



A Review of Service User Involvement in Prison Mental Health Research

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Summary

Service user involvement (SUI) in health care research is now firmly established in the NHS but few attempts have been made to find out about prisoners' experiences of mental health care in prison or to encourage their involvement in this research.

Sainsbury Centre carried out a review to see how models of service user involvement in health research could be applied to research on mental health care in prisons.

Some SUI in research has taken place in forensic services (secure hospitals) which share similarities with the prison environment and this shows how SUI in research could be carried out in prisons.

There are established examples of service user engagement in prisoner councils and in prison health service development, such as self-managed care and the expert patient programme, which could be built upon.

Introduction

The prison population of England and Wales now exceeds 82,000 and is set to rise to beyond 100,000 within a decade (Carter, 2007). The majority of prisoners have mental health problems. Many also have a complex mix of other issues including substance misuse, poverty and a history of abuse.

The Government has acknowledged the need to improve mental health care in prisons and by April 2006, responsibility for prison health care was fully transferred from the Prison Service to the NHS. Government policy (DH & HMPS, 2001) states that “prisoners should have access to the same range and quality of services appropriate to their needs as are available to the general population through the NHS”.

The transfer of responsibility for health care brought with it a commitment to service user engagement in service development (DH, 2000; 2003). Service users are now involved in planning policy at most national programme boards dealing with offender health and social care.

The importance of service user involvement (SUI) in health care research in the NHS is recognised in Government policy (DH, 2005 & 2006), and a growing number of statutory and non-statutory funding organisations, for example, the Medical Research Council, Economic and Social Research Council and The Big Lottery, now require evidence of SUI in research proposals (Beresford, 2005).

The review

This review looked at research literature on service user involvement (SUI) in health research (see Box 1) and service user engagement programmes in prisons to see how these models might be applied to research in prison mental health care.

We also undertook a consultation with key experts in mental health, substance misuse, primary care and other areas of health care. These included academics, professionals from the Department of Health, independent service user researchers, and professionals from service user-led research organisations and criminal justice charities. They all had an interest in SUI in forensic and prison settings and in some instances had conducted projects in these environments.

Why involve service users?

It benefits the research

SUI gives service providers the opportunity to hear the direct experiences of those people using their services.

“It provides services and government with insights into real lives in order to help them develop policies. Most policies ... are made up without speaking to people with life experience; often they have no involvement at all.” (Criminal justice charity)

Service users provide a different perspective to that of the clinician or researcher. They are often in a better position to identify the key priorities for the research and to recruit other service users to

Box 1: What is service user involvement in health research?

We use the term ‘service user’ to describe people who have experience of using health services either inside or outside of prison.

User involvement in health research is defined as an active partnership between ‘consumers’ [the users of the services] and researchers in the research process. It has been described as doing research with users rather than to, about or for them (Royle et al., 2001).

Levels of service user involvement

Beresford (2005) describes involvement as a continuum: from research with no user involvement to research which users initiate, undertake and control. This continuum is often divided into three levels of involvement: consultation, collaboration and user control (Hanley et al., 2004).

Consultation

At the consultation level, service users are consulted about a piece of research with no sharing of power. Users may review or give opinion on a research proposal, research topic, methodology, or a published paper (Williamson, 2001). The views of users may influence the researcher or funder but do not have to be adopted. This level of involvement has often been described as lip-service involvement, as researchers maintain ultimate control of the project (Trivedi & Wykes, 2002). Williamson, however, stresses that this level of involvement is important because it offers flexibility. She argues that consultation can be used at any stage and on any scale in the research process to gain a wider opinion (Williamson, 2001).

Collaboration

Collaboration involves active ongoing partnership with service users in the research process (Telford et al., 2002); it may be initiated by the researcher, the service user, or jointly (SURGE, 2005). Here decision making will not be changed unilaterally and is instead shared between parties. Service users may take part in any or all of the stages of the research process although the nature and amount of collaboration can differ between projects (Hanley et al., 2004).

