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van der Ham, A.J.

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CHAPTER 8

Monitoring and evaluation of service user involvement in clinical practice guideline development: lessons from the Multidisciplinary Guideline for Employment and Severe Mental Illness, The Netherlands

Abstract

The aim of this paper is to gain better insight into the quality of service user participation in clinical practice guideline development and contribute to developing approaches for monitoring and evaluation of such initiatives. In addition, we explore the potential of a dialogue-based approach for reconciliation of preferences of service users and professionals in the guideline development process. The development of the Multidisciplinary Guideline for Employment and Severe Mental Illness in the Netherlands during the period 2010-2011 served as a case study. Methods for service user involvement in guideline development included: four service user representatives in the guideline development group and advisory committee, two focus group discussions with service users, a dialogue session and eight case studies. To evaluate the quality of service user involvement we developed a monitoring and evaluation framework including both process and outcome criteria. Data collection included observations, document analysis and semi-structured interviews (n = 26). Aspects that contributed most to the quality of service user involvement included the use of different methods, reflection of service user input in the guideline text, a supportive attitude among professionals and attention for service user involvement throughout the process. The quality of service user involvement was lower with respect to representing the diversity of the target group, articulation of the service user perspective in the GDG, and clarity and transparency concerning methods of involvement. The monitoring and evaluation framework was useful in providing detailed insights into service user involvement in guideline development. Service user involvement was evaluated as being of good quality. The dialogue-based approach appears to be a promising method for obtaining integrated stakeholder input in a multidisciplinary setting.

Submitted to: Health Expectations

Introduction

The involvement of service users in clinical practice guidelines (CPGs) has been recommended for many years (Boivin et al., 2010) for a number of reasons. First, experiential knowledge of service users complements scientific evidence, increasing the relevance and quality of guideline recommendations (Kelson, 2001; Owens, 1998). Second, service user involvement improves practical implementation of clinical guidelines (Boivin & Légaré, 2007). Third, service users have the moral right to participate in decisions that affect them (Rogers, 2002).

Recently, the number of initiatives involving service users in the development and implementation of CPGs has increased (Boivin, 2010). The most common methods for service user involvement are: service user representation in guideline development groups (GDGs), service users reviewing final drafts of the guideline and consultation of service users through focus group discussions (FGDs) or questionnaires (Broerse et al., 2010; Díaz del Campo, 2011; Nilsen et al., 2006). Several scholars have identified barriers and facilitators of service user involvement in CPGs. One main barrier is the difficulty of reconciling the preferences of service users with the views of professionals and with evidence from the literature (Légaré et al., 2011). Other important barriers are lack of clarity about the roles and tasks of service users in the process, lack of resources for supporting service user representatives in GDGs, and doubts about representativeness of service users (Franx et al., 2011; Légaré et al., 2011; van Wersch & Eccles, 2001). Facilitators of participation include: involving service users actively in all phases of guideline development, clarification of the role of service user representation, attention for adequate selection of service user representatives, and provision of training and support for service user representatives (Jarret & PIU, 2004; Kelson, 2005; Lanza & Ericsson, 2000; SIGN, 2008; van Veenendaal et al., 2004).

Despite the growing number of initiatives, there is still limited insight in processes and outcomes of service user involvement (Díaz del Campo et al., 2022; van de Bovenkamp & Trappenburg, 2009). Scholars have also pleaded for more research to identify key components of successful service user involvement initiatives, better evaluation of service user involvement, and research on alternative methods of service user involvement, such as systematic reviews of published evidence on service user perspectives and tools for integrating service user input into CPG recommendations (Boivin et al., 2010; Légaré et al., 2011).

In this paper, we develop a framework for monitoring and evaluating (M&E) service user involvement during the development of the Multidisciplinary Guideline on Employment and Severe Mental Illness⁸ in the Netherlands during 2010-2011 (van Erp et al., 2013). In

⁸ Multidisciplinaire richtlijn 'werk en ernstige psychische aandoeningen'

the guideline development process, both common methods for service user involvement (service user representatives in the GDG and advisory committee, and FGDs) as well as innovative approaches (case studies and a dialogue session) were employed. Particular attention is paid to the use of a dialogue-based approach in the reconciliation of preferences of service users and professionals. This paper aims to provide insights into process and outcomes of service user participation in CPGs and to contribute to the development of comprehensive approaches for M&E of service user involvement.

