellor was working for a mental health care provider and, at the same time, promoting and protecting service users' perspectives and interests. Literature indicates that such collaboration models are promising approaches for integrating service user knowledge in care practices, and evidence is emerging on the potential for improving the quality of care (Bluebird, 2004; Cook et al., 1995; Paulson et al., 1999; Salzer, 2002). Moreover, such collaborations are seen as an important strategy for developing more recovery- and needs-oriented services (Sowers, 2005). However, the inclusion of service users as providers of care, as is the case for crisis card counsellors with their personal experience of mental illness, faces a range of implementation problems, such as role conflict and confusion among service users who are providing care, resistance from other care providers, and poorly defined strategies for implementing this collaboration in existing care structures (Chinman et al., 2006; Gates & Akabas, 2007). In the crisis card case study, this collaboration was supported at the management level, while actual care practices and routines of practitioners remained largely unaffected, suggesting that more attention should be devoted to strategies for developing partnerships in which mutual learning takes place.

## How to embed service user involvement in mental health care?

For service user knowledge to be become embedded in mental health care, fundamental changes in the system are required, affecting structures as well as ways of working and thinking. In other words, service user involvement has to be become part of the dominant structure, culture and practice of mental health care systems. This section addresses this topic from the perspective of Transition Theory by discussing the embedding of service user involvement in the different niche experiments (the three case studies) in terms of changes in structures, cultures and practices.

The niche experiment involving service user involvement in guideline development showed that service user involvement is not yet embedded in dominant culture, structure and practice of guideline development. Some changes are visible because service user involvement is taken up in protocols for guideline development. However, other aspects of structure, especially the common structure of guideline development which provides little opportunity or incentives for service user involvement and the lack of incentives for service user involvement, hamper further changes. In addition, there are few changes in culture,

mainly because of the limited value attributed to service user knowledge. In addition, guideline developers and service users often lack sufficient competences and are struggling to shape involvement. As a consequence, few changes in practices are noticeable. In the specific case of the Guideline on Employment and Severe Mental Illness, more changes were evident than in other guidelines because. This seemed mainly the result of the fact that the guideline developers were supportive of service user involvement, the guideline approach was highly multidisciplinary and there was limited scientific evidence available. Furthermore, specific attention was paid to changing structures in guideline development, allowing more opportunities for input from service users.

The niche experiment involving the crisis card showed that service user involvement has become partly embedded in mental health care. The adoption of the crisis card by a mental health care institution represents  a structural change as the crisis card became part of the services offered and the crisis card counsellor was taken up in the team of care providers. It also showed that at the management level, there was support for this development, reflecting a change in culture. In addition, empowerment of service users and crisis card counsellors seemed to take place. As a result, service user involvement became more integrated in care processes. However, crisis card development requires minimal involvement from health care professionals and changes in culture did not seem to transfer from the management level to the level of care provision by health care professionals. This indicates that for the crisis card to become more structurally embedded in care systems, strategies should be formulated to affect the structures (procedures and incentives) and competences (knowledge, attitudes and skills) of professionals. It is important that both aspects are addressed in promoting structural integration of the crisis card in care processes, without compromising the service-user based principles of this tool.

In the participatory video niche experiment, the impact of service user involvement was visible at two levels. The first level comprises the changes resulting directly from the participatory video and discussion sessions. The second level addresses the changes resulting from the larger project of which the participatory video was part, aiming to improve the quality of long-term care. At the first level, the participatory video and discussion sessions contributed to changes in culture as they affected the thinking of service users and health care professionals. Professionals shifted to more positive and humane perceptions of service users, focusing on their strengths and possibilities. In addition, service users themselves became more aware of their own strengths and started to think of themselves as being able to speak up and having the right to express their opinions. However, the effects of the participatory video in realizing changes in structures and practices was limited, mainly because the video screenings and discussion sessions were one-off meetings and their effects were temporary, fading within weeks. More embedding seemed to take place at the second level: the larger project of which the video was part. At this level, there were clear changes in attitudes with the management promoting a more service user-centred, strengths-based approach. Health care professionals had started

adopting these attitudes and some service users gained confidence and autonomy. As a result, some changes in structures were visible, for instance service users who started working as experiential experts in the institution. There was increased collaboration between service users and health care providers in care practices. The video seemed to contribute to changes within the institution by acting as a catalyst for change, showing the importance of linking to other, larger initiatives to bring about embedding of service user involvement.