User controlled research

User controlled or user-led research involves service users controlling all stages of the research process. However, it does not mean that ‘professional’ researchers are barred from the research process or that service users must undertake every stage of the research (Hanley et al., 2004). User controlled research is derived from service users’ dissatisfaction with traditional research, which some feel has disempowered them (Turner & Beresford, 2005). It has therefore been reported as the favoured method of research for some user groups, and may additionally provide perspectives not accessible through other research methods (Hanley et al., 2004).

participate in the study. Their experience can help to develop more relevant research questionnaires and tools. Collaboration between service users and professionals in the analysis of the findings may also lead to more meaningful outcomes (Allam et al., 2004).

It benefits the service users

Participation in research provides people with an opportunity to have their voices heard and the prospect of learning new skills. These opportunities may be a unique experience for prisoners who may not have been consulted in this way before.

“I think in this environment people have rarely been consulted so it can be very empowering.”
(Independent researcher)

Professionals in the consultation highlighted the valuable skills service users can gain from being involved in research. This may be particularly important for people in prison. One researcher suggested that this type of involvement could be translated into vocational qualifications.

“I think it is important as well to develop a range of vocational qualifications that service users could obtain from involvement like work based credits (NVQs).”
(Independent researcher)

One academic described the benefits of SUI research in a forensic setting which included positive mental stimulation for service users and the development of skills to resolve differences of opinion.

“We used a very democratic approach to agreeing things and we tried to resolve differences of opinion. I think they enjoyed this and it gave them confidence to actually challenge and contribute. We tried to ensure that their involvement was mentally and intellectually challenging.”
(Academic)

It improves communication

SUI in prisons can improve communication between services and prisoners.

“Service developers get a greater level awareness of key issues but also where changes can’t be made immediately it provides an opportunity for communication with service users which I think encourages respect. So even if outcomes are low, lines of communication are opened and conflicts can be brought out into the open.”
(Academic)

The challenges of SUI in research in prisons

Participants in the consultation stressed the need for additional time and resources when conducting research in a prison environment. A critical factor is the support of senior prison staff.

“There are many practical considerations of SU involvement in closed environments which need considerable money, funding, expertise and development. It can’t be done in a rushed or ad hoc way. SU involvement requires practical guidance, support and protocols to govern the process. For this to happen it needs real senior back up.”
(Civil servant)

A number of barriers to service user involvement in prison mental health care research were identified in the review.

Representativeness

User involvement in health research has been criticised on the grounds that the user researcher will not be representative of all service users. One of the challenges to SUI in prisons is the way that prisoners are often pre-selected for involvement in research or service development activities.

Professionals who took part in the consultation reported that many of the prisoners involved in their prison health research were chosen by prison staff.

“Yes, you can be limited to a pre-selected group chosen by the prison and you may not be aware of reasons for selection.”
(Civil servant)

Knowing the reasons for prisoners being included or excluded is an important part of the research process. Certain biases may be introduced which may undermine the way SUI takes place. There are many reasons for this sort of prisoner pre-selection, some of which may be linked to security issues or prisoners being at high risk.

Additional safeguards are important when selecting prisoners for involvement in prison health research. These may include only choosing those able to cope with the demands of such involvement to ensure that it does not have a detrimental impact on their mental health.

“There needs to be some assessment of their ability to cope and the general benefits need to be balanced against the impact against individuals, therefore there needs to be a careful selection process when you are dealing with people who are very unwell.”
(Civil servant)

It is important to consider the requirements of the prison regime in terms of security and risk when selecting prisoners to take part in SUI. It may be inevitable that some prisoners are pre-selected by prison staff but if a compromise can be reached, where researchers are able to be part of the selection process, then this would avoid any potential bias and other associated problems.

Engaging with prisoners

Prisoners may be involved in various programmes within the prison - drug detox, work or education - which may limit opportunities for being involved in prison health research. Involvement is also dependent on the prison regime, for example, unexpected prison lock downs, or lack of staff means prisoners may be unable to leave their cells to take part in the work. Prisoners may also be moved round the prison system at often short notice, or no notice at all, which affects any service user work they are doing.

