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ORIGINAL ARTICLE

Facilitators and Barriers to Service User Involvement in Mental Health Guidelines: Lessons from The Netherlands

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Abstract This study is the first in-depth qualitative study of service user involvement in the development of multidisciplinary mental health guidelines in the Netherlands. The study comprised a desk study of guidelines ($n = 12$) and case studies of service user involvement in five guidelines using document analysis, interviews ($n = 24$) and observations. The desk study shows that all multidisciplinary mental health guidelines have taken service user perspectives into account to some extent. The five guideline case studies led to the identification of ten main themes. Findings will assist guideline developers in making early, informed decisions on involving service users effectively.

Introduction

The involvement of service users in clinical practice guideline (CPGs) development has been advocated for many years because it is thought to increase the quality, democracy and acceptability of guidelines (Boivin and Légaré 2007; Kelson 2001; Owens 1998; Rogers 2002). Initiatives involving service users in the development and implementation of CPGs have increased in recent years (Légaré et al. 2011). There are a wide variety of approaches to service user participation and methods differ between countries, topics and settings (Boivin et al. 2010). Currently, the most common methods for service user involvement are (one or two) service user representatives in guideline development groups (GDGs) and service users reviewing final drafts of the guideline, sometimes complemented by consultation of service users through focus groups or questionnaires (Broerse et al. 2010; Díaz Del Campo et al. 2011; Nilsen et al. 2006). However, knowledge is limited with respect to how service user involvement can be carried out successfully in order to optimally contribute to improving the quality of the guideline (Boivin et al. 2010; van de Bovenkamp and Trappenburg 2009; Légaré et al. 2011).

Since 2000, scholars have identified several barriers and facilitators to service user involvement in guideline development (Franx et al. 2011; Jarrett and Patient Involvement Unit (PIU) 2004; Kelson 2005; Lanza and Ericsson 2000; van Wersch and van den Akker 2005; van Wersch and Eccles 2001). Important barriers are a lack of clarity about the roles and tasks of service users in the guideline development process; limited resources for supporting service users; and problems integrating service user input with evidence from literature in the guideline, mainly because their knowledge is considered to be of lower quality. In addition, it may be difficult for service users to represent the whole group of service users and to voice their concerns in the GDG due to professional jargon and dominance of professionals. Participation can be facilitated by involving service users actively in all phases of guideline development; clarification of the goal and role of service user representation and its limitations in the guideline development process; attention for adequate selection of service users; and additional training and support for service users in GDGs.

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A considerable number of service user participation initiatives in clinical guideline development stem from the field of mental health (Légaré et al. 2011). However, these initiatives are predominantly described in grey literature and pay little attention to methods and specific barriers and facilitators of service user participation in mental health care. Specific attention to service user participation in mental health care is needed for two reasons. First, there is a need to adapt methods to specific guideline topics and service user populations (Boivin et al. 2010; Díaz Del Campo et al. 2011). Second, service user participation in mental health may encounter particular obstacles compared to other health conditions. One such obstacle is the notion held by some health professionals that service users with mental health problems are unable to make valid statements about therapy and treatment because of their 'impaired cognitive state' (Beresford 2002; Rose 2003). In addition, tensions may arise because service users often have a greater interest in more socially oriented and holistic approaches to mental health and tend to challenge existing approaches, whereas the biomedical model of mental health is predominant among mental health professionals (Telford and Faulkner 2004; van Wersch and van den Akker 2005).

In this study, we aim to obtain insights into practices and experiences of service user involvement in mental health guideline development, and extract applicable lessons learned. This study is the first in-depth qualitative study of service user involvement in the development of multidisciplinary mental health guidelines in the Netherlands. The study presents an inventory of service user participation initiatives in Dutch mental health guidelines and provides an in-depth assessment of five mental health guidelines in order to identify facilitators and barriers to service user participation. The findings aim to inform guideline developers about the issues concerning service user participation in guideline development so that service users can be more effectively engaged.

Methodology

Study Design

Two types of methods are employed in the study design. The first consists of an inventory desk study of guideline texts to get an overview of service user participation in mental health guidelines in the Netherlands. The second consists of a case study in which service user participation in five guideline cases is explored in in-depth interviews and observation of guideline processes. Below we describe the methods of the desk study, selection of the cases and the case studies. More information on the context on multidisciplinary guideline development in mental health in the Netherlands is provided in Box 1.

Desk Study

The desk study included an assessment of service user involvement in mental health guidelines. We accessed the guidelines via the website of the National Steering Group for Multidisciplinary Guideline Development in Mental Health (NSGMH) and the Trimbos Institute (2012). The website provides an overview of Dutch multidisciplinary guidelines on diagnosis and treatment of mental health problems. During 2003–2011, a total of 12 mental health guidelines were published, of which three were updates of previous guidelines (see Table 1). All 12 guidelines stated that they had paid attention to the service user perspective. We analysed the content of these guidelines to extract information relevant to service user participation. The content analysis was guided by two main topics: (1) the process of service user involvement; and (2) the outcomes of service user involvement in guideline content. For updated guidelines, both the updated version and the original guideline were assessed.

