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How Best to Engage Users of Forensic Services in Research: Literature Review and Recommendations

Keywords

Forensic mental health, collaborative research, service user involvement, user-led research, participatory research.

Abstract

Guidance on service user involvement is available to help researchers working with people with mental health problems, but there is currently no comprehensive guidance relating to forensic settings where additional issues arise. This rapid review aims to summarise the currently available information on how best to engage users of forensic mental health services in the research process, and to make appropriate recommendations. Medline and five other databases were searched to May 2016 using relevant keywords and Medical Subject Headings, supplemented by a general Internet search. Eleven peer-reviewed journal papers and 12 reports or web-based documents were identified, the majority containing information derived using a qualitative methodology.

Five areas of particular relevance to forensic settings were identified: *power relations & vulnerability issues* (including ethical treatment; informed consent; attitudes of staff and other service users; support), *practical difficulties* (including ‘consultation fatigue’; tokenistic inclusion; tensions over security and risk management; access; payment; co-authoring); *confidentiality and transparency*; *language and communication* and *training issues*. Recommendations on engaging service users in forensic mental health research are presented.

How Best to Engage Users of Forensic Services in Research: Literature Review and Recommendations

The *Research Governance Framework for Health and Social Care*, published in the UK in 2001 and revised in 2005, was the first government document in Europe to recommend the active involvement of service users and carers at every stage of research (Department of Health, 2001). Since then there has been increased encouragement for users of health services to become actively involved in the research process itself rather than simply taking the role of ‘subjects’ (e.g. Collaboration for Leadership in Applied Health Research and Care [CLAHRC], 2014; O’Donnell & Entwistle, 2004; Wallcraft, Schrank & Amering, 2009). The potential benefits of involving service users in health and social care research have been reported in one systematic review of 66 studies as enhancing the quality and appropriateness of the research, with positive impacts arising from development of user-focused research objectives, development of user-relevant research questions, more appropriate recruitment strategies for studies, a consumer-focused interpretation of data, and enhanced dissemination of study results (Brett et al., 2012), although the authors concluded that much of the evidence base concerning impact remained weak and needed significant enhancement.

The importance of service user involvement in mental health research is also well established, including, for example, acknowledging possible difference of perspective between service users and mental health professionals about their own illness and need for care, new ways of thinking about the nature of evidence itself, the promotion of social inclusion, and the possibility that service user involvement can of itself be therapeutic (Tait & Lester, 2005). As a result,

applications for research funding in the UK are now routinely required to demonstrate how service users have been, and will be, involved in all stages of the research process. Active service user involvement may take the form of consultation, collaboration, or control of a project in roles that include helping to formulate grant applications, prioritising research topics, attending steering groups, selecting participants and disseminating findings (Hanley et al., 2004; Sainsbury Centre, 2008). Service users may also become active researchers and contribute to decisions on research design and implementation.

The European Parliament Resolution on Mental Health has called on Member States to empower organisations which represent people with mental health problems and their carers “in order to facilitate their participation . . . in all stages of research into mental health” (European Parliament, 2009, p.10). Furthermore, the World Health Organisation (WHO) mental health strategy for Europe (WHO, 2011) declared service user involvement as essential in the development and evaluation of policy and services; service user leadership in research has been suggested as the most effective way of enhancing such involvement (Callard & Rose, 2012). In North America, the National Institute of Mental Health (NIMH), an organization run by the US Department of Health and Services, currently involves ‘public reviewers’, which include individuals and family members who have been directly affected by mental illness, in evaluating the relevance and practicality of each research application (NIMH, 2015), although it should be noted that the NIMH does not represent North America as a whole.

Despite the strength of these recommendations, no formal evidence synthesis of service user involvement in forensic settings is apparent in the literature. Whereas general guidance on service user involvement in mental health research is available from groups such as the Standing Advisory Group on Consumer Involvement in the National Health Service Research and Development

Programme (INVOLVE, 2012a) and a comprehensive guidance document has been published by the Mental Health Research Network (MHRN, 2012, summarised in Table 2), information relevant to secure or forensic settings is limited (Faulkner, 2007). This is despite suggestions that forensic services that are based on evidence from collaborative research are more likely to be acceptable to service-users (Spiers, Harney & Chilvers, 2005), and that involving service users in prioritising research topics may result in research questions being more clinically meaningful (Wykes, 2003).

The objective of this review is to summarise what is currently known on the topic of involving or engaging forensic service users in the research process, and to make appropriate recommendations. This topic is particularly relevant, given the encouragement towards greater service user involvement in a number of European countries in the context of the absence of any current evidence synthesis in this area.

Terminology

The scope of this review follows Faulkner and Morris (2003) who defined service user involvement in forensic settings as the active participation of forensic mental health service users in any or all of the stages of research, from defining priorities for research, through commissioning, designing and carrying out research, to the dissemination of results. The terms 'engagement' and 'involvement' are not always used consistently in the literature, however (Tambuyzer, Pieters & Van Audenhove, 2011). 'Involvement' may be defined as members of the public becoming actively involved in research projects and in research organisations as, for example, co-applicants, in identifying research priorities, as members of steering groups, or

undertaking interviews with research participants, whereas '*engagement*' is sometimes seen as relating only to situations where information and knowledge about research is provided and disseminated (INVOLVE, 2012b). Because (a) the scope of this review encompasses all these aspects, and (b) these terms are sometimes used interchangeably in the literature, engagement and involvement are not differentiated in this paper.