Methodology

Case description

The Multidisciplinary Guideline on Employment and Severe Mental Illness provides recommendations for supporting people with chronic and severe mental illnesses in employment, with a focus on job tenure (National Steering Group for Multidisciplinary Guideline Development in Mental Health & Trimbos Institute, 2013). The initiative for the guideline was taken by the Netherlands Society of Occupational Medicine⁹ (NVAB) and the Trimbos Institute, the national institute for mental health and addiction. These organizations were supported by the service user organization, Pandora, the Netherlands Psychiatric Association¹⁰ (NVvP) and the Phrenos Knowledge Centre for treatment, rehabilitation and recovery in severe mental illnesses. Funding was provided by the Netherlands Organization for Health Research and Development (ZonMW).

A GDG performed the main tasks in developing the guideline, while an advisory committee monitored the activities of the GDG. Among the nine GDG members were two service user representatives, one of whom changed jobs during the process and no longer formally represented a service user organization. Two of the twelve members of the advisory committee were service user representatives, one of whom joined halfway through the process. In total, sixteen organizations were represented in the GDG and advisory committee, including four service user organizations and twelve professional organizations. The groups were supported by a chair (Phrenos Knowledge Centre), a guideline project manager (Trimbos Institute), a research manager (Trimbos Institute, second author) and five persons providing methodological and organizational assistance (Trimbos Institute).

Over a period of 2 years (2010-2011), the GDG and the advisory committee met respectively eight times and three times to formulate recommendations concerning the following key research questions:

1. What are effective self-management interventions that promote job tenure?

⁹ Nederlandse Vereniging voor Arbeids- en Bedrijfsgeneeskunde

¹⁰ Nederlandse Vereniging voor Psychiatrie

2. Which factors influence job tenure and should be taken into account in vocational support?
3. What are best practices for assessing personal competences in relation to finding and keeping a job?
4. Which elements of vocational support can be successfully implemented to promote job tenure?
5. What are best practices in the collaboration between professionals to promote job tenure?

Literature searches were performed by an information specialist. The reviewing and writing tasks were divided among the GDG members. In addition, four FGDs, a dialogue session and eight case studies were held to obtain insights from practice (see Box 8.1). A draft of the guideline was sent to professional organizations for feedback, after which the final guideline was sent to the involved professional organizations for formal approval.

Box 8.1: Description of FGDs, the dialogue session and case studies

Four FGDs were held separately with service users (n = 8), expert service users¹¹ (n = 10), family members (n = 9) and professionals (n = 7). The four FGDs had a similar design and aimed at articulation of the participants' needs regarding employment and severe mental illness. The FGDs were followed by a dialogue session in which fourteen participants from the FGDs took part, including service users (5), expert service users (3), family members (3) and professionals (3). In the dialogue session, the findings from the FGDs were presented in order to verify and complement them. After this, participants formulated recommendations for each key research question of the guideline. They did this in small, mixed groups of two or three participants and presented their recommendations to the group. The FGDs and the dialogue session were organized and facilitated by the research manager (second author) and a researcher from the Athena Institute (first author). For each session, a report was produced and sent to the participants for a member check.

For the eight case studies, three persons were interviewed per case: a service user, an employer or manager, and a job coach. The interviews were carried out by the research manager, a research assistant and a service user representative who was a member of the GDG. They made a case description for each case. Members of the GDG assessed the case descriptions and subsequently formulated additional questions. In a second interview round, the service user and job coach together reflected on the developments in the past months and questions raised by the GDG members after the first round of interviews were addressed. The combined results from both interview rounds were integrated in a report in which the results were presented per key research question.

The results from the FGDs dialogue session and case studies were presented during meetings of the GDG and advisory committee.

¹¹ Expert patients are persons who have been diagnosed with a mental illness and who are current or past users of mental health services providing services to other patients in the form of advocacy, self-help, counselling, training, and/or research.