Box 1 Multidisciplinary guideline development in mental health in the Netherlands

The Netherlands is one of the leading countries in the field of guideline development (Franx et al. 2011). The National Steering Group for Multidisciplinary Guideline Development in Mental Health[a] (NSGMH) led the national mental health guideline programme in the Netherlands from 1999 until 2009. The NSGMH was established by five professional organisations which collaborated with other professional organisations and service user and carer groups. The National Committee of Service User Participation,[b] a body of the NSMGH, was responsible for assessment of the quality of the participation process and the extent to which the guideline is oriented to service users. Methodological and technical support was provided by the Trimbos Institute, the national institute for mental health and addiction, and the CBO, the Dutch Institute for Healthcare Improvement.[c] The guidelines answer key research questions following a fixed format: (1) a 'literature review' with summaries and conclusions; (2) 'other considerations' which describe the translation of the evidence to recommendations for clinical practice, and (3) 'recommendations' that provide advice regarding the main questions. The NSGMH was abolished in 2009 when government funding ended and it has not yet formally been replaced. Guidelines or guideline updates published since 2009 have been commissioned by ZonMw, the Netherlands Organisation for Health Research and Development, and developed by professional organisations and the Trimbos Institute (Franx et al. 2011).

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[a] Landelijke Stuurgroep Multidisciplinaire Richtlijnontwikkeling in de Geestelijke Gezondheidszorg

[b] Commissie Cliëntenparticipatie Multidisciplinaire Richtlijnontwikkeling in de Geestelijke Gezondheidszorg

[c] Centraal BegeleidingsOrgaan (CBO)

Table 1 Twelve multidisciplinary mental health guidelines (NSGMH and Trimbos Institute 2012)

Guideline	Year of publication	Updates
Anxiety Disorders	2003	2010 + 2012[b]
Depression	2005	2010 + 2011[b]
Schizophrenia	2005	2012
ADHD in Children	2005	
Eating Disorders	2006	
Interventions Following Disasters	2007	
Personality Disorders	2008	
Alcohol Disorders	2009	
Domestic Violence	2009	
Somatically Unexplained Complaints and Somatoform Disorders	2011	
Suicidal Behaviour	2012	
Employment and Severe Mental Illness[a]	2012	

[a] Guideline waiting for formal approval

[b] The update processes of these guidelines were part of a pilot project to explore a process of 'living guidelines' with repetitive rounds op revisions

Case Studies

Cases were identified through the desk study and through exploratory interviews conducted with six key persons. The key persons were selected based upon their broad expertise in guideline development; they had knowledge of, and experience of service user involvement and multiple CPGs. Among the key persons were representatives from a service user organisation for persons with personal experience of mental illness ($n = 2$), professionals from a guideline development organisation ($n = 2$), and researchers working on service user participation in guideline development ($n = 2$). Guidelines were considered for selection if interviewees had mentioned them as interesting cases with respect to the involvement of service users, because particular attention had been paid to the organisation of service user involvement in the guideline development process, for example by combining different methods of involvement or employing alternative methods such as case studies. We decided to include both guidelines and guideline updates in the study because interviewees suggested that there were differences between them in terms of the methods employed for service user participation. If the process for incorporating service user participation is indeed different for guideline updates, understanding this process is especially useful for future guideline updates because all guidelines will inevitably be updated. Finally, guidelines were included if at least two GDG members (one of which was a service user representative) could be interviewed.

The final selection included five guidelines: Schizophrenia, Employment and Severe Mental Illness, Personality Disorders, Schizophrenia (update) and Anxiety Disorders (update). The cases and associated key characteristics of service user involvement are highlighted in Table 2.

The five selected guidelines were studied using document analysis, in-depth interviews and observations. In total, 24 interviews were held with different stakeholders, including: guideline development professionals (GDPs) ($n = 4$), health care professionals ($n = 10$), service user representatives [1]($n = 9$) and one carer representative ($n = 1$) (see Table 2). Potential interviewees were identified through the key persons interviewed in the case selection process and through the guideline texts. The interviews were semi-structured and addressed the following topics: (1) the process of service user involvement; and (2) outcomes of service user involvement. The number of interviews per guideline case comprised: Personality Disorders ($n = 3$), Schizophrenia ($n = 2$), Schizophrenia update ($n = 4$), Anxiety Disorders update ($n = 3$), and Employment and Severe Mental Illness ($n = 11$). [2]

Interviews were audio-recorded and transcribed verbatim. A summary of each interview was sent to the interviewee for a member check, to check for accuracy. Data were coded manually following standard qualitative coding procedures (Strauss and Corbin 1998). First, codes were given to features of the data that the researchers considered essential to the research question. A distinction was made between codes explaining the process of service user involvement and codes related to the outcomes of this. Second, core themes were identified and named. These themes explain larger sections of the data by combining different related codes. Third, barriers and facilitators associated with the different themes were identified as subthemes. The coding was done independently by two

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[1] We use the term 'service user representatives' to refer to service users as well as non-service users (for example family members or employees of service user organisations) who represent the service users' perspectives in the guideline development process.

[2] For the guideline on Employment and Severe Mental Illness, the researchers had good access to the guideline development process and were able to monitor the whole process. Because of this it was possible to conduct more interviews for this case study than for the other case studies.