Terms to describe the patients (or, indeed, members of the public) who become involved in research are widely debated in the literature, and there is no universally acceptable phrase. In this paper the term '*service user*' is used because it is not easily misinterpreted. The term '*user*' is avoided as it can be controversial in mental health settings because of the connotations associated with alcohol and substance use or misuse.

Method

A rapid review was undertaken with the objective of summarising what is currently known on the topic of involvement of forensic service users in the research process. Rapid reviews are an emerging type of knowledge synthesis which aims to '*to inform health-related policy decisions and discussions, especially when information needs are immediate*' (Lal & Adair, 2014, p.34). In a rapid review, '*components of the systematic review process are simplified or omitted to produce information in a short period of time*' (Tricco et al., 2015, p.2). The methodology for this approach remains underdeveloped, however, and there is no universally accepted definition of what constitutes a rapid review. The limitations of the rapid review compared to the full systematic review include absence of a universally agreed methodology and a tendency towards poor quality reporting (Tricco et al., 2015). Notwithstanding this, it has been argued that the rapid review can

offer a streamlined approach to synthesizing evidence in a timely manner and can address a need for timely, user-friendly and trustworthy evidence (Khangura, Konnyu, Cushman, Grimshaw & Moher, 2012). Furthermore, a comparative study by Watt et al., (2008) reported that the essential conclusions of the rapid and full reviews which they evaluated did not differ extensively, even though the scope of the rapid reviews was substantially narrower than that of full reviews.

The approach adopted in this review was to follow Lal and Adair (2014) who used methods similar to Khangura and colleagues' 7-step process for conducting a rapid review (Khangura et al., 2012). These steps can be summarised as (1) identification of the research question in collaboration with the knowledge user, (2) development of the search strategy, (3) identification of relevant studies, (4) screening and selection of studies, (5) conceptual mapping/identifying topical areas, (6) charting information, and (7) report production (Lal & Adair, 2014).

The objective of this review is to summarise what is currently known on the topic of involving or engaging forensic service users in the research process. This objective was developed following consultation with a carer (SF) and a Service User Reference Group for a research study which contained service users. Following these consultations, it was decided that findings resulting from analysis of any documents included in the review would be structured around the primary themes which emerged from a grounded theory analysis of their content. These findings would then be compared with the MHRN (2012) guidelines on service user involvement in mental health research. Of particular interest is how service users can use, or be helped to use, their experience to interact with professional researchers and advise on the research process, rather than acting solely as an additional professional who conducts research, although it is important to acknowledge that these two roles often coincide.

The search strategy was based on three concepts: patient involvement, forensic setting, and research activity. Both textword and Medical Subject Headings (MeSH) were used as search terms (see Appendix for the Medline search strategy). Six bibliographic databases were searched from 1980 to 20th May 2016: Medline, Embase, PsycINFO, King's Fund, the Health Management Information Consortium (HMIC) and the Cochrane library. Google and Google Scholar were searched separately and the first 150 hits examined in each case. A check for additional articles that might meet the inclusion criteria was made by examining the references cited in all included documents and listed on the websites of the following organisations: CLAHRC, INVOLVE, NIMH and MHRN. Searches were confined to documents written in the English language. No restrictions were placed on study design or publication type.

All hits were initially screened against the inclusion and exclusion criteria (Table 1) by inspection of title and abstract. Hard copies were then obtained of all articles which were identified in the screening process as potentially relevant, or for which there was insufficient information within the title and abstract to allow a decision to be reached. Hard copies were then inspected and selected for inclusion against the criteria in Table 1. Screening and selection were carried out by a doctoral-level mental health services researcher (NH). A second doctoral-level mental health services researcher (BV) who is also an experienced forensic psychiatrist validated the conclusions by screening all titles and abstracts, extracting and synthesizing data, and reviewing the findings.

In summarising the content of the included papers, the main focus was on issues specific to forensic settings.. Each included document was first read carefully and any text relating to forensic or secure settings marked. The marked text was then analysed following the main steps in grounded theory to discern potential emergent themes which were then refined and reduced

following the constant comparative method (Strauss & Corbin, 1990). The findings were then reviewed to check for any disagreements with regards to the general principles and the recommendations in the MHRN (2012) document which does not have a specific forensic focus. All authors contributed to the conceptual mapping and developing a narrative synthesis of relevant material from the included documents. The quality of included documents was not assessed because the nature of the material meant that an appropriate validated quality assessment tool could not be identified.

Results

Characteristics of the Included Documents

A total of 5034 unique records were screened on title and abstract. Hard copies of 67 were inspected following screening. Forty four documents were excluded for the following reasons: focus on participation (29), not forensic (5), not research focused (4), duplicate material (3), no service user involvement (1), other reason (2). Twenty three primary documents were identified for inclusion, comprising eleven papers published in peer-reviewed journals and twelve reports (Table 3). Of these, 18 originated in the UK, two in Northern America and three in Canada. Seventeen focused wholly or partly on forensic mental health settings, and six focused on prison or correctional environments.