Monitoring and evaluation of service user involvement in guideline development

An M&E framework with quality criteria was developed to assess the participation process and its outcomes. The framework is based on one previously used for evaluating stakeholder participation in health research agenda setting, as well as the results of an inventory of service user participation in clinical guideline development [Broerse et al., 2010; Caron-Flinterman et al., 2006]. The **process criteria** included *involvement of service users*, *process structure* and *process management*, while the **outcome criteria** entailed *direct outcomes* and *indirect outcomes* of service user involvement. The quality of service user involvement is determined by the extent to which the process and outcomes of service user involvement meet the indicators of these criteria (see Box 8.2). M&E comprised a reflexive process, following principles of Reflexive Monitoring in Action (RMA) (Grin and Weterings, 2005; Regeer, 2010). RMA aims to stimulate learning processes by enhancing reflection and dialogue between stakeholders concerning the process and outcomes. This is facilitated by a monitor who observes the process, gathers related data, and reflects with stakeholders on the activities with the option to adapt the process.

In this study, triangulated data collection included document analysis, (participatory) observations and semi-structured interviews. Data were collected by a monitor (first author). Drafts and final texts of the guideline, correspondence among the GDG members and advisory committee, and minutes of the meetings were subject to document analysis. Observations were made during the meetings of the GDG and the advisory committee, the four FGDs and the dialogue session. The monitor contributed to the design and facilitation of the FGDs and the dialogue session. Research logs were kept to document the observations and activities of the monitor. During several meetings, the monitor presented provisional findings to reflect on them with GDG members and the advisory committee.

Some 26 semi-structured interviews were undertaken: five at the start of the guideline development process with two guideline developers (the process manager and chair) and three service user representatives; ten halfway through with three guideline developers (the chair, the research manager and the process manager), two service user representatives and five professionals from the GDG; and eleven interviews at the end with three guideline developers (the chair, the research manager and the process manager), four professionals from the GDG and four service user representatives. At the start of each interview, its purpose was explained to the participants. Sessions were audio-recorded with consent of participants. A summary of the transcript was sent to the participants for a member-check. Data were treated confidentially. Data were coded manually following standard qualitative coding procedures (Strauss and Corbin, 1998). The criteria in the M&E framework were main categories for coding.

Box 8.2: Monitoring and evaluation framework

<i>Process criteria</i>	<i>Evaluation indicators</i>
<i>Involvement of service users:</i>	<ul style="list-style-type: none"> - Attention should be paid to the balance between number of involved service users (or service user representatives) and professionals. Ideally the numbers should be equal. - Diversity of the population of people with mental illness (e.g. demographics, ethnicity, and severity and duration of the disorder) should be acknowledged and taken into account. - Attention should be paid to representation of service users. Who is the service user representative? Is he or she able to represent service users' perspectives?
<i>Process structure:</i>	<ul style="list-style-type: none"> - A guideline development process needs to be structured transparently. - Service users should be informed about what is expected from them, the aim of the overall project, the activities in which they will participate, and their influence on the process. - Service users should be involved from the start to the completion of the process and there should be direct interaction between service user representatives and professionals. - Service users should be involved in significant aspects of decision-making to ensure use of service users' input.
<i>Process management:</i>	<ul style="list-style-type: none"> - Independent facilitation of service user involvement is crucial for equal treatment of service users and professionals. An open and respectful atmosphere should be created so that service users feel able to share their views. - Good process management involves adjustments in the guideline development process to suit abilities of service users, and provision of training/support. - Project management and professionals should have a positive attitude towards service user involvement
<i>Outcome criteria</i>	<i>Evaluation indicators</i>
<i>Direct outcomes:</i>	<ul style="list-style-type: none"> - Consensus on the content of a clinical guideline is an important indicator of success. In order to reach consensus, the outcomes – in this case the final guideline - should reflect the input and perspectives of involved service users. - The extent to which service users' input is incorporated in the final guideline is important. What aspects are incorporated in the guideline, and why? - Service users need to recognise the clinical guideline as practically relevant. - Dissemination of the clinical guideline is considered important.
<i>Indirect outcomes:</i>	<ul style="list-style-type: none"> - Indirect outcomes are related to the stimulation of learning processes and the achievement of mutual learning, resulting in changes of thinking of both service users and professionals. - Mutual learning implies learning in a substantive way (concerning content-related matters), in a procedural way (concerning participatory approaches) and in a reflexive way (concerning their own and each other's knowledge, perspectives or roles).

Results

Process

For each criterion, we discuss findings concerning the different service user involvement methods used in the guideline development process: service user representatives in the GDG and advisory committee, the case studies, and the FGDs and the dialogue session.

