An Evaluation of the Implementation, Management and impact of service user involvement initiatives in secure care, Yorkshire & Humber.

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Introduction

This study of involvement initiatives across secure mental health services in the Yorkshire and Humber region was commissioned by the Specialist Secure Services Commissioning Team. The research was required to take stock of a regional involvement strategy published in 2007, with groundwork going back to 2006. A key principal of the overarching approach is that this is about *involvement* for everyone – that is it is not restricted to a notion of *service user involvement* (which is typically the way of describing such things elsewhere). Instead, in this context what is being referred to is a concerted effort to promote alliances between staff and service users to promote, support and sustain involvement. There is a strong emphasis on cooperation and collaboration, what has lately come to be called co-production.

In Yorkshire and Humber progress has been made in involving service users and staff together in a wide range of initiatives to develop and improve services. A significant investment has been made in supporting this; including the appointment of Regional Involvement Leads. This was grounded in the *Reaching Joint Solutions*[1] programme of involvement activity and a comprehensive *Women's Involvement Project*[2]. All of the particular developments are different, varying in terms of setting, client group or focus for change. The different involvement activity includes:

- the establishment of a region wide forum, the *Involvement Strategy Group*
- standards for the operation of CPA meetings
- the recording of service user wishes for future care and treatment, *My Future Plan*
- filming projects to make DVDs associated with particular units and promoting aspects of the involvement strategy
- significant work on recovery planning leading to a *Shared Pathway and Recovery Framework*
- associated work on *Choice, Lifestyle and Responsibility*
- support for the delivery of *25 hours of meaningful activity*

- service user-led audits such as a review of the *Whole Dining Experience*

- an interactive web-space called CHATNET, for communication about involvement

Many of these initiatives have been developed through the efforts of participants in i4i (involvement for improvement) network meetings. These are convened to focus on specific CQUIN target areas and bring together staff and service users from secure units across the region to share ideas for best practice and innovation.

The focus of the research was involvement and we also wanted the study itself to be involving of people. We attempted to include involvement practices in the course of doing the research by having service users and staff involved at different stages. Involvement Strategy Group members have acted upon emergent findings to help refine these and support the work of the research team. They also took part in two specially convened workshops to address the strategic relevance of the research findings. Service users have also been actively involved in helping with the writing of this report. The idea of involvement is certainly topical in modern mental health services. It is our opinion that the research findings indicate that such involvement has been particularly well- developed in secure services in this region.

We hope that this report will support the further development of involvement locally and also be of interest to others wishing to implement involvement initiatives in other regions or other settings. The report turns first to a review of relevant policy, practice and research in the field.

Involvement: policy, practice and evaluation

Service user and carer involvement is an important part of today's health and social care policy. Mental health service users can be viewed as part of a wider service user, carer and disability movement, who seek positive changes in services[3-7]. The policy agenda links research, practice and education with calls for increasing levels of meaningful involvement in all these domains[8-29]. There are numerous examples of excellence, innovation and best practice guidelines[30-42]. Despite this progress, the quality, authenticity and sustainability of some developments have been questioned. There are

also concerns about the extent to which new practices or research findings fail to be brought into routine practice[7, 43].

A growing interest in recovery can be linked with participatory approaches to research to ensure both greater levels of involvement and effective application of research ideas into practice[7, 44, 45]. Recovery itself can mean different things to different people, so it is vital for research to involve service users to ensure their views are not ignored[46, 47]. Interesting developments in this regard include the recent Wellness Recovery Action Plans or the Recovery Star. Personalisation approaches have added a further dimension to this, noting that service users and carers require choice and control so that they can be sure of having individual needs met[29].

The politics of public participation and user involvement are complicated. Policies based on consumerism can seem to clash with the more radical demands of the service user movement[4, 5, 6, 48-50]. It has been argued that service users' goals to transform services may be frustrated if they are brought too closely into the systems they are trying to change[46, 51, 52]. Critics refer to a process of incorporation or co-option to describe these sorts of threats to the effectiveness of involvement. A recent critique, based upon the ideas of Michel Foucault, highlights problems with this policy agenda, and the possibility that less than ideal forms of involvement merely support other ways in which social control is exerted over people's lives[53]. In this light, service user involvement faces real challenges to move beyond tokenism to achieve genuine empowerment[7, 54]. Associated with these concerns have been efforts to measure different levels of participation[34, 55, 56] which value true partnerships over more limited or tokenistic involvement. We must also take into account certain problems in the culture of secure units, and indeed wider mental health care, which despite offering opportunities for involvement, may perhaps fail to fully appreciate people's involvement work[57, 58]. Nationally, this can be seen in the relative lack of resources devoted to supporting involvement.