Professionals in the consultation highlighted the difficulty of getting service users interested in SUI.

“The main problems we have are that service users don’t feel valued for what they do. They are not shown the value of what they have done, sometimes not for a couple of months and sometimes not at all. When they feel they are not actually being listened to they become demotivated. They need to see the end result of their labour.”
(Criminal justice charity)

One professional in the consultation stressed the importance of ensuring that service users were realistic when they became involved in research work.

“You don’t want to raise unrealistic service user expectations so you have to be aware of the very basic stage of development that mental health services are at. There is still a need for a big cultural shift. You need to understand the system and levels of enthusiasm.”

(Civil servant)

Another professional said it was important to explain to service users that their input would not change their situation directly. It may be particularly important to emphasise this to prisoners who may have many individual complaints about their care in prison.

“We are honest with people though and we do say that there won’t be any benefits in terms of practical outcomes and changes to their situation directly. We hope that the wider benefits and the chance to talk about situations will be sufficiently beneficial.”

(Criminal justice charity)

Supporting prisoners

Support for prisoners involved in research is essential. There should be procedures to refer people to more appropriate forms of treatment and support if they cannot cope with the SUI work or if it is not suitable for them to take part due to other concerns that need addressing more urgently.

“...the levels of support that can be provided need to be made clear i.e. it is not a form of treatment and there has to be a system in place to refer quickly to appropriate support if issues arise.”

(Civil servant)

Prisoners may also need support prior to involvement.

“We found that in our work the service users were initially very reticent to talk about that period of their lives as many of them felt very bitter about it ... We had to build in support mechanisms and consider confidentiality issues....Once we had overcome the barriers of talking about these issues, some of the service users were quite antagonistic, angry and unreasonable so we had to work on ways of expressing those views.”

(Academic)

It is also important to be aware of any tensions that might arise within the prison as a result of SUI in research.

“We were able to have focus groups and prisoners liked the idea of being consulted in this way but staff made us aware that it was causing tension on the wings because others felt they were getting special attention.”

(Academic)

Confidentiality

Issues of confidentiality are inherent in many pieces of research, and particularly within the prison environment. Hayes and Senior (2007) highlight the challenges of service user involvement in prisons:

“Involving current or past prisoners in the planning, execution and dissemination of health care research is challenging. The culture of prisons may lead to mistrust on the part of users

or staff for the reasons and motivations for involving prisoners or ex-prisoners in research. There may be concerns relating to security and access to sensitive, personal information which could potentially be vulnerable to misuse.” (Hayes & Senior, 2007)

A service user-led organisation in the consultation stressed the importance of addressing issues of confidentiality in advance.

“Confidentiality issues can be a problem but can be addressed with ethics [committee] guidance. I think often confidentiality issues are used to exclude service users when these issues can be clearly addressed.” (Service user-led organisation)

An independent researcher felt that service users can be cautious about taking part in service user projects because of fears surrounding confidentiality.

“There is also a lot of fear among service users about being involved in projects in this environment. It is difficult for people because they are afraid of repercussions and worry that they will not be listened to properly. There is real scepticism and because of the systems in place these issues are difficult to address.” (Independent researcher)

When addressing fears concerning confidentiality within the prison environment it is important to make clear those situations where confidentiality may need to be broken, for example, when prisoners are discussing breaches of security, or threats to harm themselves or others.

Obtaining ethics approval

Delays in obtaining research ethics committee approval, NHS and primary care trust (PCT) research governance procedures and the prisons’ own systems of approving and vetting procedures for research, may present significant hurdles for researchers to negotiate.

Security

Security issues are an every day part of the prison environment and should be taken into account when planning SUI in prison research. Some research methods used in non-secure settings might be considered a security breach if used in prison. The use of, for example, digital recorders or video equipment requires specific approval from prison authorities and very often is not permitted.

Additional time will need to be allowed for external researchers to obtain Criminal Records Bureau (CRB) clearance, honorary contracts and HM prison service security clearance. This may be particularly difficult for service users from outside the prison with previous experience of the criminal justice system.