The different niche experiments highlight the importance of change agents or frontrunners, people or organizations who are committed to inducing change and are willing to invest their efforts in this (Essink, 2012; Loorbach, 2007). In each of the described niche experiments, such change agents can be identified, mostly at the management level, in which the people involved actively collaborated with service users. In the case of the development of the Guideline on Employment and Severe Mental Illness, the guideline development group supported service user-centred and recovery-based approaches, and were actively facilitating service user involvement by collaboration with service user representatives. In the participatory video niche experiment, the development of the participatory video was part of the managers' vision to change long-term care from a strengths-based perspective. Also, in the niche experiment involving the crisis card, there was active support at the management level for the crisis card and the appointment of crisis card counsellors. Management visions in the different niche experiments seemed to connect to larger trends in mental health care, promoting recovery-based, community based and service user-centred approaches. The fact that these managers are change agents who are part of the existing regime is advantageous because they are in the position to facilitate the alignment of niche activities with current structures, cultures and practices (Essink, 2012). In particular, they can endorse the structural changes at the regime level which are needed for the embedding of the niche experiments.

The different niche experiments show that, although the concept of service user involvement in mental health care is generally accepted, it is rarely embedded in dominant structures, cultures and practices. Current regimes are, as expected, fairly resistant to change. Given that only parts of constellations of culture and structure were addressed, there was little or no embedding of service user involvement in mental health care practices. Initiatives described in the case studies focused either on structures or cultures, while it is necessary to bring about changes to both to have an impact on practice (Broerse et al., 2010; Essink, 2012). There seemed to be limited understanding of which changes in structures and competences are required, demonstrated by the paucity of strategies to translate service user input into care processes. The niche experiments provide some insights into how the embedding of service user involvement can be enhanced. The most important lessons comprise: formulation of strategies that target learning in terms of both structures and competences; linking niche experiments to other larger niche experiments;

identification and support of change agents; and linking niche experiments to broader trends in mental health care and society.

# What is the potential of service user involvement in weak mental health systems?

To gain better understanding of the potential of service user involvement in a global context, Part 2 of this thesis explored the factors potentially influencing service user involvement in countries with relatively undeveloped, weaker mental health systems in LMICs. This section discusses the findings on this subject for each of the 3 sub-research questions. For each research question, I present insights derived from the case studies with respect to the potential of service user involvement in the context of weak mental health care systems.

## What is 'good mental health care'?

Exploring service user perspectives on 'good mental health care' in LMICs requires insights into local notions of mental health and illness. Currently, culture-specific notions receive limited attention within existing regimes in mental health care. Concepts and explanatory models of mental health and illness can vary considerably between cultures, reflecting the norms and values held by societies, communities and individual service users (Herrman et al., 2005). Integrating local notions of mental health in care systems could strengthen systems from a needs-based perspective (Feierman et al., 2010). Different explanatory models of illness and reasons for seeking care provide a platform for professionals and service users to begin to negotiate collaborative treatment (Kleinman, 1980). Furthermore, local knowledge and beliefs should also be considered as factors in fighting stigma as some studies showed that explaining distress in terms of supernatural phenomena can contribute to reducing stigma. However, this requires service providers to be reflective of their cultural competences and to have an open attitude towards involving service users in care (Petersen, 2012; Swartz, 2007). It also requires more understanding of local concepts of mental health care. The study on perceptions of mental health in Vietnam presented in Part 2 provides an example of how research can contribute to building this knowledge. The study showed, for instance, that Vietnamese respondents could not spontaneously name any mental illness and used the words 'mad' and 'insane' to describe this condition. The most common DSM-listed mental illness as identified by respondents was schizophrenia while depression and anxiety disorders were less often recognized as a mental illness. This seemed to reflect the scope of the national mental health programme which, for a long time, only focused on schizophrenia and epilepsy. Ventevogel et al (2013) present an interesting example of research which provides more understanding of local conceptualizations of mental illness by providing insights into similarities and differences

of local concepts of mental illness across four locations in Burundi, South Sudan and Congo.