Table 2 Overview of key characteristics of service user involvement in original guidelines and guideline updates

Guideline	Methods of service user involvement	Outcomes of service user involvement
Anxiety Disorders (2003)	Two service user representatives in GDG	Interwoven in text
	Committee of Service User Participation	Separate chapter
	Existing research on service user preferences	Service user summary
Depression (2005)	Three service user representatives in GDG[a]	Interwoven in text
	Committee of Service User Participation	Separate chapter
		Not authorized by service users
		Service user summary
Schizophrenia (2005)	**Three service user representatives in GDG**	**Separate chapter**
	Committee of Service User Participation	**Service user summary**
ADHD in Children (2005)	Four parents in GDG[a]	Separate chapter
	Two panel meetings with parents, one with youth	Service user summary
	Committee of Service User Participation	
	Existing research on service user preferences	
Eating Disorders (2006)	Five service users representatives in GDG[a]	Not authorized by service user organisation
	Committee of Service User Participation	
Interventions Following Disasters (2007)	Group interview about victim preferences with 12 persons	Integrated in text
	Committee of Service User Participation	
Personality Disorders (2008)	**Four service user representatives in GDG**	**Integrated in text**
	Questionnaire on service user perspective	**Separate chapter**
	Committee of Service User Participation	
Alcohol Disorders (2009)	Three focus groups with service user representatives	Integrated in text
	Committee of Service User Participation	Critique from Committee of Service User Participation
Domestic Violence (2009)	Personal narratives of victims	Integrated in text
Somatically Unexplained Complaints and Somatoform Disorders (2011)	Committee of Service User Participation	Not specified in guideline
Suicidal Behaviour (2012)	Focus group with service user representatives	Not specified in guideline
	Service user representatives in advisory committee (number not specified)	Service user summary
Employment and Severe Mental Illness (2012)	**Two service user representatives in GDG**	**Integrated in text**
	Two service user representatives in advisory committee[a]	**Specific section in 'additional considerations'**
	Two focus groups with service users	
	One dialogue meeting (including service users)	
	Eight case studies with service users	

Guideline update	Methods of service user involvement	Outcomes
Anxiety Disorders (2010 + 2012)	**Two service user representatives in advisory committee**	**Similar to original guideline**
	Two focus groups with service users	**Not specified for update**
Depression (2010 + 2011)	Two service users representatives in advisory committee	Not specified in guideline
	—	Not specified for update
Schizophrenia (2012)	**One service user representative in GDG**	**Similar to original guideline**
	Two service user representatives in advisory committee	**Not specified for update**

The five case studies are highlighted in bold

[a] Not all service user representatives were involved during the whole guideline development process

researchers (first and second author) and a validation meeting took place to discuss the codes and obtain consensus on the emerging themes and the barriers and facilitators. The fourth author provided assistance by reflecting on the final theme names. The researchers were able to reach consensus on the themes.

Results

Overview of Service User Involvement in Mental Health Guideline Development

All 12 identified multidisciplinary mental health guidelines devoted attention to the service user perspective, but the guidelines varied in terms of the process of involvement and the outcomes of service user participation (see Table 2).

Process of Service User Involvement

The service user perspective was obtained from service user representatives, but limited information is provided about them in the guidelines. When service user representatives were connected to an organisation, this was stated in the guideline. However, most guidelines did not explicitly describe whether these representatives were service users with personal experience of mental illness, or non-service users who were considered experts on the service user perspective for other reasons. In the guideline on ADHD in Children, it was stated that parents represented the service users (children with ADHD). Carers also contributed to the guidelines on Personality Disorders and Schizophrenia, but in these cases they represented the carers rather than the service users and can therefore not be considered service user representatives.

Just over half of the guidelines ($n = 7$) had service user representatives as members of the GDG. The total number of service user representatives per guideline ranged from two to five. Most service user representatives were involved during the entire guideline development period, but some of them joined later in the process or left before the end. Reasons for this are in most cases not indicated in the guidelines. Two guidelines had an additional advisory committee in which service user representatives participated. Almost half of the guidelines ($n = 5$) used focus group discussions or panels for consulting service user representatives. In two of these guidelines, this was supplementary to having service user representatives on GDGs, while in the other three this was the only method used. The input from focus groups was primarily used to reflect on the key research questions formulated by the GDG and for content of an 'additional considerations' chapter. Alternative methods of service user involvement were applied in three more recently developed guidelines, including case studies, a dialogue session, questionnaires and personal narratives. In one other guideline, results from an earlier study on service user preferences were used. Nine guidelines reported involvement of the National Committee of Service User Participation which assessed the quality of the participation process and the service user orientation of the guideline recommendations.

Three of the guidelines have been updated. In all three updates, service user representatives were members of an advisory committee advising the GDG. In one of the guidelines updates (Schizophrenia), a service user representative was part of the GDG. In one case (Anxiety Disorders), additional methods (focus group discussions) were used to obtain input from service users.

Outcomes of Service User Involvement

Two guidelines were unclear in identifying the impact of input from the service user perspective, while the rest ($n = 10$) specified the impact of service user input on the guideline process. In five guidelines, a specific chapter was dedicated to the service user perspective and seven guidelines indicated that the service user perspective was interwoven throughout the text, while two guidelines did both. Almost half of the guidelines ($n = 5$) have a guideline summary specifically developed for service users and carers. Four of these guideline summaries are linked to a decision-making tool.