“In my work we came up with a host of barriers all to do with process, for example, the security clearance process was unclear and seemed to take forever.” (Civil servant)

Uniformed staff may be present when SUI work takes place if, for example, particular prisoners are considered high risk or if the co-ordinator of the work is external to the prison and needs escorting in the prison. This may make prisoners feel apprehensive about taking part in the work but need not necessarily be a barrier.

“Some research is obviously affected by the presence of uniformed staff but in other situations staff don’t pay any attention and it seems to be okay.”
(Academic)

Prison lock downs may also limit access to prisoners and prevent service user researchers from participating.

Staff culture

Prison staff will be an integral part of any research carried out within prison. There may be barriers relating to staff culture which reflect a lack of understanding or a negative attitude towards supporting SUI in prison health research.

“Gaining access involves convincing staff of the merits of what you are doing and working with staff. In many ways this type of work goes against the grain for staff, but in order to get anywhere at all you are reliant on the staff...”
(Independent researcher)

One professional suggested that health care staff in a prison were keener to take part in SUI activities but security staff were less likely to see the benefits.

“We found in terms of staff reception, health care staff were generally convinced of the merits of SU consultation and the need to improve services but security staff were less so.”
(Civil servant)

Quelling fears among prison staff and educating them about the benefits of SUI in prison research is a necessary step in ensuring this type of involvement takes place.

“I think staff fears about SUI are that they are just going to develop lists of what’s wrong and moan about things, so it is important to involve staff equally in the process and show small changes can happen and make a real difference.”
(Academic)

A few professionals suggested the need for staff training about SUI, so that they understand what it involves and what it means for prisoners involved in the work.

“I think there also needs to be training in mental health awareness and SUI for uniformed staff. There is still a lot of scepticism as to the benefits of SUI and if there was more understanding things may be easier. Governors also need to be encouraged to include SUI.”
(Civil servant)

One academic described how a member of staff acting as liaison between the researchers and service staff had helped with the practical aspects of a research project in a forensic service.

“What we did very early on was establish a staff liaison member ... this covered practical issues ... arranging meeting rooms and ensuring staff were aware that users were doing practical tasks for the project such as reading transcripts.”
(Academic)

A similar liaison member of staff in the prison would also be useful in negotiating practical issues within the prison. It is important to obtain the support of the prison governor so that the importance of the SUI work can be cascaded down to relevant staff.

“Focus groups with prisoners have been hugely problematic. You need real commitment from the prison, i.e. to provide the practical resources such as a large room etc., and a governor who is committed to the work.” (Civil servant)

Payment

The issue of paying prisoners for SUI in research needs to be considered. The professionals in our consultation discussed their experiences of conducting research in forensic services. They highlighted the importance of paying service users who worked on research projects in forensic services.

“One of the problems, I think, with these models is that they propose service users act as researchers but they are not always paid and so they are expected to act as cheap labour. We ensured that our service users were properly paid.” (Academic)

The Offender Health Research Network states that service users should not be expected to “give their time for free”. It recommends following the INVOLVE national guidelines for paying service users not resident in prison. These state that “people who use services should be paid for their time and expertise to a level consistent with other members of the research team, and expenses, such as travel, subsistence and child care, should be reimbursed”. Some people may choose not to be paid because they are concerned that they will lose their entitlement to state benefits, but payment should always be offered (INVOLVE / DH, 2006).

At present, the Prison Service does not support direct payment to prisoners (Hayes & Senior, 2007). There are concerns that payments to prisoners might undermine prison security and fund illicit drug use (Seddon, 2005). But some prisons have schemes where prisoners are paid for involvement in ‘meaningful activity’, such as work and education (Jayne, 2006). Prisoners involved in health research should receive appropriate payment and a system could be developed based on existing policies for in-prison work, education and training schemes (HM Prison Service, 2000).