Involvement of service users

The two most important issues concerning service user representation in the GDG and advisory committee were: 1) balance between number of service user representatives and number of professionals, and 2) characteristics of the service user representatives. The number of service user representatives in the GDG (two among ten members) was considered sufficient by most interviewed professionals, service user representatives and guideline developers. The advisory committee initially counted one service user representative among twelve members, which was considered insufficient by many service user representatives, guideline developers and professionals. The monitor also signalled this as an issue needing attention. As a result, a second service user representative was invited to join the advisory committee halfway through the process. Observations indicated that at least one service user representative was present at all meetings. Two of the four service user representatives were known to have personally experienced mental illness. It was not known if the other two representatives had this experience because the personal background of service user representatives was not discussed during the process. Some interviewed professionals could not distinguish service user representatives from the other GDG members because of their professional attitude.

The most important issue regarding the FGDs and the dialogue session involved the diversity of the population of people with mental illness. There were two FGDs with service users: one with ordinary service users and one with expert service users. The monitor suggested making such a distinction because ordinary service users might have different views from expert service users who are used to speaking in public and tend to have a broader view on issues. It was relatively easy to recruit expert service users through service user organizations. Finding ordinary service users initially took more effort but they were eventually recruited through the network of professionals in the GDG. People with psychotic disorders were more highly represented than people with other mental illnesses, mainly due to successful recruitment through a service user organisation for psychotic disorders. Most interviewees did not find this problematic because psychotic disorders represent a substantial proportion of severe mental illnesses, and the issues raised in the FGDs were recognized by the GDG members as being of general importance. However, some professionals indicated that perspectives of other severe mental illnesses were inadequately represented. Both guideline developers and professionals mentioned that

diversity in ethnic background was limited, not reflecting the ethnic diversity of the population.

Prominent issues concerning the case studies included: 1) representation of the diversity of the service user population, and 2) the ability of service users to voice their concerns. As in the FGDs, service users with psychotic disorders were more highly represented in the case studies. In contrast to the FGDs, there was more diversity in terms of ethnicity. Furthermore, the research manager indicated that some service users found it difficult to articulate their stories and voice their concerns. This might have made the service user perspectives less visible in the case studies than those of employers and job coaches.

Process structure

Structural aspects that influenced service user involvement in the GDG and advisory committee involved: 1) clarity of roles, goals and tasks, 2) active involvement in different phases of the process, and 3) service user representatives' influence on decisions. The structure of service user involvement was explicitly addressed in the guideline development proposal and at the first working group meetings, but observations showed that attention for this topic declined during the process. Some service user representatives were uncertain about what was expected of them because the roles of service user representatives were not explicitly discussed. According to various interviewees, the involvement of the service user representatives throughout the process, from the writing the draft of the proposal onwards, contributed to the quality of service user involvement. Observations and correspondence between GDG members indicated that the influence of service user representatives on decision-making might have been limited because many decisions were not finalized during the meetings but were taken afterwards by a small group of guideline developers. Several service user representatives and guideline developers indicated that the influence of service user representatives was most evident when discussing qualitative research and formulating additional considerations relating to conclusions from literature.

Several issues appeared to be important for service user involvement in the FGDs and dialogue session: 1) design of the sessions, 2) perceived added value, and 3) translation of findings to the guideline development process. The FGDs were helpful in obtaining insights into the participants' issues (see Box 8.3).

Box 8.3: Main findings from FGDs (A) and dialogue session (B)

A. FGDs: needs of expert service users, service users, family members and professionals

Expert service users

- Reducing stigma of severe mental illness
- Increasing and improving options for adjustments in employment
- Better adaptation of social security services to needs of people with mental illness

Service users

- Improving ability to deal with illness and symptoms in the workplace
- Better matching of work to individual characteristics

- Increasing opportunities for personal (career) development

Family members

- Strengthening the role of family members
- Enhancing service user-centred approach of professionals
- More individually tailored approach for service users in the workplace

Professionals

- Improving collaboration and communication between professionals
- Solving the 'disclosure' (service user providing information about his mental condition) dilemma
- Closing the gap between the need for support and actual provision of support

B. *Dialogue session: shared recommendations from expert service users, service users, family members and professionals*

1. *What are effective self-management interventions for service users to promote job tenure?*

- Stay in control / keep responsibility over care processes and employment support structures
- Avoid a dependent attitude towards professionals
- Ask for support when needed and be specific in what is asked for
- Follow a training course on job tenure