The 23 documents in Table 3 comprised eleven which addressed service user involvement broadly and offered recommendations for good practice (CLINKS, 2011; CLINKS, 2013; Faulkner & Morris, 2003; Faulkner, 2004; Faulkner, 2007; INVOLVE, 2009; National Survivor User Network [NSUN]/WISH, 2011; Spiers et al., 2005; SURGE, 2005; SURGE, 2006; Sainsbury

Centre, 2008). Four documents described projects in which service users had acted as researchers (Banongo et al., 2006; Godin et al., 2007; MacInnes, Beer, Keeble, Rees, & Reid, 2011; Martin et al., 2009). Two documents summarised studies exploring professionals' experience of involving service users in research in a prison setting (Byrne, 2005; Patenaude, 2004); four were studies involving service users at each stage of the research (Livingston, Nijdam-Jones & Team P.E.E.R., 2013a; Livingston, Nijdam-Jones, Lapsley, Calderwood & Brink, 2013b; McKeown et al., 2014; McKeown et al., 2016), one was a study on communication between researchers and service users (Davidson, Espie & Lammie, 2011), and one was an evaluation of peer support in secure mental health settings carried out by people with personal experience of mental distress (Shaw, 2014). In summary, five articles focussed mainly on providing guidance for good practice (CLINKS, 2013; Faulkner, 2004; NSUN/WISH, 2011; SURGE, 2005/6), eleven were qualitative or empirical studies (Banongo et al., 2006; Davidson et al., 2011; Godin et al., 2007; Livingston et al., 2013a; Livingston et al., 2013b; McKeown et al., 2014; McKeown et al., 2016; MacInnes et al., 2011; Martin et al., 2009; Patenaude, 2004; Shaw, 2014), and seven were overviews or discussion documents (Byrne, 2005; CLINKS, 2011; Faulkner, 2007; Faulkner & Morris, 2003; INVOLVE, 2009; Sainsbury Centre, 2008; Spiers et al., 2005).

Content of the Included Documents

Only one of the included documents provided quantitative results directly relevant to the objective of this review (Livingston et al., 2013b, discussed in the following section). Because the vast majority of the information identified in the included documents had been derived using an approach that was essentially qualitative, the results are presented as a narrative synthesis of the

relevant material. Given the nature of these documents, it could have been misleading to attempt to comment of the relative weight of ‘evidence’.

There was no disagreement within the 23 included documents with the MHRN guidance in relation to any of the themes listed in Table 2. However, a number of issues specific to forensic settings were identified and these are presented below under the headings: Power relations & vulnerability, Practical difficulties, Confidentiality & transparency, Language & communication and Training.

Power Relations & Vulnerability

One study of an intervention to increase patient engagement that included the creation of a research team led by service users found evidence that working together on a research project in a forensic mental health hospital can foster a sense of empowerment for those who act as peer researchers (Livingston et al., 2013b). However, several of the documents consulted paid attention to difficulties associated with the balance of power in forensic research settings, with general recognition of the need for researchers to share power and negotiate openly with service users, and to provide appropriate support (e.g. SURGE, 2005). The issues most commonly raised concerned obtaining informed consent, addressing tensions arising from the attitudes of staff and other service users, and providing support for those who display vulnerability or lack confidence.

The MHRN (2012) guidance recommended that service user researchers be treated in the same way as any other member of the research team by ensuring any consent obtained is truly informed and through insistence on adherence to a confidentiality policy. These issues emerged as particularly relevant in forensic settings in the included documents. CLINKS (2013) observed that

it is particularly important for offenders, ex-offenders, and their family members to know that they will be treated in an ethical manner and will not be obliged to divulge anything that they do not want to, and to have a good understanding of how their views could be used. With regards informed consent, Davidson et al. (2011) noted there is evidence that poor literacy impairs the understanding of research terms to the extent that some prospective research participants may struggle to understand what they might be committing themselves to. Faulkner (2007) reported on a project exploring how research terminology could be explained to service users with learning disabilities in a medium secure unit in such a way that they could provide fully informed consent; one finding was that simply substituting 'agree' or 'disagree' for the word 'consent' could have considerable impact on how a message is actually perceived. Davidson et al. (2011) found that for a group of men with poor literacy the preferred way of gaining information about a project was through discussion with a researcher, with this used to supplement written information. Interestingly, the least preferred communication methods were those that relied on technology.

Support may also be required to address any tensions arising from the attitudes of staff as well from fellow patients or prisoners as a result of service user involvement in research (Sainsbury Centre, 2008). Methods suggested for providing support included setting up mentoring schemes (CLINKS, 2013), researchers working in pairs for mutual support when carrying out interviews (Faulkner & Morris, 2003), holding regular individual and group meetings between service-user researchers and the principal investigator (MacInnes et al., 2011), and having service users accompanied and supported by individual members of staff (Faulkner, 2007). The possibility that service users find their personal resources burdened by the amount of work they take on was also acknowledged (McKeown et al., 2014). Peer support schemes may also be valuable (Shaw, 2014), although the concept of peer support may be contentious amongst staff in prison or secure settings

(Sainsbury Centre, 2008). Methods of supporting a project more generally included identifying a specified liaison member of staff at each participating site (MacInnes et al., 2011), and providing adequate orientation for new members of the research team (Martin et al., 2009).