Service user representatives or service user organisations thought that the service user perspective was insufficiently represented in three guidelines. One of these guidelines (Alcohol Use Disorders) includes the criticism and the recommendations of the National Committee of Service User Participation, which was responsible for assessment of the quality of the participation process and the service user orientation. In the two other cases (Eating Disorders and Depression), it was stated that service user organisations rejected the final guideline. No explanation for was provided for in the Depression guideline, while the Eating Disorders guideline indicates that it was rejected because the service user perspective was insufficiently represented with respect to certain visions and treatments. Since no formal approval from service user organisations was required, their rejection of the guideline had no implications for endorsement of the guideline.

The guideline updates maintained the format in which service user input had been presented in the original guidelines. Although different methods were employed to obtain service user perspectives in the updates, the consequences of this and specific contributions of service user representatives to the update were not specified.

Table 3 Overview themes and associated barriers and facilitators of service user involvement in mental health guidelines

Themes	Barriers	Facilitators
Process		
Characteristics of a 'good' service user representative	Insufficient articulation of service user perspective by service user representatives	Helicopter view; having insight in the different perspective of the service user population
	Service users focusing too much on own experience	Knowledge of, or previous experience with guidelines
	Service users lacking knowledge/experience on guideline development	Training on guideline development to service user representatives
Service user recruitment and representation	Difficult recruitment of service user representatives	Access to/use of network of service user organisation
	Doubts about representativeness of service user representatives	Using the network of GDG
		Attention for subgroups of service users
Participation and the course of mental illness	Drop-out of service users due to mental illness	Involving multiple service user representatives
	Difficulties reading long guideline texts	Offering content-related support to service user representatives
		Providing process-related support to service user representatives
Clarity and transparency of roles/structure	Lack of transparency servicer user representatives role	Use of feedback sheets about given input
	Lack of clarity on methods for user consultation	Use of clear action plan on service user participation
	Poor communication about guideline process	Chair and project manager monitoring service user involvement
Phase of involvement	Service user representatives joining halfway guideline process	Early involvement of service users representatives in guideline process
	Service user involvement in literature review	Assisted involvement in literature review
Service user consultation methods	Presenting guideline information in a comprehensive way to service users	Provide service users with a summary of the guideline's key points
	Incorporating data from service user consultation methods in the guideline	Organising a dialogue to integrate input from different stakeholders
Attitudes to service user involvement	Experiential knowledge lower in hierarchy than scientific knowledge	GDG members having a supportive attitude towards service user involvement
		Service user perspective as an agenda item in GDG meetings
Outcomes		
Service user agreement with the guideline	Lack of service user agreement with scope of guideline	Early involvement of service users representatives
		Explicit communication about guideline scope
Incorporation of user perspective in guideline	Insufficient incorporation of service user perspectives	Careful weighing of different options to incorporate service user perspective
	Lack of clarity on how to incorporate service user perspective in final guideline	
Practical applicability of the guideline	Doubts about practical applicability of guideline recommendations	Lay/service user versions of guidelines
		Action plan on implementation involving service users

Service User Involvement in the Case Studies

Analysis of the five guideline cases led to the identification of ten main themes (see Table 3). Seven themes relate to the process of service user involvement, including: characteristics of a 'good' service user representative, service user recruitment and representation, participation and the course of mental illness, clarity and transparency of roles/structure, phase of involvement, service user consultation methods, and attitudes toward service user involvement. Three other themes related to outcomes of service user involvement: service user agreement with the guideline, incorporating service user perspectives in the guideline, and practical applicability of the guideline. The results are described in detail below. They are structured following the ten main themes. Sub-themes (barriers and facilitators are highlighted in italics in the text).

The Process of Service User Involvement

Characteristics of a 'Good' Service User Representative The data reveal certain barriers and facilitators in relation to characteristics of service users involved in guideline development, according to the interviewees. A characteristic considered a barrier by several professionals and service user representatives is *the tendency of certain service users to focus merely on their personal experiences* with illness and care. However, high levels of professionalism of service users may lead to *insufficient articulation of the service user perspective*, as was the case in the Employment and Severe Mental Illnesses Guideline. Some professionals could not identify the service user representatives among the members of the GDG and indicated that the service user perspective could have been better articulated. Service user representatives and professionals also highlighted a number of characteristics that could be facilitators for service user participation in guideline development. First, *the 'helicopter view'* that certain service user representatives have is considered beneficial, meaning that they have an overview of a wide range of experiences from a range of service users. In addition, *previous experience of guideline development* or other situations in which service user representatives interact with professionals can contribute to developing the professional skills and qualities needed in guideline development. *Training on guideline development* may also be helpful. However, several professionals and service user representatives perceived a lack of training on guideline processes as a barrier.

Service User Recruitment and Representation Several barriers and facilitators are concerned with the recruitment and representation of service users in guideline processes. Service user representatives and professionals mentioned *difficulty concerning the recruitment of service user representatives* as a main barrier. For example, in the guideline on Personality Disorders it was difficult to find suitable service user representatives due to the absence of service user organisations for this illness. When *active service user organisations are absent*, the *network of the GDG* can also be used to obtain access to service user representatives. Another main barrier is *uncertainty about the representativeness of service user representatives*. For example, in the Employment and Severe Mental Illnesses Guideline, most participants were recruited through the network of a service user organisation for schizophrenia. For this reason, certain interviewed professionals doubted the applicability of the findings to other mental illnesses. To optimize service user representation, it may be necessary to pay specific attention to the *consultation of sub-groups of service users* who otherwise remain unheard, such as people from specific age groups or ethnic populations. For instance, the GDG of the Employment and Severe Mental Illness Guideline gained insight into experiences of service users with different ethnic backgrounds through case studies.