There have not been many previous studies of service user involvement in secure care settings[59-63]. Service users have not routinely been involved in setting the research agenda. Nor have they been offered the opportunity to develop their knowledge or skills to enable meaningful involvement in the research process. Faulkner and Morris[59] also suggest that mental health service users are critical of the dominance of the medical model both in services and research. They state that 'this does not naturally lead to a willingness to become involved, unless they have the opportunity to influence the research topics or priorities from the start or to gain in skills and confidence'.

Parr makes some interesting observations about the ways in which different types of space or place might support service user autonomy and empowerment[64]. It is possible that this is more relevant in secure conditions as the need for security makes a big difference to the places people occupy and the relationships that take place within them. Banongo and colleagues in a study funded by the Forensic Mental Health Research and Development Programme used participatory approaches to study service user experiences of secure care. They also posed questions about how such services might be improved, including by enhancing the levels of involvement[62]. Given that this is the only previous UK study to address user involvement in secure care settings, it is worth noting some of the key conclusions and recommendations that are relevant to our study of involvement practices in the Yorkshire and Humber Region. These researchers, based at City University, London, noted a lack of involvement in both forensic research and the routine planning and delivery of care, a set of omissions that have a negative impact for service users[62]:

> *Perhaps the question that needs to be asked is not: 'how can professionals provide services that are more in keeping with what service users want?' Rather a more challenging question might be: 'how can professionals facilitate service users' greater access to and control of the means of forensic mental health care production?'* (p 37).

Other questions arising from this team's study findings focus upon the quality of communication between service users and practitioner staff and largely unfulfilled possibilities for empowered involvement in a process of change:

> *Why cannot there be more open and honest dialogue between service users and staff about treatment and the organisation of service delivery? Why cannot service users assume a more active and meaningful role in the production of health as part of the multi-disciplinary team? The simple answer to these questions is that there is much within the organisation of…. forensic mental health care that militates against such change* (p 37)

The researchers tried to make the most of involvement within their project, pulling together a panel of people who had experience of being a service user in secure settings. They held meetings at the university and supported service users to get involved in other things that were going on in the university, such as seminars and workshops organised for academics. They observed a big difference between the more open discussion and debate possible within the project team and in the university

compared with what was possible in the secure care settings:

> *What would it take to disrupt the traditional mode of forensic mental health care production to enable such open discussion about the service between staff and patients? Were it possible to bring about such change, would it lessen service users' distrust of services and their second-guessing of what professionals are up to?* (p 37)

The City University research team have also tried to make sense of their finding of a relative lack of service user involvement in forensic settings by looking for insights from sociology. They draw on ideas first put forward by the German thinker Jurgen Habermas[65, 66] Habermas has put together some interesting theories about how best to achieve social change. As we will see later in this report, some of these ideas are good for helping us make sense of the research findings from our study. Habermas makes a case for the importance of a type of communication that might drive action for change, where the people involved are respectful of each other, are open to the possibility of changing their mind, and start from fairly equal positions. He has also coined the phrase *deliberative democracy* to describe a process where people spend as much time as is needed to talk things through and listen to alternative points of view before making decisions together. Habermas suggests that if communication can be as free and open as possible and people have the time to cooperate on careful decision making, then the best ideas will come out in the end. In other words, rushed decisions, or communication where one person imposes their view on others, usually results in bad decisions.

For Godin and colleagues[60] the sort of ideal communication wished for by Habermas is hard to achieve in secure settings and trust between staff and service user participants is difficult to establish. This conclusion is supported in other mental health contexts by the work of Susanne Hodge[67-69] who similarly reflects upon the means by which communication is constrained. This is even the case within the process of involvement, either due to imbalances of power and authority or simply because of limitations on what is allowed to be discussed in the first place: not everything is up for discussion.

Lewis[70] makes similar observations on the ways in which it is difficult for service users to set off on an equal footing in any communication with professionals who will always have a higher status and hold more power. This is effectively seen as a human rights issue and can be wrapped up with the effects of stigma. Not least of the ways in which service user voices can be constrained or even silenced can be a

set of assumptions that comes with a psychiatric diagnosis and detention in mental health services. The most obvious of these is the denial that service users are capable of rational debate and discussion. This is of interest, because Habermas grounds his theory of communication for social change in the influence of *reasoned* and *reasonable* communication[65, 66].