The use of service user researchers to conduct qualitative interviews with participants raises a number of issues. In one study on treatment planning, encouraging peer researchers to share their own personal experiences with the participants was found to be a positive and effective way to stimulate discussion, although the potential for introducing bias was also acknowledged (Livingston et al., 2013a); having service users as interviewers may influence the way in which participants respond to the questions, and some participants, such as staff members, may be reluctant to disclose certain information to interviewers who are also service users (Livingston et al., 2013a). The report by INVOLVE (2009) noted that appropriate support and training may minimise the risk of bias that can result when the ‘shared experience’ between interviewee and service user interviewer limits the discussion so that certain issues are not fully explored.

The possibility that forensic service user researchers have additional needs for supervision and support was specifically acknowledged in five of the included documents. These needs were seen as arising from lack of clarity about trust and confidentiality (Faulkner, 2007; McKeown et al., 2014), difficulty in knowing when and how concerns might be raised in a forensic setting (Faulkner, 2004; MacInnes et al., 2011), and possible negative consequences resulting from a ‘shared experience’ with their interviewees (INVOLVE, 2009).

Only one of the included studies provided quantitative results directly relevant to the objective of this review. Livingston et al. (2013b) examined the impact of a peer support program that included the creation of a research team led by service users within a Canadian forensic

hospital. Although the majority of the service providers surveyed indicated that the service users' experiences in the hospital had been "moderately" or "extremely" improved as a function of their participation, no significant change in scale scores on instruments measuring personal empowerment, internalized stigma, personal recovery, service engagement and therapeutic milieu were detected for the service users within the research team. This apparent discrepancy between the qualitative and quantitative aspects of the study may have arisen from the limited statistical power that resulted from the small sample size (n=10) (Livingston et al., 2013b).

Practical Difficulties

Research grant applicants are often required to show they have consulted with service users when developing their research proposal, and there were reports of this leading to practical difficulties. Faulkner and Morris (2003) found some secure settings reported that their patients were over-consulted ('consultation fatigue'). Two particular challenges were acknowledged in prison settings: (a) administrative barriers to allowing forums/focus groups to take place as part of a consultation, and (b) tokenistic efforts where only a few service users are involved within a consultation group mainly comprised of professionals (Sainsbury Centre, 2008). One possible solution might be to establish a commissioning panel of service users with experience of forensic health services to act as expert reviewers of all research proposals, particularly when commissioning and prioritising research topics (Spiers et al., 2005). The advantages of involving such a panel are reported as the ability to discuss and resolve how to ensure that all members can contribute on an equal footing, and being able to provide a consensus opinion on individual research proposals based on a facilitated panel meeting (Spiers et al., 2005). Spiers and colleagues

also reported that the panel members demonstrated an active interest, not only in the user involvement aspects of the research, but also in the research topic and implications.

A number of other practical barriers to involvement were reported as arising in forensic settings, including tensions between involvement practices and staff concerns about security and risk management, and variations in the support of different professional disciplines (McKeown et al., 2014). In prison settings, Sainsbury Centre (2008) recommended taking account of any potential conflicts with prisoners' other activities (such as group therapy), and educating prison staff in advance about the benefits of service user involvement in research. Similarly, CLINKS (2013) recommended anticipating staff apprehension as a possible problem, noting that prison staff can sometimes be wary of service user involvement because they themselves have not been consulted, or because they fear participants will be negative about, for example, the service. It has also been observed that many service users do not wish to be involved in service planning or policy and prefer instead to focus on user-controlled activities (Faulkner & Morris, 2003).

The challenge of accessing service users who might wish to assist in the co-production of research process in a forensic setting was acknowledged, and negotiation may be needed in environments where professionals act as gatekeepers to patients (Faulkner, 2004; McKeown et al., 2014). Such negotiation would need to take into account any local policies and protocols on service user involvement (NSUN/WISH, 2011). Even when access is gained, service users may be reluctant to get involved. Several strategies aimed at enhancing 'recruitment' of service users to various roles were reported in the included documents; although none were described in the context of user involvement in the research process, they appear relevant to it. In prison settings for example, CLINKS (2013) advocated asking staff to engage with prison service users about how involvement might enhance future employment prospects, and Byrne (2005) recommended

designating a named staff member to the project, or having inmates who could serve as study consultants to “spread the word”. Having a member of the research team with previous experience of detention in secure mental health services may also assist with service user participant recruitment and ongoing communication (McKeown et al., 2016). The documents consulted provided little advice on encouraging forensic service users to become involved in specific roles such as research advisors or interviewers, although several mentioned the need to address diversity issues (e.g. Faulkner, 2004). These included matching interviewers with interviewees on race, sex and sexuality where appropriate and ensuring varied ethnic backgrounds with a mixed level of educational achievement (Banongo et al., 2006).