Participation and the Course of Mental Illness The data reveal that the participation of individual service users in guideline development could be affected by the course of mental illness and related symptoms or disabilities. The two main barriers relating to this finding include service users experiencing *difficulties with reading large texts* in preparation for the GDG meetings, due to energy and concentration problems, and the risk of *service users dropping out* of the guideline development process. For example, the Personality Disorders guideline lost one service user due to two hospital admissions. This left only one service user representative, limiting the role of services users in the overall guideline process. Many interviewed professionals and service user representatives mentioned *involving multiple service user representatives* in the guideline development as an important facilitator as it reduces the consequences of potential drop-outs and provides opportunities for service users to divide tasks.

Provision of additional support to service user representatives was also mentioned as a potential facilitator. This can be either *process-related support*, such as monitoring of service user representatives and their needs throughout the process by the project manager, or *content-related support*, for example by organising collective input from the service user organisation that is represented. In the Personality Disorders guideline, a questionnaire was conducted among a large number of service users. This was considered very helpful for service user involvement in the rest of the process (content-related support). However, one service user representative in this guideline process also mentioned an absence of support from her organisation (process-related support). In this case, colleagues felt they did not have enough knowledge on guideline development and therefore could not support her in her tasks.

Clarity and Transparency of Service User Participation in the Guideline Process A number of identified barriers and facilitators relate to clarity and transparency concerning service user participation in the guideline process. The main barriers were *a lack of transparency on the roles of service user representatives*, a *lack of clarity on the use of methods to consult service users and a poor communication in the GDG*. For example, service user representatives in the Anxiety Disorders guideline stated that they were unclear as to what was expected from them. This was further exacerbated by the fact that the structure of the guideline update process was complicated, and there were no meetings or communications to discuss this. The *use of feedback sheets*, indicating how input from service user representatives was processed, functioned as a facilitator by providing insights into how decisions were made. *Using a clear action plan*, specifying activities of service user participation, was also considered beneficial by guideline development professionals. In the Employment and Severe Mental Illness guideline on, such a plan of action was used and positively evaluated. Furthermore, *the project manager and chair* can play a facilitating role by *monitoring service user involvement* during GDG meetings and the entire guideline development process.

Phase of Involvement A number of barriers and facilitators were related to the timing of service user involvement in the guideline development process. A considerable number of professionals and service user representatives interviewed emphasized the importance of *involving service user representatives as early as possible in guideline development processes*. In the Employment and Severe Mental Illness guideline, a service user representative was involved in writing the proposal for guideline development; this was mentioned as a facilitator to further service user involvement. *Service user representatives who joined halfway through the guideline process* indicated that it was difficult to catch up. This may also be an issue in the case of guideline updates, especially for service user representatives who were not involved in the original guideline.

According to both service user representatives and professionals, *involvement of service user representatives in the literature review* can be difficult, as many service user representatives have limited experience with reading and assessing scientific literature. In addition, some of the interviewed service user representatives indicated limited interest in these aspects of guideline development. Some professionals mentioned that service user representatives do not necessarily have to be involved in this phase of guideline development because it can be burdensome for them due to their illness. However, in several instances, often *with support, service user representatives were able to contribute* to reviewing the evidence, especially in identifying qualitative studies and literature on topics relevant for service users. This type of involvement was considered particularly relevant for guidelines with limited available scientific evidence, such as the Employment and Severe Mental Illnesses guideline.

Service User Consultation Methods Certain barriers and facilitators related to methods of service user consultation, such as focus groups, case studies and questionnaires. For example, in the Personality Disorders guideline, a questionnaire was conducted; and in the Anxiety Disorders guideline update, focus groups were held to obtain service users' feedback on the draft guideline. A main barrier to such consultation is *presenting guideline information in a comprehensive way to service user representatives* who often have no prior guideline experience. In the case of the Anxiety Disorders guideline, the research team and a service user organisation dealt with this issue by *providing service users in the focus groups with a summary of the guideline's key points*. A second barrier includes the *incorporation of data from service user consultation methods in the guideline*. Several professionals indicated that it is often difficult to integrate input from service users into the guideline because it generally focused on aspects of care, such as the organisation of care or the service user-provider relationship, which are often not the focus of a guideline. Moreover, methods for integrating input from focus groups and case studies in the guideline are often not defined at the start of a guideline process. In the Employment and Severe Mental Illness guideline, *a dialogue meeting in which service users exchanged perspectives with vocational professionals* facilitated integration of input in the guideline and carers, suggesting shared recommendations for the guideline.

Attitudes to Service User Involvement The attitudes of guideline developers toward service user representation in guidelines can both hinder and facilitate service user participation. Several service user representatives and professionals noted that, although input from service user representatives was valued, *evidence from literature holds a more prominent position* in the guideline process and final guideline text. Some of the professionals and service user representatives considered this to be a barrier to service user participation. Others thought it would not be feasible to treat experiential knowledge equally to evidence from literature in guideline development, as it would negatively affect the acceptability of the guideline to professionals. An important facilitator regarding attitudes toward service user representation included a *general supportive attitude toward service user involvement among GDG members,* especially the chair and project manager of the GDG. In the Employment and Severe Mental Illnesses guideline, many GDG members had positive experiences with service user involvement in guideline development or other aspects of mental health care, and they therefore valued service users' knowledge and experience. Another facilitator is *to direct attention to service user perspectives during GDG meetings by making it a specific item on the meeting agenda* as in the case of the Employment and Severe Mental Illnesses guideline.