Undoubtedly, these criticisms pose some serious questions regarding the value of Habermas's theory for understanding involvement initiatives in mental health services. Yet Habermas is also keen to stress the importance of the relational side of any communication. He also makes an appeal to include the marginalized or challenge the oppressive consequences of treating people as distinct and different from ourselves. Gardiner[71] argues that the ideas of Bakhtin can be used to improve Habermas's theory. Different views, different ways of making sense of the world need not be seen as irrational just because they are voiced by a service user. Furthermore, the talk within user movements or involvement activity must achieve some degree of clarity of expression and be understood by others to take the movement or involvement initiative forward. Arguably, it is equally oppressive to deny capacity for rational thinking to the person deemed *irrational* by psychiatry. There is also a need to find ways of accessing people's views if they have difficulty communicating for any reason.

Coleman[72] charts the extent to which psychiatric survivor activists have shown they can be capable of voicing clear and relevant views on their own care and what could be done differently. They have over a number of years 'significantly contributed to a reconfiguring of the relationship between madness and rationality' and 'forcefully nullified entrenched stereotypes of their incapacity through vibrant political expression' (p341). She concludes that users of mental health services must be seen as holding 'a rational capacity to speak credibly about their condition and their treatment and ... on the science of psychiatry'.

Methodology

We aimed to achieve three main objectives in this project:

- First, to thoroughly evaluate service user involvement in secure care settings.
- Second, to maximise service user involvement within this research project.
- Third, to utilise the research findings and facilitated service user involvement in the project to inform the formulation of strategy to take forward involvement initiatives in the region.

The study comprised a series of case studies of particular user involvement initiatives with parallel Action Learning and Inquiry activity with two groups (i) a selected reference panel of service users located in Yorkshire, and (ii) a selected panel of service users and carers located in Preston, affiliated to the host institution. Additional service user input into the project came from a service user researcher, Fiona Jones, with prior training in participatory research methods who supported the work of both of these service user groups and assisted the project team facilitators in connecting the work of the two groups. Having two groups maximised the extent of user involvement in the project, taking advantage of expertise built up locally and in alliance with the university, and allowed for user expertise with close knowledge of local initiatives and services to interact with user knowledge and experience from a different context.

The case study aspect of the project focused upon:

- The Involvement Strategy Group
- CPA (Care Programme Approach) Standards
- Women's involvement in developing and influencing women's services
- A service user directed filming project across various secure services

Participants were recruited into the study purposively to reflect their involvement in the different initiatives allowing us to study these four involvement initiatives in depth. Numerous participants

were involved in more than one of the respective initiatives, and various viewpoints and observations were expressed which were relevant to a more general appreciation of involvement in the region.

Provisional findings from the study have been presented and acted upon by a full meeting of the ISG and a further meeting of this group worked to turn the findings into strategic thinking, making recommendations for future involvement priorities.

The Case Studies

Case study evaluation methods are characterised by the inclusion of different stakeholder groups such as service users and multi-disciplinary care staff. Both qualitative and quantitative data can be collected to provide a rich overview of the range of perspectives held regarding the various involvement initiatives[73]. This includes analysis of relevant documentation. The chosen methods implicitly acknowledge complexities in different settings and the sensitivities of undertaking research with marginal groups[74, 75]. The task of the evaluator then is to highlight the degree to which viewpoints are shared, and supported by different forms of evidence[76, 77]. This triangulation of data and sources attests to the credibility of the evaluation[78].

Particular aims included:

1. To scope and audit the implementation and impact of the various involvement initiatives

2. To explore different views on the value of service user involvement as an organising principle for secure care services

3. To evaluate the impact and perceived impact of implementing these by key stakeholders, including service users, practitioners, managers and commissioners.

4. To identify 'critical incidents' in the timelines of the initiatives which are viewed as significant moments in the realisation of change, or impediments to change.

5. To identify the ways in which individual staff and service users make sense of the practice of

involvement in their own terms. That is: what are people's personal 'theories of change'? How do they account for what seems to work and what doesn't?

6. To explore commonalities and differences between the practice and perceptions of user involvement in secure care and other mental health settings.

With regards to evaluating the different approaches to service user involvement, there were 3 broad objectives:

1 To assess any shift in culture, if so:

- what processes have enabled this?
- what values may have informed this?
- common features between the different case initiatives.
- lessons learnt.