The employment and payment of service user researchers were viewed as raising particular challenges. All documents that addressed this issue commented favourably on employing forensic service users as co- or peer-researchers and interviewers where appropriate, and on paying a reasonable rate for their time. The benefits of such employment were reported as gaining a sense of value and worth from the experience (Faulkner, 2007), enhanced self-esteem and improved prospects for future employment (Banongo et al., 2006; CLINKS, 2011). Challenges identified in connection with such employment were: (a) personnel departments being unfamiliar with employing service users in this way (Faulkner, 2004), (b) if an individual is employed as a research assistant, their views may no longer be respected as those of a service user (Faulkner, 2004), (c) payment may result in more formal expectations being placed on the service user (Faulkner, 2004), (d) care is needed to observe professional and personal boundaries and for researchers not to assume any clinical role with their service user colleagues (Sainsbury Centre, 2008), and (e) slow payment of fees and expenses can contribute to people dropping out of a project (Faulkner, 2007).

Difficulties were also acknowledged when service users become involved in co-authoring the final report of a research project, although there have been few reports of the impact of public involvement on writing research publications, possibly because service users are rarely involved at this stage of research (INVOLVE, 2009). One challenge identified is the difficulty service users can experience in reacting to negative comments from peer reviewers when, for example, a final report is submitted to the research funder. In one forensic research project, for example, the service user researchers perceived their report to have been severely and unjustly criticised by reviewers who they felt had not understood the nature of the research methods used (Faulkner, 2007) and it seems this reaction had curtailed dissemination of the findings. In a study exploring factors perceived as important for developing collaborative research in forensic mental health settings, MacInnes and colleagues suggested including team members experienced in the peer reviewing process to provide support and help towards a constructive response to external reviewers' comments (MacInnes et al., 2011).

Confidentiality and Transparency

The MHRN guidance noted the need for both clarity and transparency at all stages of a project (MHRN, 2012), and this was supported in all the included documents. Particularly significant in a forensic setting was clarity about confidentiality and any rewards for being involved in a project (Faulkner, 2004), about roles and responsibilities (SURGE, 2006), and about the goals of the proposed research (Byrne, 2005). Ensuring confidentiality rules are established from the start and regularly restated as the project proceeds were seen as particularly important in a forensic setting (Faulkner, 2007). Holding regular meetings was found to help team members understand what was required at each stage of the project, allowing them to make decisions about their level of

involvement (MacInnes et al., 2011) as well as to support one another, discuss the research process, and reflect on the emerging findings (Livingston et al., 2013a). The need to repeat an explanation over time was also recorded (Byrne, 2005).

Language and Communication

Many of the included documents drew attention to the importance of using plain language and replacing jargon with easily comprehensible terms. Although these issues are relevant to any research setting, Patenaude (2004) observed that the language commonly used in academic research can inhibit or destroy rapport when conducting research in prison by, for example, using wording that infers equality between groups, or using words like ‘informant’ that may have a different meaning within the prison community. A study by Davidson et al. (2011) found the least preferred communication methods for those with poor literacy were those that relied on technology, and the assumption that every young user of forensic services is completely comfortable with social media and texting on mobile phones may be misplaced. This raises the possibility that researchers familiar with information technology may fail to appreciate that their study participants might see the world differently.

Considering how best to describe those involved in a research project may be of particular importance in a forensic setting. Although a recent study by Simmons et al. (2010) suggested it is still uncertain whether those who are invited to plan and participate in research are representative of those who regard themselves as ‘patients’ or ‘clients’ or ‘service users’, Shaw (2014) observed that the majority of people using secure mental health services prefer to be known as ‘patients’ rather than ‘service users’. A suggested alternative, which may have particular relevance to users of forensic mental health services, is to adopt a neutral term such as ‘project advisor’ which has the

advantage that someone's involvement experience can be listed on CVs and other documents without it betraying their use of mental health services (MHRN, 2012).

Training

The MHRN (2012) guidance noted the importance of training for people seeking to get involved in research to provide them with confidence to participate and to improve their research skills. This was endorsed in a number of the included documents, together with the recommendation that an individual assessment of training needs should be carried out prior to involvement in a research study. Several of the included documents also recommended that academic researchers and groups such as forensic mental health and prison staff should also receive training to help them to function effectively within this context (Faulkner & Morris, 2003; Sainsbury Centre, 2008). In forensic settings, dealing with risk, security issues, boundary setting, the particular nature of the environment, and exposure to the range of offences that might have been committed were seen as particularly important topics for a training agenda (e.g. Faulkner, 2004; Shaw, 2014). In so-called 'high-risk projects', it has been suggested that providing de-escalation training to interviewers be considered (Faulkner, 2004). With regards timing, Faulkner (2004) observed that some service users felt that training should precede the research for it to be useful, whereas others felt it should follow the research process in a step-by-step manner. In one study, training was viewed as more effective when centred on specific research tasks, with the training sessions timed to occur when specific knowledge/skills would be required (MacInnes et al., 2011).