The studies in Part 2 of this thesis emphasize the important role of the service user's social network of family and friends in dealing with mental health problems. The Vietnamese study identified the central role of family in caring for relatives with mental illness. Findings also showed that traditional or alternative healing strategies, in addition to clinical care, were preferred by some people. The importance of family was also apparent in the study from the Philippines which found family to be both a source of mental health problems as well as a source of support and coping strategies. This study also highlighted the importance of other actors in this social network, including recruitment agencies, employers, larger social networks and membership of organizations.

The findings of the case study from the Philippines furthermore indicate that livelihood issues play a central role in mental health needs and emphasize strengths and capabilities. Migrant workers in this study were willing to accept and deal with the stressors they face in order to pursue the goal of financial security and earn a livelihood for themselves and their family. Escaping poverty and improving quality of life appear to be their main motivations. Workers draw on various resources in dealing with stress. In this study, social resources for dealing with stress had a more beneficial impact on stress levels and wellbeing than personal resources. In addition, environmental aspects, such as having actual access to resources, play an important role.

The findings described above connect to trends in mental health care which have global relevance but are currently mainly described in high-income countries. This trend involves a focus on strengths and promotes a more holistic approach to care, acknowledging social contexts and needs of service users in LMICs. Such an approach implies a more needs-based approach to care, which would allow more space for the integration of local concepts of mental health and mental health care.

## How can service users be involved effectively in mental health care?

Current literature provide limited insights into the processes and outcomes of service user involvement in mental health care in LMICs. Additional operational research on processes of service user involvement and its outcomes in LMICs would be beneficial to investigate how integration of service user knowledge can be optimized in these contexts. This thesis provides some potential leads for such research, focusing on the articulation of service users' voices and the establishment of dialogue and partnership.

A promising approach identified in the Philippines' case study  is the 'capable agency approach' which emphasizes the evaluation and promotion of capabilities instead of merely treating people as passive victims in need of rights-based protection: "*Framing rights in the context of capability can allow the 'victim' herself to reclaim her right for her intended and valued quality of life*" (Briones, 2009b, p. 141). Strategies aiming to enhance the position

of potential service users from such a strengths-based perspective might be particularly effective in embedding service user involvement in mental health care in LMICs. More research is needed to develop concrete methods for articulating service users' voices from this perspective.

The studies presented in Part 2 of this thesis show that many different stakeholders play a prominent role in mental healthcare practices in addition to mental health professionals, including traditional healers, faith-based practitioners, non-governmental organizations (NGOs) and, perhaps most important, the service user's social network of family and friends. Given the recent trend of 'decompartmentalization' of healthcare in which boundaries between disciplines, stakeholder groups and sectors are being removed, more attention is being devoted to finding potential avenues for collaboration between different types of service providers (e.g. Campbell-Hall et al., 2010; Shields et al., under review). The study from the Philippines also provides a clear example of the beginning of such collaboration as the findings of the survey were discussed by representatives of governmental organizations, NGOs, health care professionals and field interviewers who were often migrant workers themselves. During this discussion, prototypes for interventions addressing the mental health of migrant workers were formulated. Such settings provide useful insights and starting points for the development of dialogue and partnership. Principles of Participatory Action Research (PAR) can be useful for further developing methods of service user involvement in partnership with other stakeholders, especially in the context of LMICs (McTaggert, 1991; Reason & Bradbury, 2001).

The challenge for the future will be to find ways of integrating knowledge of different stakeholders, while ensuring that service user knowledge is not compromised or overshadowed by knowledge of these other stakeholders. Therefore, the next steps for these types of collaboration should include strengthening the valuation of different types of knowledge to improve care, and incorporating experiential knowledge from service users and families.