The Outcomes of Service User Involvement

Service User Agreement with Guidelines Some barriers and facilitators relate to the extent to which the service users agree with the overall focus of the guideline and final guideline texts. In the majority of guideline cases, both professionals and service user representatives indicated that consensus was reached. In the Anxiety Disorders guideline, *service user representatives had reservations regarding some aspects of the guidelines or disagreed with the focus of the guideline*. Despite their reservations, the service users involved said they would rather have little involvement in the guideline process than no involvement at all. *Early service user involvement and explicit communication on the scope of the guideline* during the process may have helped in signaling possible points of disagreement, thereby providing the opportunity for timely action.

Incorporating Service User Perspectives in the Guideline The interviewed professionals and service user representatives generally agreed that insufficient *incorporation of the service user perspective in the final guideline* would hinder the effectiveness of service user involvement, but there was no clear standard as to what is 'insufficient'. Methods of incorporating service user perspectives in guideline texts varied. Some guidelines interwove service user experiences throughout the text, while others devoted a separate chapter to this. The interviewees were *unclear about the best way to incorporate the service user perspective*; they mentioned advantages and disadvantages of both strategies. When the service user perspective was interwoven through the guideline text, the voice of the service users is represented in the guideline as a whole, but is not easily distinguishable. In an individual chapter of the guideline, the service user perspective is clearly identifiable but the impact of such a chapter may be limited because professionals can easily skip or disregard it. *Careful weighting of different options* in close collaboration with service user representatives may help in arriving at the best solution.

Practical Applicability of the Guideline In several guideline cases, interviewees (especially service user representatives) had *concerns about the practical utility of the guideline*. They wondered to what extent the recommendations would be applicable to the practice of professionals and how the guideline recommendations would be implemented. This was also the case in the Employment and Severe Mental Illnesses guideline; professionals and guideline developers thought that the *development of a service user or lay version of the guideline and an implementation action plan* would help to make to guideline more practical.

Discussion

All multidisciplinary mental health guidelines developed in the Netherlands during the last decade have taken into account the service user perspective to some extent. This is probably a response to the requirements of funding agencies and to the fact that service user experience is incorporated in protocols at the Trimbos Institute, the primary mental health guideline development organisation in the Netherlands. Inclusion of service user involvement in protocols for guideline development indicates that service user participation is generally accepted. However, service users participate in guideline development at different levels of intensity and in different ways, depending on a range of contextual factors. Our study highlights a number of these factors. First, the size of the evidence base from the literature appears to be an important factor. The knowledge of professionals and service users gets more weight when the scientific evidence base is small. Second, the availability of service user representatives and service user organisations varies widely between guideline topics. Therefore, careful selection of appropriate methods is needed, taking into account that certain methods provide in-depth insights and require few participants (e.g. case studies and interviews), while other methods give broad insights using larger numbers of participants (e.g. questionnaires and focus groups). Third, when guidelines are updated, time and budget available for the development process is generally limited, creating the risk that less attention will be devoted to service user involvement.

Our study shows that service user participation in mental health guidelines has many barriers and facilitators in common with guidelines focusing on other health conditions. The main overlapping issues include clarity and transparency on the role of service user involvement in the guideline process, training and support opportunities for service user representatives, and selecting methods of representing service users. (Broerse et al. 2010; Jarrett and Patient Involvement Unit (PIU) 2004; Kelson 2005; Lanza and Ericsson 2000; van Wersch and Eccles 2001). Our study additionally highlights a number of other issues, which have not (or to limited extent) been described before.

Our study indicates that mental health service users were able to contribute to guideline development; they were able to make valid and relevant statements about guideline topics. No particular obstacles due to an 'impaired cognitive state' (Beresford 2002; Rose 2003) were encountered with respect to focus groups, surveys and case studies. Service users were generally able to participate in GDGs, although concentration problems and a lack of energy may require additional support or adaptations in the guideline process. Relatively high importance is placed on the stability or capacity of service users in mental health guideline development, mainly because these are associated with service users dropping out from the guideline process. At the same time, it is widely acknowledged that capacity and stability fluctuate throughout the course of mental illness. It seems key to gain more insight into the reasons and consequences of service users leaving the process early or joining late, since guidelines currently provide no information on this. Furthermore, it may therefore be helpful to adapt the process of guideline development to the capacities of service users by anticipating possible periods of instability, for example by including multiple service user representatives, and providing support and assistance where needed. Another solution may be to create ‘pockets of participation’, where participants are able to take ownership of specific sections of the guideline process (Franks 2011).