Lessons from forensic services

SUI faces very similar challenges in forensic services to those experienced in the prison environment. Faulkner and Morris (2003) highlight the following barriers to conducting SUI research in forensic services:

- Problems in gaining access to service users who might wish to be involved in research;
- Difficulties in gaining the necessary cooperation from staff and management;
- Lack of practical advice on how to involve service users in research;
- Problems regarding the high levels of anxiety about the security of information;
- Lack of knowledge about SUI in research amongst providers and commissioners;
- The high expectations of service users about what is deliverable.

The National Forensic Mental Health Research and Development Programme addressed some of these issues in four research projects (Spiers et al., 2005) (see Box 2).

Box 2: SUI research project funded by the Forensic Mental Health Research and Development Programme

This project to assess levels of service user satisfaction with forensic inpatient services aimed to involve service users in all stages of the research from conceptualisation through to submission of the final report. It addressed some of the barriers common to SUI in forensic services and prisons:

Gaining access to service users

The principal investigator, who was working at two of the forensic units in the study, was able to gain informal access to the service users. This enabled service users to participate in early discussions about the project.

Participation and support

The research team acknowledged at the start of the project that there might be periods of limited participation. Service user researchers were encouraged to take a level of involvement that was appropriate for them. Information was distributed at every stage of the project to ensure that everyone was kept up-to-date.

Regular formal, informal, group and individual meetings allowed relationships and trust to develop between all researchers. Service user researchers provided peer support for each other.

Cooperation of staff

Staff cooperation was essential to this project. A member of staff acted as liaison passing information between researchers and assisting in communication with the administration and management teams.

Confidentiality

This was addressed at the start of the research process. At the end of the project that there was no evidence that anything had been disclosed outside of the research meetings. It was reported that participants had been open and honest, and were not inhibited by the presence of service user researchers.

The following areas for improvement were identified:

- Better ways of ensuring that research meetings do not clash with service user activities (such as group therapy);
- Prompt payment for service user researchers – delays led to frustration and anger;
- Additional time to allow collaborative research to develop.

Beer et al., (2005)

Lessons from SUI in prisons

This section describes some key examples and models of existing service user engagement in prisons.

Consultation / listening exercises

The majority of SUI in the development of mental health services in prison has been in the form of consultation. This has included self-report surveys of health needs, focus groups and consultation with advocacy services.

One example is a prison listening programme carried out by the Department of Health and the Home Office, which looked at lifestyle, emotional health, social integration and health care across four prisons. The purpose was to gauge the views of prisoners and the extent to which their health needs were being met, particularly on release from custody (DH & HO, 2007).

The research team invited 11 prisons to take part but were disappointed by the poor uptake with only four prisons ultimately recruited. The final report suggests that such prison listening exercises need to be given a much higher priority if they are to be successful in the future (DH & HO, 2007).

Security and other operational factors in individual prisons can and do act as a barrier to supporting listening exercises. One way of overcoming this is to negotiate with the relevant PCT-Prison management which oversees health care services in each prison (DH & University of Birmingham, 2004). Other challenging barriers identified by Jayne (2006) include:

- Attitudes of gatekeepers (e.g. prison staff) to forums, steering groups and committees;
- The level of commitment to embracing service user representation;
- Administrative and bureaucratic barriers and whether ethical approval is needed to allow forums / focus groups to take place as part of a consultation, particularly when considering that ethical approval for research is both time consuming and difficult;
- Tokenistic efforts and the lack of fully integrated consultation, where only a few service users are involved in making a contribution and are isolated within a group mainly comprised of professionals;
- Power imbalances that exist between various professional groups – clinicians, managers and policy makers - are amplified for service users and become more apparent when considering the status of prisoners and offenders in society, in view of their compromised rights on receipt of a custodial sentence.

Jayne (2006) adds that perhaps the most significant challenge is where the outcomes of such listening exercises significantly oppose existing practices, which can undermine practitioners' ability to take on board issues raised.

What is notable about the listening exercises illustrated here is that the level of involvement is mostly concentrated on consulting prisoners rather than the use of more participatory approaches in which they play a more active role.

Prisoner councils

Although not necessarily health care specific, prisoner councils are an established mechanism for prisoner participation. Since the 1970s prisoner councils have sought to influence the way prisons are run.