2 To audit the people who engage with the different user involvement initiatives:

- who they are (demographic information)?
- in what ways they are involved?
- any recorded impact data

3 To explore people's perspectives on the process and principles of engagement and involvement and its impact:

- explore stakeholders views on the impact of involvement. Most importantly this will include the views of current service users,

- how they, individually or collectively, make sense of the process,

- links that can be made between views on quality of service, service user satisfaction and notions of personal recovery,

- different opinions regarding the value placed on involvement – is it involvement itself that is valued or the outcomes that accrue from it,

- links between the experience of involvement and capacity to make use of problem solving approaches to other aspects of individuals' care,

- links between successful features of innovative and creative developments in user involvement and quality and improvements,

- explore the extent to which the forensic environment impacts upon the experiences and outcomes of involvement,

- explore the features of involvement activity that sustain people's enthusiasm for it,

- address questions of funding for involvement and the most appropriate budgeting arrangements,

- reflect upon the *Reaching Joint Solutions* model for involvement and views on its effectiveness,

Methods of data collection

The approach to data collection was largely qualitative, with 60 individual interviews, 12 individuals interviewed in pairs, and 10 focus groups undertaken, comprising 67 participants. In total there were 139 participants, taking together all interviews and focus groups. Critical Incident Technique (CIT) was used to guide the questioning of participants. The CIT is fundamentally a flexible approach to studying effective and ineffective ways of doing things, looking at helping and hindering factors, collecting descriptions of events and functions and determining characteristics that are critical to important aspects of an activity or event[79].

These individual and collective interviews were semi-structured to allow participants to focus on issues pertaining to felt culture and their perspectives on the process and principles of engagement and involvement. Depending upon the stage of implementation pertaining at particular case study sites, or the personal circumstances of interviewees, participants were encouraged to reflect upon how they saw things before, during and after being involved in the particular involvement initiative.

The interviews and focus groups also explore, where possible, 'theories of change'; that is we looked for how the participants develop their own understanding of how and why an initiative works. This involved exploring how they make connections between activities, outcomes and contexts with reference to the critical incidents timelines. These theories of change are seen as making explicit the links between project activities and their outcomes in order to explain how and why the desired change is expected to come about[80-82].

Interviews and focus groups also enquired into participants' identification of key features of involvement that in their view connect to care or service outcomes and/or service user satisfaction. Views relating to enhancement of well-being and recovery, and how participants theorise these concepts were of particular interest. A critical standpoint to the complexity of these issues and links to service user satisfaction and its measurement was brought to bear in the analysis[46, 83]. This element of the study will allow for the future development of an assessment tool for rating the quality and extent of user involvement and link this to recovery and/or service user satisfaction. One possibility is an adapted ladder of involvement that has specific utility and relevance for forensic settings. There would be no attempt made in this project to formally validate such tools, but this could possibly be the basis for a future project.

Full NHS Ethical approval was secured via the Integrated Research Approval System for NHS sites and approval was also secured for the relevant independent sector sites.

Findings

The findings are presented as follows. First will be a review of the different case studies, drawing out detail of their development, perceived impact and key learning points. Second will be presentation of the analysis of the qualitative data from interviews and focus groups. The latter themes cut across the specific case study examples and are best thought of as accounting for how the participants make their own sense of involvement.

The Case Studies

The Involvement Strategy Group

The Involvement Strategy Group (ISG) was first convened in 2006. It began with small numbers of service users and staff members but has now grown to a present size of around 80 participants and is open to delegates from all units across the region. The meetings are obviously, as the name indicates, a forum for developing strategic thinking about involvement and cooperative approaches to finding solutions. The setting is conducive to freeing up discussions and improving the quality of conversation, wherein there is a sense that mutual respect is more readily achieved than at ward or unit level. The meetings take place in a community facility, rooms booked in a rugby club in a reasonably central location for access from the region. Staff and service user delegates travel together from their various units, opening up the possibility for other dialogue and communication.

One of the ways in which the ISG is seen to work is because it acts to share experiences from delegates from the various units. Finding out what is going on around involvement practices in one unit informs, inspires and motivates people in other units. Individual members, both staff and service users, often have experiences of working or residing in more than one unit and this can add to the wealth of experience in the group and assist with insights into different practices.

Information is shared about people's experiences of what works or doesn't work to make meaningful involvement happen. Creative approaches are used to facilitate group work, and time is taken to talk about issues in ways which are inclusive of all members and aim to get things right rather than rush things. When focusing on a particular question or task, the large meeting sub- divides into smaller groups with a mix of staff and service users who work together to develop new ideas or solve problems before offering feedback to the group as a whole. On occasion, a key member of staff from

the region, charged with lead responsibility for a service development for instance, will make a presentation to the meeting and ask for feedback from the group or pose questions that the group will work to provide answers for. As such, there is a strong sense of ownership and loyalty to the group and the process of authentic involvement is modeled in the group's working practices. There is a rotating service user co-chair who volunteers to act in this role for two meetings, and other service users regularly share the tasks of presenting feedback and reports to the group. All of this is appreciated by members.