## How can service user involvement be embedded in mental health care systems?

Integration of service user knowledge can be a powerful instrument for strengthening mental healthcare systems from a needs-based perspective. Currently, service user involvement appears to be gaining momentum in LMICs. A growing number of initiatives of service user involvement is emerging at the niche level and this is supported by larger landscape trends. Much service user involvement occurs on a small scale, at the niche level, and in absence of a well-functioning mental healthcare system. This absence could be seen as an opportunity for innovation at the niche level because few structures are present to block transition and change. In addition, this bottom-up approach could facilitate incorporation of local practices, attitudes and beliefs. At the same time, landscape trends

such as the decentralization of healthcare, the growing public and user movement, a shift to demand-based care and an increased focus on wellbeing are putting pressure on the current regime. However, the barriers posed by the current regime, including the scarcity of policies, legislation and resources and the institutionalized setting of mental health care, remain important challenges for the embedding of service user involvement in mental health care. I therefore suggest that efforts should be directed to exploring different strategies for enhancing niche experiments, while trying to connect to broader landscape trends.

## Overall conclusions and lessons learnt

The research presented in this thesis explored the role of service user involvement in realizing 'good mental health care' and how service user involvement can be carried out effectively. The thesis as a whole provides an overview of the role of service user involvement at different levels (micro-, meso- and macro-level) and degrees (consultation, partnership, control). The different sub-research questions address service user involvement through different lenses, with a widening scope: 1) the perspective of service users themselves; 2) the role of service user involvement in specific initiatives; 3) the role of service user involvement in health care systems; 4) the role of service user involvement at the global scale. This heterogeneity of case studies allows for a broad exploration of the dynamics and complexity of service user involvement in mental health care. Although no simple answers or golden standard can be provided in response to the main question, several overarching conclusions and lessons can be formulated.

First, this thesis shows that the perspectives and needs of service users regarding mental health care reflect the different roles and ambitions users have in society, as well as their individual strengths and weaknesses. These findings connect to more general trends in mental health care that promote a broader, holistic approach to mental health care. The views of service users differ from those of other stakeholders, such as health care professionals, because they take a broader approach to mental health in which mental illness and related symptoms are merely one aspect of their lives. Development of 'good mental health care', therefore, requires the development of approaches that are responsive to such holistic views, requiring exchange and integration of knowledge from different domains and disciplines.

Second, the findings show that service users were able to participate and provide relevant input. However, fundamental challenges include the integration and utilization of service user knowledge and the establishment of partnerships. Although service user knowledge is mostly likely to become integrated in mental health care occurs in a partnership, the power imbalance between service users and professionals and the lack of recognition of experiential knowledge often prevent true collaboration. For this reason, consultation

methods might sometimes be more effective. However, this requires commitment from those in power because they need to take service user knowledge into account in decisions on care. User-controlled initiatives might also be a useful strategy, particularly because this contributes to the empowerment of service users. Still, additional implementation strategies are needed to ensure that results of such initiatives find their way into the practices of professionals.

Third, although service user involvement is gaining momentum, limited changes are yet visible in dominant structures, cultures and practices in mental health care systems. Our findings suggest that existing initiatives tend to focus either on structures or on cultures, while changes to both of these structuring aspects are necessary to have an impact on practice. More attention is thus required to change procedures and incentives relating to service user involvement, as well the competences needed by stakeholders if they are to implement such changes in practice. Linking niche experiments to broader trends in mental health care and society, and the identification of change agents and facilitation of their role, might enhance the impact of initiatives at the niche level.

This research indicates that service user involvement has global relevance. Integration of service user knowledge can be a powerful instrument for strengthening weak mental health care systems from a needs based perspective. However, service user initiatives are still scarce and often occur on a small scale. The current regime is largely defined by a lack of infrastructure for integrating service user involvement due to a lack of policies, legislation and resources, and hampered by the institutionalized setting of mental healthcare. However, the absence of a well-functioning mental health care system could be seen as an opportunity for innovation at the niche level because there are fewer structures in place to block transition and change. In addition, this bottom-up approach could facilitate incorporation of experiential knowledge, taking into account local practices, attitudes and beliefs. Embedding service user involvement within broader community involvement initiatives through participatory methods might be a strategy for connecting to local contexts, thereby enhancing knowledge integration. Intermediaries or knowledge brokers, such as families, activists, NGO staff, traditional or faith-based practitioners and community change agents, can potentially play a bridging role by encouraging and strengthening the voice of the service user and placing more emphasis on experiential knowledge.