Findings from this study emphasize that the representativeness of service users is considered highly important. Despite this, methods for service user consultation are often applied in such a way that representation is questionable. For example, when focus groups are used, there are often very few focus groups employed, mainly due to budget and time constraints, so that it is unlikely that saturation of data is reached. To obtain representative input from service user consultation, more efforts and resources are required. The representativeness of service users as GDG members was also questioned as professionals sometimes claimed that service users’ input is too personal and anecdotal. However, professionals may be unaware of the sources of service users’ knowledge; they can be merely personal experiences but also gathered knowledge from a service user organisation. This distinction appears particularly unclear with respect to service users representing a service user organisation, since they are expected to speak on behalf of other service users, but may give individual accounts instead. Furthermore, it seems key to identify clearly whether representatives of a service user organisation are service users themselves, as our findings point at a blurring of roles of service users, and representatives of service users such as family members and employees of service user organisations. These findings indicate that more insight is needed into the actual representativeness of service user representatives and service users’ sources of knowledge. It should be noted that similar remarks can be made about the representativeness of professionals who are GDG members.

Many guideline processes experienced difficulties in incorporating experiential knowledge into guidelines in a systematic manner without compromising the richness of the accounts of service users. In general, input from methods of service user consultation cannot be directly integrated in a guideline format. Additional translation steps or changes in guidelines formats are needed to do this. Some guidelines in this study experimented with this, for example by making summaries of focus group findings per key research question or by organising dialogue sessions to formulate shared recommendations for the guideline. Renfrew et al. (2008) also describe a promising example of a structured process of developing evidence-based recommendations while involving a broad constituency of practitioners, service commissioners and service user representatives. The National Collaborating Centre for Mental Health (NCCMH) in the UK is also working towards a more robust and inclusive way of incorporating service user knowledge into clinical guidelines (Kendall et al. 2012).

Our research indicates that input from service users is generally attributed a lower value than the scientific evidence base in process of guideline development. This deviates from the ideal scenario proposed by Sackett et al. (1996) in which evidence is equally based on service users’ values and expectations, individual clinical expertise and the best available clinical evidence. It should be noted that this issue has also been reported for guidelines on somatic conditions, but it seems to play a more prominent role in guidelines on health conditions for which there is considerable debate on etiology and evidence, such as mental illnesses (Broerse et al. 2010). Mental health guidelines generally place more emphasis on evidence-based effectiveness of treatments for mental illness, while paying less attention to psychosocial interventions and non-medical issues such as employment, social support and quality of life for which there is often limited scientific evidence (Franx et al. 2011). Service users are often particularly interested in non-medical issues which may create tensions between service users and professionals (Telford and Faulkner 2004; van Wersch and van den Akker 2005). In our desk study, such tensions were apparent in the explicit disapproval of the final texts of two guidelines. Service user organisations did not approve of these guidelines because they were too focused on medical aspects of treatment.

There were concerns about the practical applicability of several guidelines. Sinnema et al. (2009) reported that only 28 % of the care-providers used the guidelines. This indicates that additional translation steps are necessary to implement guideline recommendations in practice. Guideline organisations, such as the Trimbos Institute in the Netherlands, are currently working on tools to assist implementation. Active involvement of service users in these implementation steps is needed to prevent a situation in which user perspectives get lost in the process, and loses its potential to affect daily practice positively.

Two main limitations apply to this study. First of all, our findings reflect characteristics of the Dutch context of multidisciplinary guideline development and this should be taken into account when applying the results in other contexts and countries. Service user involvement is widely accepted and practiced in the Netherlands, which may not be the case in other countries. Second, the case studies may provide more positive experiences of service user involvement than is the case for other guidelines because, in these cases, guideline development organisations were supportive of the evaluation of service user involvement. Considering that the five guideline cases covered a substantial part of all twelve multidisciplinary mental health guidelines developed during the past decade, the impact of this is likely limited. Further, it should be noted that the presence of the researcher may have stimulated attention for service user involvement. The qualitative approach applied in the case studies showed to be particularly useful for obtaining detailed descriptions of guideline processes and outcomes.

Conclusion

This study identified barriers and facilitators for service user involvement in CPG development. Insights into these facilitators and barriers will aid in the planning, monitoring and evaluation of service user involvement. Specific attention should be paid to integrating evidence obtained through service user involvement with evidence from scientific literature; proper selection and use of service user consultation methods; and the potential of service user involvement in enhancing the practical applicability of CPGs. Structures of guideline development processes may need to be reconsidered, taking barriers and facilitators of service user involvement into account.

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References

Beresford, P. (2002). User involvement in research and evaluation: Liberation or regulation? *Social Policy and Society, 1*(2), 95–105. doi:10.1017/S1474746402000222.

Boivin, A., Currie, K., Fervers, B., Gracia, J., James, M., Marshall, C., et al. (2010). Patient and public involvement in clinical guidelines: International experiences and future perspectives. *BMJ Quality & Safety, 19*(5), e22. doi:10.1136/qshc.2009.034835.

Boivin, A., & Légaré, F. (2007). Public involvement in guideline development. *Canadian Medical Association Journal, 176*(9), 1308–1309. doi:10.1503/cmaj.1060241.

Broerse, J.E.W., van der Ham, L., van Veen, S., Pittens, C., van Tulder, M. (2010). *Inventarisatie patiëntenparticipatie bij richtlijnontwikkeling.Onderzoeksrapport.* (*Inventory Patient Participation in Guideline Development. Research Report,* in Dutch) Amsterdam: Athena Instituut, Vrije Universiteit Amsterdam.

Corrigan, P. W., & Matthews, A. K. (2003). Stigma and disclosure: Implications for coming out of the closet. *Journal of Mental Health, 12*, 235–248.

Dalgin, R. S., & Gilbride, D. (2003). Perspectives of people with psychiatric disabilities on employment disclosure. *Psychiatric Rehabilitation Journal, 26*, 306–310.