2. *Which factors influence job tenure and should be taken into account in vocational support?*

- Assess symptoms interfering with work for each service user individually
- Use an individualized, tailor-made approach
- Increase employers' general knowledge on mental illness and related vocational limitations
- Disclosure of individual (illness-related) information of service users to employers can help to reduce stigma, but advantages and disadvantages should be carefully considered

3. *What are best practices for assessing personal competences for finding and keeping a job?*

- Use a service user-centred, tailor-made approach
- Provide continuity in employment support and evaluate competences on a regular basis
- Societal stigma attached to mental illness should be addressed; it influences ideas of competency

4. *Which elements of vocational support can be successfully implemented to promote job tenure?*

- Clarify wishes and expectations of employers toward employees, and vice versa
- Support employers of service users in supported employment

5. *What are best practices in the collaboration between professionals to promote job tenure?*

- Increase transparency/clarity regarding roles of different stakeholders in supported employment
- Improve collaboration between occupation physicians and mental health professionals
- Involve service users in all meetings of professionals

Separating ordinary and expert service users appears to have been vindicated because ordinary service users generally formulated issues from an individual perspective, while service user experts mainly addressed contextual factors. An important aspect of the design of the FGDs and dialogue session was that the different groups first met separately in homogeneous groups, and then in mixed, heterogeneous groups. In this way, the different groups were able to articulate their needs and set an agenda before engaging in a mixed-stakeholder dialogue. During the dialogue session, stakeholders formulated and agreed on guideline recommendations in small mixed stakeholder groups (see Box 8.3).

The FGDs and dialogue session were specific items on the regular agenda of the GDG meetings and meetings of the advisory committee. Interviewed professionals indicated that

the findings of the FGDs were generally recognizable. Some of them thought this helped to give lived experiences a more central place in the guideline development process, while other professionals doubted the added value because many issues were already known to them. An important process step was how to incorporate the information from FGDs and the dialogue session in the guideline text, since the procedure for this had not been set out in advance. The GDG members discussed this with the monitor and agreed that the results would be summarized per key question (by the research manager and monitor) and integrated under the ‘additional considerations’ chapter in the guideline.

The findings highlight three main issues concerning service user involvement in the case studies (see Box 8.4): 1) integrating information from the case studies in the guideline, 2) transparency of the goal and structure of the case studies, and 3) integration of perspectives of different stakeholders. Many GDG members initially expressed concerns regarding the way findings from case studies would be incorporated in the guideline. In response, GDG members agreed to summarize the findings per key questions in the guideline as was also decided for the FGDs. The purpose of the case studies was unclear to many professionals and service user representatives, possibly because limited time was paid to the case studies during GDG meetings. The inclusion of the perspectives of different stakeholders in each case was positively evaluated by professionals, guideline developers and representatives because it provided in-depth insights into specific cases and included employers.

Process management

Management-related aspects that particularly affected service user involvement in the GDG and advisory committee involved: 1) the attitude towards service user involvement, and 2) provision of support and training. The guideline chair and manager considered service user involvement to be an important aspect of guideline development. They emphasized this during meetings and sometimes explicitly asked for representatives’ input although they did not formally organize additional support or training for representatives. Most service user representatives felt that they did not need specific training and support although one, who had joined later in the process, found it difficult to catch up and considered that support was limited.

Important managerial issues of the FGDs and dialogue session related to: 1) communication of guideline-related information, and 2) the role of the monitor. The efforts to communicate guideline-related information in a comprehensive way in the FGDs and dialogue session made it possible for participants to quickly gain insights into guideline development. The monitor played a substantial role in this process by making suggestions for the structure of this dialogical approach and providing assistance to facilitation of the sessions and data processing.

Box 8.4: Example of a case study

According to Irene¹² (service user), vocational support is especially important when starting a new job. When she started her new job as an administrative assistant, she had the feeling that she was left to herself because her supervisor only contacted her once a month. In addition, she would have liked more clarity about her tasks and responsibilities. In her opinion, the lack of a clear task description forms a barrier to job tenure. In the case of Irene, she could call her job coach and she occasionally talked to her therapist. This helped her through this difficult period of uncertainty. Looking back, she would have considered it appropriate if there had been communication between her therapist and her employers, but this was not the case. Other issues that Irene considers to be important in job tenure are for her to indicate in a timely fashion when things are not going well and being able to plan a day off.