# Validity

In this section, the validity of the case studies and their findings are discussed. The strategies applied to minimize threats to internal validity were presented in Chapter 3. Below, the most important issues of internal and external validity are discussed.

## Internal validity

The role of the researcher in the different studies described in this thesis should be taken into account when interpreting the findings. The presence and activities of the researcher may have enhanced attention for the issues under study, although the impact of this probably varies between the different studies. In the case study on guideline development, the researcher had an influential role in designing and conducting focus group discussions, stimulating reflection among the stakeholders, and making suggestions for guideline development processes. The active role of the researcher was part of the Reflexive Monitoring in Action approach which facilitates rich insights into the case and enables critical reflection on the process (Grin & Weterings, 2005; Regeer, 2010). Triangulation of methods and data sources, member checks (feedback from respondents), analysis by multiple researchers and thick description of data ensured that bias from self-evaluation was kept to a minimum. In the crisis card case study and the participatory video case study, the researcher's role was more distant because both studies involved evaluation of processes in which the researcher had not been involved. In these studies, member checks, analysis by multiple researchers and thick descriptions of data were also applied, indicating that the researcher probably had no significant influence on the outcomes of the research. In the studies taking place in the Philippines and Vietnam, the researcher's role was most distant since the data collection was carried out by local research teams. However, the researcher's 'Western' knowledge and perceptions on this topic might have influenced the research to some extent. As the research teams were aware of potential threats to internal validity by such biases, several measures were taken to minimize this, including triangulation of methods and data sources, member checks to validate the findings, and interpretations and data were analysed by multiple local and non-local researchers. This helped to keep the researcher bias to a minimum but it is inevitable that the researcher's knowledge and perceptions coloured the interpretation and presentation of the outcomes to some extent.

Another issue potentially affecting the internal validity of this thesis is self-selection of individuals to participate in interviews, focus group discussions and committees. In some studies, the participating service users might have differed from 'standard users' and this could have affected the findings of the research. Purposive sampling is part of the case study approach and characterizes niche experiments carried out in Part 1 of this thesis. However, participants of the case studies, in particular the crisis card study and the participatory video study, might have been more positive about the project than others who chose not to participate. Still, the diversity in participants' answers and opinions indicated that a range of perspectives was taken into account. In Part 2 of this thesis, random sampling methods were employed to select respondent for surveys, and triangulation of data was used to minimize bias of self-selection.

## External validity

The findings presented in Part 1 allow for 'naturalistic' generalization which means that the lessons learnt in the case studies can be used for learning in initiatives in different contexts (Stake and Trumbull, 1982; Stake, 1995). However, grand-generalization (drawing causal conclusions) is not possible based on this type of case study research. The possibility of petit-generalization of findings is supported by the fact that findings are consistent with the bulk of literature on service user involvement in mental health care, and user involvement in other health care settings. Furthermore, the case studies included in Part 1 represent a broad range of initiatives, suggesting that shared outcomes are probably applicable to a range of settings. These findings are also supported by other studies of high-income countries with strong mental health care systems. However, they might report more positive experiences with service user involvement because they were selected because active service user involvement took place and because the other stakeholders were generally supportive of the assessment of service user involvement. Furthermore, as the case studies were selected on the basis of service user involvement, service users who were unable or unwilling to participate are outside the range of this research. Indeed, no inferences can be made about the applicability of research findings to these groups.

The findings of the studies included in Part 2 can be generalized to some extent. The external validity of the studies from Vietnam and the Philippines is supported by the large number of randomly sampled respondents and by the fact that our findings are largely consistent with other studies undertaken in these countries. However, caution should be exercised in the making of causal inferences because the research was exploratory in nature and findings are probably coloured by culture- and context-specific notions of mental health and illness. The conceptual study presented in Chapter 9 emphasizes that current initiatives focusing on service user knowledge and involvement are scarce and insufficiently described in literature, indicating that more niche experiments and research reporting on them is needed to make generalizations on service user involvement in LMICs.

# Future research

This sections presents recommendation for future research, based on the findings of this thesis. A general recommendation concerns the need for more research on the process and outcomes of service user involvement at different levels of involvement, reflecting the exploratory nature of this research. Notions from Transition Theory can be helpful for gaining better understanding of the role of service user involvement in systems as a whole. Below, I provide some specific recommendations for future research.