Díaz Del Campo, P., Gracia, J., Blasco, J. A., & Andradas, E. (2011). A strategy for patient involvement in clinical practice guidelines: Methodological approaches. *BMJ Quality & Safety, 20*(9), 779–784. doi:10.1136/bmjqs.2010.049031.

Franks, M. (2011). Pockets of participation: Revisiting child-centred participation research. *Children and Society, 25*(1), 15–25. doi:10.1111/j.1099-0860.2009.00258.x.

Franx, G., Niesink, P., Swinkels, J., Burgers, J., Wensing, M., & Grol, R. (2011). Ten years of multidisciplinary mental health guidelines in the Netherlands. *International Review of Psychiatry, 23*(4), 371–378. doi:10.3109/09540261.2011.606538.

Jarrett, L. & Patient Involvement Unit (PIU). (2004). *A report on a study to evaluate patient/carer membership of the first NICE Guideline Development*. London: National Institute for Clinical Excellence (NICE).

Kelson, M. (2001). Commissioned papers patient involvement in clinical guideline development: Where are we now? *The Journal of Clinical Governance, 9*(4), 169–174.

Kelson, M. (2005). The NICE patient involvement unit. *Evidence-based Healthcare and Public Health, 9*(4), 304–307. doi:10.1016/j.ehbc.2005.05.013.

Kendall, T., Crawford, M. J., Taylor, C., Whittington, C., & Rose, D. (2012). Improving the experience of care for adults using NHS mental health services: Summary of NICE guidance. *BMJ, 344*, e1089. doi:10.1136/bmj.e1089.

Lanza, M. L., & Ericsson, A. (2000). Consumer contributions in developing clinical practice guidelines. *Journal of Nursing Care Quality, 14*(2), 33–40.

Légaré, F., Boivin, A., van der Weijden, T., Pakenham, C., Burgers, J., Légaré, J., et al. (2011). Patient and public involvement in clinical practice guidelines: A knowledge synthesis of existing programs. *Medical Decision Making, 31*(6), E45–E74. doi:10.1177/0272989X11424401.

National Steering Group for Multidisciplinary Guideline Development in Mental Health (NSGMH), & Trimbos Institute. (2012). GGZ-Richtlijnen [*Mental Health Guidelines*, in Dutch]. Retrieved from: http://www.ggzrichtlijnen.nl.

Nilsen, E. S., Myrhaug, H. T., Johansen, M., Oliver, S., & Oxman, A. D. (2006). Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews,* (3). doi:10.1002/14651858.CD004563.pub2.

Owens, D. K. (1998). Patient preferences and the development of practice guidelines. *Spine, 23*(9), 1073–1179.

Renfrew, M. J., Dyson, L., Herbert, G., McFadden, A., McCormick, F., Thomas, J., et al. (2008). Developing evidence-based recommendations in public health—incorporating the views of practitioners, service users and user representatives. *Health Expectations, 11*(1), 3–15. doi:10.1111/j.1369-7625.2007.00471.x.

Rogers, W. A. (2002). Are guidelines ethical? Some considerations for general practice. *The British Journal of General Practice, 52*(481), 663–668.

Rose, D. (2003). Collaborative research between users and professionals: peaks and pitfalls. *Psychiatric Bulletin, 27*(11), 404–406. doi:10.1192/pb.27.11.404.

Sackett, D. L., Rosenberg, W. M. C., Gray, J. A. M., Haynes, R. B., & Richardson, W. S. (1996). Evidence based medicine: What it is and what it isn't. *BMJ, 312*(7023), 71–72. doi:10.1136/bmj.312.7023.71.

Sinnema, H., Franx, G., van 't Land, H. (2009). *Trendrapportage GGz 2009. Multidisciplinaire richtlijnen in de GGz. Themarapportage*. [*Reporting Trends in Mental Healthcare 2009. Multidisciplinary Guidelines in Mental Healthcare. Report Themes,* in Dutch]. Utrecht: Trimbos-Instituut.

Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory.* Thousand Oaks, CA: Sage.

Telford, R., & Faulkner, A. (2004). Learning about service user involvement in mental health research. *Journal of Mental Health, 13*(6), 549–559. doi:10.1080/09638230400017137.

Trivedi, P., & Wykes, T. (2002). From passive subjects to equal partners: Qualitative review of user involvement in research. *The British Journal of Psychiatry, 181*(6), 468–472. doi:10.1192/bjp.181.6.468.

van de Bovenkamp, H. M., & Trappenburg, M. J. (2009). Reconsidering patient participation in guideline development. *Health Care Analysis HCA, 17*(3), 198–216. doi:10.1007/s10728-008-0099-3.

van Wersch, A., & Eccles, M. (2001). Involvement of consumers in the development of evidence based clinical guidelines: Practical experiences from the North of England evidence based guideline development programme. *Quality in Health Care, 10*(1), 10–16.

van Wersch, S.F.M., & van den Akker, P.A.M. (2005) *Ervaringskennis is geen kennis!? Cliëntenparticipatie bij multidisciplinaire richtlijnontwikkeling in de GGZ. Eindrapportage. [Experience-based knowledge is no knowledge!?Client Participation in Multidisciplinary Guideline Development in Mental Health. Final Report,* in Dutch]. Utrecht: Trimbos Instituut.