Solomon and Edgar (2004), in a survey of 27 prisons, showed how councils work and the difference they make. They found that council representatives were selected using a form of election, based on constituencies of individual wings. Prison staff were involved in encouraging prisoners to participate, as well as occasionally actively seeking appropriate representatives. Council representatives would then canvass constituents on the wing to decide topics to be considered at meetings; management also contributed to this process. What became clear from this survey was that councils were effective in improving communication between management and prisoners.

A range of subjects was included in prisoner council agendas including drug treatment, food / diet, staff-prisoner relations and other topics relating to the prison regime. There were several ways in which prisoner councils reached decisions. Solomon and Edgar (2004) found that a minority of councils were democratic and decisions were made on the basis of majority voting. Shared decision making between staff and prisoners occurred in a minority of prisons and for the most part both sides ‘compromised’ when reaching a consensus. For the majority of councils, issues were discussed at great length but ultimately the chair had the final word, either making a decision there and then or deferring it to seek advice. In some instances prisoner councils were not there to make decisions, instead they provided informed opinion as part of the decision-making process. In either case, whether councils exist to make decisions or simply act as a discussion forum for the decision-making process, lively debates usually take place.

The difference councils can make in effecting change varies depending on their perceived purpose by the prison management. Often prisoner councils provide a forum to discuss and debate proposed policy changes by the management. The priority for some prison managers would be to ensure policy changes do not lead to unnecessary dissent. For some governors councils are simply a forum for explaining proposed changes and gaining prisoners’ support. However, as Solomon and Edgar (2004) point out:

“...for prisoners to have a real stake in the running of the prison on a wide range of issues, the consultation must lead to more tangible outcomes. Prisoner representatives need to be given the opportunity to initiate reforms and then persuade management of the benefits. Only then are prisoners’ opinions given equal value.” (Solomon & Edgar, 2004)

The greatest advantage of prisoner councils is the vehicle they provide for creating dialogue between the management and prisoners. Decision-making processes are better informed even if prisoners are unable to effect direct changes in regimes. At their best, when organised democratically and supported and taken seriously by management, potentially councils can allow prisoners to express their opinions and concerns, and thus help avoid unnecessary conflict and dissent, and result in better informed policy changes within the prison.

Expert patient programme (EPP)

The expert patient programme (EPP) encourages the self-management of long-term health problems in the NHS (DH, 2001). An EPP training course was introduced into two adult male Category C prisons and evaluated by Gately et al., (2006), who explored prisoners’ perceptions of the barriers and opportunities for managing long-term conditions in prison. The range of long-term conditions

included diabetes, high blood pressure, arthritis and back problems. Most prisoners recognised the impact that prison had on health and their self-management of it. Some prisoners had to devise new ways of managing their condition, which they found difficult. Others found their health improved once in prison, as chaotic lifestyles ceased. Further themes identified included: diet and exercise, management of medication, prison staff attitudes towards prisoners with long-term conditions and access to health care staff.

This work shows that, by engaging with prisoners, health care providers can gain a broader picture of prisoners' needs and prisoners can improve their wellbeing.

Peer-mentoring training and user-led services

Peer mentoring is another example of service user engagement in prisons. The Mentor2Work (2005) project at HMP Liverpool sought to develop and deliver peer mentoring training to prisoners with mental health problems in order to help them gain employment on release. It aimed to use the unique skills and experience of prisoners who had used mental health services to mentor other prisoners (Mentor2Work, 2005).

This user-led prison / community project experienced some practical problems which highlight issues that can arise when carrying out SUI in prisons. Firstly, the project coordinator experienced difficulties moving around the prison; however, this was resolved once keys were provided. Secondly, collecting prisoners and accompanying them to training sessions proved difficult which meant that the course had to be flexible to allow for this and any prison lock downs. This affected the course length and timescales for its completion.