Several documents commented on the importance of ensuring comfortable physical surroundings, regular breaks, and refreshments (e.g. Faulkner, 2004); these considerations, which arguably are important in any research setting, may be a particular challenge in a secure environment. When attempting to provide training in prisons, difficulties reported included problems with finding a suitable room, collecting and accompanying prisoners to training sessions, and ensuring the training course was sufficiently flexible to allow for any prison lock downs (Sainsbury Centre, 2008).

Discussion

Summary of Findings

From our search of the literature, information specific to forensic service user involvement in the research process appears very limited compared to that for mental health in general. Only one of the 23 documents included in the review provided relevant quantitative results, and although this did not indicate a significant impact on those service users who were actively involved in the research team, it is likely that the study was insufficiently powered to detect such effects due to the small size of sample. Although quantitative results were lacking, each of the included documents provided information that could be useful to researchers wishing to engage forensic service users in the research process.

Notably, all but five papers included originated from the UK, which may suggest a lack of interest in the topic elsewhere. It is not clear why policy makers and researchers in the UK appear to place more importance on this topic though it is hoped the distribution of knowledge in this field, as done in our review, might facilitate uptake of the approach beyond the UK.

Where forensic-specific recommendations were made, these were broadly in keeping with the MHRN (2012) guidance that relates to the broader group of people with mental health problems. From this literature a number of issues of particular relevance in forensic settings were identified.

Many of the documents consulted mentioned the need to pay attention to the balance of power in a forensic setting, with a general recognition that negotiating the power dynamic in a culture that is essentially restrictive and controlling is not straightforward. Extra effort may be needed to establish clear, informed consent if the participant resides in a highly controlled environment where compliance may be a survival strategy and refusal may close down opportunities or win peer approval. Poor literacy (as identified in Davidson et al., 2011) and the presence of autistic traits or learning difficulties (Faulkner, 2007) can impact on a person's ability to comprehend research terms, and this can lead to disempowerment and perhaps a perception of somehow being coerced into taking part.

Comments from the Service User Reference Group who were consulted when establishing the objective for this review suggest it is also possible that some people with personality disorder or other difficulties will cycle through a series of attitudes towards the work, from giving informed consent at one point to feeling coerced and resentful at another. There may be other reactions too which people prone to high levels of suspicion may experience from time to time, casting doubt on whether consent has been granted. Researchers will also need to remain aware of power dynamics when working with people who experience difficulties in social interaction and address safeguarding issues in any group-based research activity.

The importance of providing adequate support to forensic service users who are involved in the research process was acknowledged in all the documents. This included the need to address

any tensions arising from the attitudes of both staff and peers. In some cases, service users take on multiple roles within a project, of which Banongo (2006) is an example, and additional support may be needed where such roles overlap as occurs when participants also act as advisers on the same research project.

The imbalance of power in a secure setting is also likely to impact on the ability to hear the authentic voice of the patient when accompanied by a staff escort or prison officer. A number of the documents noted the advantages when a service user researcher conducts interviews where the balance of power between interviewer and participant may be perceived as less (e.g. Faulkner, 2004). Here the service user interviewer who shares a similar lived experience to the participant may position their boundary marker differently from the traditional professional, and they may wish to tell more of their personal story than a traditional worker would do (Bates, 2010).

Interestingly, one issue not raised in the included documents is that of sanctions. If the service user researcher is formally employed, they can always be dismissed for misconduct, creating a powerful incentive to abide by appropriate governance rules, such as confidentiality. In contrast, volunteers or people receiving paltry participation payments may not feel significantly affected by the threat of loss. These issues may have particular significance in a forensic environment.

A number of practical difficulties were raised. These included issues with consultation, tokenistic inclusion, tensions with staff over security and risk management, gaining access to service users and co-authoring. Several potential helpful solutions were suggested, although these might not be universally relevant. For example, the process suggested by Byrne (2005) of having prison inmates who could serve as study consultants to 'spread the word' will be impeded if the service users have limited communication with one another. Involving service users in

co-authoring of reports appears to be a valuable, if challenging, initiative; where it occurs, there is evidence that it helps to engage the target audience and makes the findings more credible and accessible (INVOLVE, 2009). Methods of providing support for service user co-authors and help towards a constructive response to external reviewers' comments have been suggested (MacInnes et al., 2011), and specific guidance on co-authoring is also now available (e.g. Bates, 2014).

The practical difficulties identified when attempting to provide training in prisons (for example, finding a suitable room, and accompanying service users to training sessions) will be true of many other forensic psychiatric settings, but in prisons service users may need a staff escort which may inhibit disclosure, and video conference suites may be unavailable. There is also the possibility that forensic service users who are also researchers will require an honorary contract with a university or the custodial organisation; the criminal record checks that are normally required for such a contract may raise difficulties. Although having clear rules on confidentiality is important (e.g. Faulkner, 2004; SURGE, 2006), it is also important to acknowledge the possibility that long stay service users who get involved in research will be privy to confidential information, or will be able to reattribute identities to supposedly anonymous vignettes, simply because everyone knows everyone in long stay forensic settings.