Regarding the case studies, two important issues were emphasized. First, some interviewed service user representatives and guideline developers thought that the involvement of a service user representative as an interviewer in the case studies might have enhanced the service user perspective. Second, the research manager indicated that case studies are an effective, simple method for involving all sorts of service users, especially those without prior knowledge of guideline development and those who have trouble speaking in groups.

Outcomes

In this section, we discuss the outcomes of service user involvement by looking at its impact on the guideline development process, focusing on the final guideline (direct outcomes) and learning processes (indirect outcomes).

Direct outcomes

All interviewees thought that the input from service user FGDs, the dialogue session, case studies and individual service user representatives was adequately represented in the guideline (see Box 8.5). The summarized findings of the FGDs, dialogue session and case studies were all included in the guideline under the separate heading ‘additional considerations’, providing contextual information to complement evidence from the literature. Service user input was unique in emphasizing specific topics such as service users’ vocational limitations, their needs at the workplace and in terms of employment support. Final guideline recommendations were generally based on evidence from literature, although findings of the FGDs, dialogue session and case studies were also taken into account. Input from service user representatives was most evident in the critique of methods of vocational rehabilitation, reference to qualitative studies and incorporation of evidence from grey literature.

The practical applicability of the guideline was an important issue according to the majority of interviewees. Service user involvement may have enhanced the practical applicability of the guidelines, but various interviewees expressed concerns about the

¹² To respect the patient’s privacy, a fictive name is used in the story.

extent to which the guideline could affect daily practice. The development of a version of the guideline for non-experts was mentioned by the guideline developers as one way to enhance the practical applicability of the guideline. However, the development of the non-expert guideline version was unfinished by the end of the guideline development process. In addition, an implementation plan was formulated to facilitate guideline implementation. This plan also incorporated issues that were raised during the FGDs and dialogue session, such as the development of interventions for addressing stigma in the workplace and the role of service user organizations. However, implementation of this plan was beyond the scope of the guideline development process.

Box 8.5. An example of how input from the FGDs and the dialogue session was integrated into the guideline

Key question: What are effective self-management interventions that promote job tenure?

Additional considerations from FGDs and dialogue session

Participants emphasized that self-management strategies have to be mastered before they can be applied. Good support is considered crucial. Changes in support structures, provided by the job coach, negatively affect the monitoring of progress of service users regarding self-management strategies. However, service users should have the opportunity to change job coach if needed. Support for service users should also pay attention to the balance between work and private life. In addition, it is important to regularly evaluate and monitor both the strengths and weaknesses of service users. Service users also play a role in ensuring that regular evaluation takes place.

Additional considerations from case studies

The case studies show that employees try to prevent relapse or recurrence of symptoms by taking moments of rest during work time, or by resting directly on return home. Other forms of self-management mentioned include: learning to recognize signs of relapse or recurrence of symptoms, finding ways to relax at home, having a stable daily routine, seeking support from others, taking a day off, and keeping a diary on thoughts and feelings about the work or home situation.

Recommendations

Despite the lack of scientific evidence, the GDG recommends using assessed self-management strategies (strengthening positive self-image, accepting limitations, setting boundaries, taking breaks, involving peers and a healthy lifestyle) in practice. Professionals and service user experts (with personal experience of self-management strategies) can support service users if needed, and should try building on the strengths of service users as much as possible.

Indirect outcomes

Learning processes and capacity building of service user representatives and service user organizations took place to a limited extent during the guideline development process. About half of the interviewed professionals and guideline developers mentioned that service user involvement helped them to keep the guideline service user-focused. Some of them specifically stated that the monitor had played a central role in this. Two service user representatives indicated that they had learned more about guideline development. This had a limited impact on the associated service user organizations because there was little communication between the service user representative and the service user organization. However, one service user representative indicated that her involvement in guideline

development had led to a discussion in the service user organization on how to provide robust input in guideline development processes. Approximately half of the interviewees (service user representatives and professionals) could not identify indirect outcomes resulting from service user involvement.