The project involved working with other agencies, both internal and external to the prison. Some prison staff reacted negatively towards the project. Finding space in the prison and a suitable room for training was problematic. The role of a peer mentor was initially misunderstood both by prison service and health service staff. The notion that people with a diagnosed mental health problem could become a mentor for others with a mental health problem was difficult to comprehend.

The barriers encountered in conducting this peer mentoring project were slowly but surely overcome. Prisoners who took part in the training found employment on release and the prison made an extended commitment to continue peer mentoring when the pilot project came to an end.

Conclusion

The importance of service user involvement in research and development is well established. The benefits are far reaching and can apply to different parts or all stages of the research process (Hanley et al., 2004). Numerous barriers still exist despite various government and research funding policies endorsing its practice. Effective methods for SUI in health research are outlined in guidance (Royle et al., 2001; SURGE, 2005).

The dearth of research literature on SUI in prison health research reflects its relative infancy. Prison health research lags behind its equivalent in non-custodial settings. Restrictions due to security, prison regimes and cultures will inevitably have an impact on any health research that takes place within a prison.

Research ethics approval, NHS and primary care trust (PCT) research governance, Criminal Records

Bureau (CRB) clearances for external researchers, together with the prisons' own systems of approving and vetting procedures for research, present significant hurdles for researchers to negotiate. It may be particularly difficult to involve service users from outside the prison with previous experience of the criminal justice system.

Some SUI in research has taken place in forensic services (secure hospitals) which share similarities with the prison environment and this shows how SUI in research could be carried out in prisons. There are also established examples of service user engagement in prisoner councils and in prison health service development, such as self-managed care and the expert patient programme, which could be built upon. The principles of good practice for effective SUI in health research (see Box 3) could provide a useful foundation for developing prison mental health research.

The challenges of SUI in prison health research are surmountable. The basic principles of service user involvement in health research can be applied to prison environments with patience, careful planning, extra resources and additional time as pre-requisites. Building good relationships with prisons is also fundamental.

The need for prison managers to be supportive of meaningful involvement is a necessity. Persuading prison governors and other prison staff of the benefits of SUI will require patience and perseverance.

Box 3: Good practice for SUI in health research

We identified the following basic principles:

- Involve service users as early as possible in the research, preferably at the beginning of a project and maintain their involvement throughout;
- Agree roles between service users and researchers and be clear about why SUI is needed;
- Offer service users payment for their time and expertise at a level consistent with other members of the research team and reimburse expenses;
- Understand how payment may affect entitlement to state benefits and discuss this with service users;
- Budget appropriately for the cost of SUI and allow sufficient time;
- Respect the skills, knowledge and experience that service users bring to a research study;
- Provide adequate training, personal support and supervision;
- Establish good relationships between service users and researchers over time and avoid recruiting service users in a hurry;
- Ensure researchers have the necessary skills to involve service users;
- Involve service users in decisions as to how participants are recruited and provide updates on the progress of the research;
- Detail in research reports and / or other publications how the SUI was carried out;
- Make the research findings accessible to service users in a format that is easily understood;
- Dissemination and implementation are also important parts of SUI in the research process.

Recommendations

We recommend:

1. SUI should become a regular feature of prison health research.
2. Levels of involvement may vary from one project and one prison to another: there is no single model.
3. Existing practices such as listening exercises, peer mentoring and prisoner councils could be adapted for health care research / development.
4. Prison research governance procedures and approval committees should be aware of the importance and benefits of service user involvement in prison health research and allow systems of approval to support such involvement.
5. A system for paying prisoners involved in health research should be developed based on existing policies for in-prison work and training.
6. Involvement in research should aim to help prisoners gain skills and lead directly to academic or vocational qualifications where appropriate.
7. Planning for SUI should account for potential conflicts with prisoners' other activities.
8. Confidentiality and security issues should be managed sensitively using relevant guidelines produced by the prison, Offender Health Research Network or Research Ethics and Governance.
9. Prison staff should be educated about the benefits of SUI before work starts.
10. Prisoners doing SUI may need ongoing support and, if necessary, treatment to help them to cope with any traumatic issues that arise.
11. The support of prison governors is vital to SUI in prisons.

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