Regarding communication, the study by Davidson et al. (2011) raises the possibility that researchers, who tend to be well educated and enthusiastically familiar with information technology, may fail to appreciate that their study participants might see the world differently. This study found the least preferred communication methods for those with poor literacy were those that relied on technology. Furthermore, some forensic patients still live in a pre-internet world because of their age and the date at which they entered a restrictive environment where access to the internet is usually prohibited. It is also worth noting that some people on the autistic

spectrum have difficulties with metaphor, and this presents challenges to researchers trying to find accessible ways of explaining research concepts.

Strengths and Limitations of This Review

In attempting to summarise what is currently known on the topic of involving or engaging forensic service users in the research process, this review has identified a number of issues that are of particular relevance in forensic or correctional settings, together with some potential solutions. A systematic approach has been adopted: the key steps defined by Khangura et al., (2012) for conducting a rapid review were followed, the search strategy was comprehensive, and the reference lists of all the included documents were searched in attempt to identify any additional relevant papers. Any bias towards UK literature is therefore unlikely to have arisen from not using a systematic approach to searching the literature, although the fact that 18 of the 23 documents originated in the UK may limit the generalisability of the findings. The rapid review approach has limitations, however, and there is no guarantee that every relevant document has been identified; it is possible, for example, that some government reports from non-English language European countries were not identified. It is also possible that relevant information on this topic may not have been published, or not in sufficient detail, in academic or professional journals because, for example, of limits on word length.

Implications for Research

A future review on this topic might benefit from a more extensive search of the grey literature for unpublished reports, and from communication with selected academic researchers and service user researchers who have had personal involvement in relevant studies.

Implications for Practice

In summary, the following recommendations on the involvement of forensic service users can be drawn from our rapid review of the literature. They centre around particular characteristics of service users in those settings as well as practical challenges. When consulting with forensic service users, researchers need to consider and mitigate against an increased risk of tokenistic involvement, ‘consultation fatigue’ and an amplified power balance. It may take longer to develop working relationships with forensic service users than with users of other mental health settings due to issues of trust. Confidentiality is of particular relevance as service users may be suspicious about disclosure to the institutions they are detained in. Issues around confidentiality may also arise when consultation involves more than one service user. Access to service users may be restricted due to security reasons or due to a poor understanding of staff about the values of such engagement. Particular attention therefore needs to be given to developing positive relationships with staff. Once engagement has been established, researchers need to be aware of the often complex mental health and psychosocial needs of forensic service users, and this may necessitate adaptations in communication and timescales. The practical difficulties arising in forensic settings cannot be overestimated and some researchers may simply give up in the face of these difficulties, in particular around criminal background checks and payment. However, this would further

marginalise an already doubly stigmatised group. Researchers need to be aware, however, that more time and resources may be needed in engaging forensic service users and this has to be taken into account in the planning and costing of projects in these settings. Achieving successful service user engagement in forensic settings can be of particular value though in terms of, for example, self-esteem and skills building and may have long-lasting positive effects for those involved.

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Appendix

Search Strategy for Medline

The search strategy for the Medline database is listed below. The MeSH terms were modified for the Embase, PsycINFO, King's Fund, HMIC and Cochrane databases.

[exp consumer participation/ or exp patient participation/ or ((patient\$ or user\$ or consumer\$ or client\$ or carer\$ or caregiver\$ or research) and (involv\$ or participat\$ or engag\$)).ti,ab. or *consumer satisfaction/ or *patient satisfaction/]

AND

[exp Forensic Psychiatry/ or exp Hospitals, Special/ or forensic psychiatric hospital.ti,ab. or forensic psychiatric patient\$.ti,ab. or secure hospital\$.ti,ab. or (forensic adj3 (psychiatr\$ or care or healthcare or health care or mental health)).mp or ((high or medium or low) adj5 (secure or security)).ti,ab. or regional secure unit.mp. or forensic community mental health.mp. or community forensic mental health.mp. or exp Prisoners/]

AND

[exp Research/ or evaluat\$.ti,ab. or research.ti,ab. or audit.ti,ab. or exp Medical Audit/ or exp Clinical Audit/]

Table 1

Inclusion and Exclusion Criteria

Inclusion criteria

- provides information or guidance on the active participation of forensic mental health service users in any or all of the stages of research, from defining priorities for research, through commissioning, designing and carrying out research, to the dissemination of results.
 - focuses on current or former users of forensic mental health services or their carers. Studies or reports involving those detained in prisons or correctional facilities were included if they contributed information relevant to involving or engaging forensic service users in the research process.
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Exclusion criteria

- the service user involvement was not research-focused, unless the information provided was of clear relevance to the research process.
- the service user involvement was not related to forensic or secure settings.
- service user satisfaction surveys.
- studies in which service users were involved solely as participants (such as by completing questionnaires, being interviewed, or being recruited to a clinical trial) unless additional information on engagement in the research process was identified.