Discussion

The M&E framework proved to be a useful tool for providing detailed insights into the process and outcomes of service user involvement in guideline development. Service user involvement was generally evaluated as being of good quality. Aspects of service user involvement that particularly contributed to the quality of service user involvement comprise: the number of service user representatives in the GDG and advisory committee, the use of different methods resulting in evidence-based validation by triangulation of data and the way in which service user input was incorporated in the guideline. Furthermore, the supportive attitude of professionals and guideline developers and the explicit attention to service user involvement throughout the process appeared to be crucial for the quality of service user involvement. The role of the monitor was important because it increased the attention and resources for service user involvement. This was possible within the scope of this study, but such a monitor is usually not available to guideline development processes. The need for such a monitor could be addressed by incorporating monitoring activities in the tasks of the project manager or chair or by allocating resources to appoint a monitor.

In this study, an innovative dialogue-based approach was used to reconcile the perspectives of service users and other stakeholders. Our findings show that stakeholders were able to hold a constructive discussion based on each other's concerns and formulate shared recommendations for the guideline. This approach seems particularly useful in stimulating interaction in a multi-stakeholder setting and may help to increase the guideline's acceptability among different stakeholders (Boivin & Légaré, 2010; Wallerstein, 1992).

Integrating the perspectives of service users with the evidence from literature was a bigger challenge than reconciling the views of the different groups, mainly because guideline development was primarily focused on evidence from literature. According to Sackett (1996), evidence-based medicine should be equally based on service users' values and expectations, individual clinical expertise and the best available clinical evidence. In this guideline process, a strategy was developed during the process for integrating the input from the FGDs, dialogue session and case studies into the guideline text as there was no predetermined strategy for this. This helped to give input from the service user perspective a place in the guideline text, but the evidence from literature still formed the main focus. Renfrew et al. (2007) provide an example of a more structured process in which evidence from the literature and the views of a broad constituency of stakeholders were more fully integrated to develop evidence-based recommendations.

The evaluation revealed several other challenges to service user involvement in the guideline development process. First, it was difficult to represent the diversity of the target group in the guideline development process with respect to ethnic diversity and types of severe mental illnesses. When guidelines are relevant to a broad target group, attention should be paid to issues of diversity, for example by organizing additional FGDs. During this guideline development process, there were limited resources for including a diversity of stakeholders and, as a result, it is unclear whether saturation was reached for each stakeholder group. The dilemma of having to choose between either saturation of data or diversity and completeness is not easily solved without adequate resources (Elberse et al., 2012).

Service user involvement was also negatively influenced by the fact that some service user representatives did not clearly distinguish themselves from professionals in the GDG. This may be related to a high level of professionalization (proto-professionalization) of service user representatives who learn about research during the process and adapt themselves to the scientific approach of professionals (Caron-Flinterman et al., 2007). However, it may also be the result of the lack of clarity concerning service user representatives' roles. Preparing an agenda or listing priorities from the service user perspective beforehand might assist service user representatives to provide input.

Third, some professionals indicated that the added value of service users' input from the FGDs, case studies and dialogue session was not evident as they were already familiar with most of the findings. However, service user involvement did contribute to greater priority being given to issues important to service users and to making practice-based knowledge more explicit in the guideline. In addition, a high degree of consensus between professionals and service users contributes to triangulation and realizing evidence-based medicine as defined by Sackett (2006).

The practical applicability of the guideline was an issue of concern among the interviewees. Although service user involvement contributed to connecting the guideline to practice, further implementation steps, maintaining the service user perspective, are still needed (Boivin et al., 2010). To achieve this, a stronger link between guideline development and implementation is required. To assess service user involvement in the context of guideline implementation, long-term outcomes should be incorporated in the monitoring and evaluation framework.

When interpreting the results of this study, one should keep in mind that the experiences reported may be more positive in terms of service user involvement than is the case for other cases of guideline development because there was a relatively high level of service user involvement and the guideline developing organizations were supportive of service user participation. In addition, the presence of the monitor further enhanced attention for service user involvement. Results may be particularly relevant to the development of

guidelines with a strong multidisciplinary character, mental health guidelines and guidelines based on limited scientific evidence.

Conclusions

This study provides insights into the quality of service user involvement in a particular guideline development process, using an M&E framework developed for this purpose. The findings highlight the need to accommodate service user involvement and input into the professional and evidence-led process, and the need for additional resources. A dialogue-based approach appears a promising method, enabling a broad range of stakeholders to provide input tailored to the guideline topic and key research questions. More research is needed for further development of methods for reconciling the preferences of service users with evidence from literature, and to address service user involvement in the context of guideline implementation.