## The challenge of establishing genuine partnerships

The relationship between service users and professional is an important determining factor for effective service user involvement but little is known about how to establish equal partnerships. Special attention needs to be paid to the power balance in service user-provider relationships, and how this is embedded in the structure, culture and practices of mental health care. Research could focus on negotiation between the different types of knowledge of service users and professionals, and how this affects decision-making. This might also provide opportunities to address issues of intercultural interaction as negotiations in multi-cultural settings might be particularly challenging. In addition, the stigma of mental illness should be addressed because too little is known about it, despite the fact that it is generally acknowledged to be an important barrier to effective service user involvement.

We further strongly suggest that more research should be carried out on how partnerships and dialogue can be effectively established between diverse stakeholders. The role of the family has also been somewhat neglected when compared to the attention focused on service users. The guideline development case study indicated that involving family has an added value and also that family members seem to desire a larger role in care processes. In addition, inter-sectoral partnerships between different types of professionals are an important topic for research considering the broadening context of mental health care in which mental health is increasingly linked to social wellbeing and livelihood issues. In particular, opportunities for establishing more links, collaboration and mutual learning between biomedically-oriented stakeholders and recovery-oriented stakeholders should be explored.

## 'The uninvolved': gaining insights into exclusion mechanisms

When looking at mechanisms for inclusion of service users, one should be aware of possible exclusion mechanisms. More insights are needed into the service users who have, so far, been excluded from involvement processes. Some users might be excluded because they do not want to be involved and this should be respected. However, exclusion could also be the result of stigma, either internalized by service users themselves, or engrained in care structures, culture and practices of professionals. Thus, excluded people should also have the possibility to become involved. Some of these service users might be avoiding formal care and could hold particularly valuable knowledge regarding informal care and strategies of personal resilience.

## Towards sustainable service user involvement: long-term effects

The findings presented in this thesis provide insights into processes and outcomes of service user involvement. However, the outcomes discussed in this thesis are mostly short-term outcomes of involvement. No insights could be provided into the long-term

outcomes of involvement, although this would be invaluable for determining the impact of service user involvement of care and the extent to which this impact is actually sustainable. I therefore suggest that more research is done on this topic. Issues of implementation relating, for example, to guidelines and crisis cards, should be addressed. In addition, attention should be paid to determining which long-term outcomes are considered relevant from service users' perspectives and matching methods and indicators for assessment and evaluation.

## Exploring the local and the global

The growing number of grassroots initiatives of service user involvement in LMICs provide fertile ground for research to learn from these niche experiments and gather insights into how these experiments can be scaled up to regime level. The lessons learned from efforts to enhance niche experiments should be shared on a global scale as high-income countries with stronger health care systems are partly facing similar challenges, and might also learn from innovative approaches at the niche level. Transition Management offers some useful concepts that can help to formulate strategies to enhance niche experiments, namely deepening, broadening and scaling up (Loorbach, 2007; van den Bosch, 2010). *Deepening* involves learning processes in specific contexts which could stimulate shifts in organizing, thinking and doing. This involves paying attention to best practices and lessons learned from the processes and outcomes of the current initiatives. *Broadening* entails linking and repeating niche experiments in different contexts. As a consequence, more actors would become involved in the transition and related learning processes. The strategy of *scaling-up* includes activities to embed the new culture, structure and practice at the regime level, requiring fundamental changes at the regime level. Scaling up requires lifting the barriers imposed by dominant regimes which appears as a considerable challenge for the case studies in this thesis. In addition to addressing regime-related barriers, it is important that landscape developments support the transition as they might facilitate the scaling up of niche experiments. Relevant trends at the landscape level include the decentralization of healthcare, the growing public and user movement, a shift to demand-based care and an increased holistic focus on wellbeing. Explicitly linking up niche experiments to these broader societal trends might facilitate the embedding of service user involvement in mental health care, thereby contributing to 'good mental health care' which is responsive to the needs of all stakeholders. This will bring us one important step closer to realizing 'good mental health care' from the perspective of all stakeholders, including service users.