- studies involving service user-researchers (i.e. fully qualified professional researchers who have personal lived experience of the condition being studied) on the basis that this group would require different guidance.
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Table 2

Key Themes and Recommendations derived from MHRN (2012) Guidance on Service User Involvement in Research

Theme ^a	Advice & recommendations
Identifying priorities for research (23)	Consult with individual service users and service user groups about research priorities.
Consulting with service users (29)	Always involve more than one service user. Clarity regarding how advice will be acted upon.
Commissioning research (24)	Researcher funders to offer advice on SU involvement. Make sure funds are available. Always involve at least two service users. Involve in funding panels and commissioning procedures. SUs as paid reviewers for all research proposals.
Planning & resourcing a project (12, 20, 28)	Careful planning of resources (time and money). Early involvement, building relationships. Training service users.
Language & terminology (14, 18)	Plain language. Beware of terms used for people with mental health problems.
Clarity & transparency (13)	Need for clarity & transparency throughout.
Flexibility (14)	Flexibility needed at all levels.

Employment & payment of service user researchers (18, 31)	Offer payment wherever possible. Use quick means of payment. Be aware of potential impact on benefits. Potential culture clash between institution and SU.
Service user-controlled & service user-led research (35)	Particular benefits of service user controlled research but challenges in relation to identity.
Training (15)	Provide relevant training to all Sus. Assess training needs. Provide ongoing support.
Recruitment of research participants and advisors (12, 24, 27, 32)	Importance of diversity. Clarity regarding purpose of involvement, roles and expectations.
Supporting a project (14, 30)	Everyone involved needs support (researchers, SUs, etc.) - emotional and practical.
Dissemination & implementation (33)	‘Open access’ publications. Dissemination to local and national SU groups. Summary in plain English sent to all participants. Consider SUs as co-authors. Manage frustrations regarding perceived lack of impact of findings on service delivery.
Assessing the impact of involvement (36)	No single accepted way of measuring impact available yet; however, positive impact of involvement in research noted by SUs, including on employment.

Note. SU = service user

^a Numbers in parentheses indicate the relevant pages in the guidance document

Table 3

Summary of the Included Documents

Identifier	Nature	Type ^a	Country	Focus
Banongo et al. (2006) ^b	Report describing an evaluation of forensic mental health care led by seven service users who acted as both researchers and participants.	R	UK	FMH
Byrne (2005)	Paper discussing ethical participation strategies in the context of studies implemented by the author in women's prisons.	A	USA	Prison
CLINKS (2011)	Report reviewing service user involvement in prisons and probation trusts.	R	UK	Prison
CLINKS (2013)	A guide to service user involvement for organisations working with offenders, ex-offenders and their families.	R	UK	Prison
Davidson et al. (2011)	Study exploring the most effective ways of communicating	A	UK	FMH

about research participation with men with antisocial personality disorder.

Faulkner & Morris (2003)	Report summarising the experiences of organisations and individual researchers with a track record of research into service user involvement.	R	UK	FMH
Faulkner (2004)	A set of guidelines for the ethical conduct of research carried out by mental health service users and survivors.	R	UK	FMH
Faulkner (2007)	Report summarising key factors facilitating service user involvement by considering four forensic mental health projects, with eleven recommendations.	R	UK	FMH
Godin et al. (2007) ^b	Qualitative study on communication & participation within a service user-led research project evaluating forensic mental health care.	A	UK	FMH
INVOLVE (2009)	A report on the impact of public involvement in the UK National Health service and in public health and social care	R	UK	FMH ^c

research

Livingston et al. (2013a)	Qualitative participatory action research study examining treatment planning from the perspectives of inpatients and service providers at a forensic mental health hospital.	A	Can	FMH
Livingston et al. (2013b)	Mixed methods study of an intervention to increase patient engagement by establishing a peer support program that included the creation of a patient-led research team in a forensic mental health hospital.	A	Can	FMH
MacInnes et al. (2011)	Qualitative study on factors perceived as important for developing collaborative research in forensic mental health settings.	A	UK	FMH
Martin et al. (2009)	A participatory research study in which incarcerated women in a Canadian prison formed a research team.	A	Can	Prison
McKeown et al. (2014)	Qualitative study of involvement initiatives within secure mental health services across one UK region.	A	UK	FMH

McKeown et al. (2016)	Qualitative study of staff and service users' views of recovery undertaken in a UK high secure hospital.	A	UK	FMH
NSUN/ WISH (2011)	Overview and recommendations relating to provision of service user involvement in secure settings	R	UK	FMH
Patenaude (2004)	Study exploring some of the challenges of conducting qualitative research within correctional environments.	A	USA	Prison
Sainsbury Centre (2008)	Report examining the application of service user involvement in health research to research on mental health care in prisons.	R	UK	Prison
Shaw (2014)	Report of a survey of staff and patients in UK secure settings on peer support, examining how the challenges might be addressed.	R	UK	FMH
Spiers et al. (2005)	Editorial considering the strengths and challenges of	A	UK	FMH

involving a group of service users in research prioritisation and commissioning.

SURGE (2005)	Report summarising good practice guidance on service user involvement in mental health research.	R	UK	FMH ^c
SURGE (2006)	Report summarising good practice guidance on service user involvement in mental health research.	R	UK	FMH ^c

Note. FMH = forensic mental health

^a Document type. R = report or web-based document; A = article in a peer reviewed journal

^b Godin et al. (2007) and Banongo et al. (2006) are papers arising from the same core study

^c Focused on mental health research but including some references to forensic settings