A crucial aspect of the effective working of the group is the presence of key personnel from the commissioning team, including lead commissioners for secure services and the involvement leads. This presence is important in establishing the credentials of the group to have real influence. This is true for service users, practitioner staff and managers – the authority of the group is respected, as it has a direct line of influence into the contracting arrangements for the provision of services.

There is a strong sense that participating members of the ISG make a link between involvement activity and the promotion of recovery, and this can be in a context of previous negative experiences of services. The group holds out the opportunity to transform these negative experiences into something positive which seeks progressive change for the value of other service users. There is a shared goal that the efforts of the group help to improve services for the better, making them more personalised and responsive to individual needs.

The culture of the ISG reflects aforementioned inclusive working practices and also the fact that a number of relationships between members of the group have matured over time. Though the membership is continually refreshed with the turnover of staff and service users, or changes in units as to who will be a representative, there are a number of people who have been a consistent member for a considerable time, some from the start. This makes for confident expression of views in the course of the meetings and also has led to processes whereby new members are inducted into the culture and practices of the meetings. There is also evidence of a degree of mutual respect and trust amongst participants, leavened with an easy banter and humour at times, with professional rank being no protection from having the micky taken. Another positive aspect of the culture of the ISG reflected in its working practices is the notion of respect across difference. It is clear that efforts have been taken to make the meetings as inclusive as is possible, and distinct equalities issues are addressed. This is most apparent in the use of sign language interpreters to include deaf service users and staff. Care is also taken to work at a pace and level of comprehension that includes people with learning difficulties. It is attempted to circulate written material in advance of meetings in plain language formats; delegate staff at unit level expect to talk through such materials with service user

delegates before the meeting takes place.

There are ready examples of instances where this inclusion bears fruit within the meetings and individuals are supported to have their voice heard; sometimes in a stark contrast to previous negative experiences of exclusion in services or society. When individuals with such impairments were interviewed, there was a strong sense from them that these efforts at inclusion were effective and having a positive impact on their sense of efficacy and confidence in the meetings. There were some occasional grumbles that in certain meetings there were some difficulties with inclusion, perhaps if the pace of the meeting gathered steam people could feel left behind or sometimes there were criticisms of written materials not being as accessible as they might be. The most obvious inclusion deficit is the fact that the ISG takes place away from secure settings. This, one of its most positive features, is also a barrier to many people without the requisite leave entitlements attending. Some ISG service user members suggested that a solution might be to have some meetings that rotated around the units to open up some access for such individuals.

Observations of a series of ISG meetings revealed a dynamic and vital set of working practices and comfortable relations between parties. The latter point is undoubtedly influenced by the quality of facilitation and the fact that, over time, members have become used to particular ways of working; the positive ways in which they relate to each other and the absence of difficult or challenging communication seems to be taken for granted. It was reported that in the early history of the group some work was done to think about ground rules and write these down, yet these were 'immediately ripped up and thrown away'. The group simply decided to act civilly and respectfully to each other and carried on, without recourse to written-down rules. Interestingly, there was also a view within the group that resisted being subject to rule or regulation; good behaviour could be expected without being formally insisted upon and to do otherwise seemed against the spirit of the group, perhaps feeling more like a professionalised or clinical practice rather than true involvement.

The impact of the ISG has been significant. At the strategic level, the work of the group has, directly or indirectly, led to the drawing up and enactment of a number of important policies that have been translated into real changes in practice across the various units in the region. The ISG effectively leads involvement developments for the region. Amongst others, the CPA standards work is an example of this (see below). The work of the group has also resulted in the development of the i4i groups, which reflect the setting, culture, working practices and membership of the ISG in their own deliberations on key aspects of service quality. Each i4i group focuses on a particular quality issue which has been decided upon by the democracy of the ISG and then collaborative sharing of ideas for best practice help the various units drive up quality and hence meet their CQUINs targets. This is a particularly

innovatory development, especially within the current climate of NHS competition.

At the individual level, being a member of the ISG can have a profound impact. Both staff and service users spoke, sometimes movingly, of the impact for themselves. Service users and staff remarked upon a perceived link between participation in the ISG and positive effects in terms of recovery. The most obvious of these is a growing sense of efficacy and confidence, but there are also some more subtle changes to sense of self or identity; where people begin to overturn a negative self-image and doubts about self worth. This is inextricably linked with feeling changes to how they are perceived by others: they begin to see themselves in a better light as their sense grows that others see them positively. Affirmation for contributions to the meetings feeds into this, as does a sense of pride that one is part of a process that is changing things for the better in services. For some service users and staff, this positive sense of self also connects with the idea that they are often working on behalf of others; those other service users on a ward or even those yet to come into services. This feeling that one is making a difference, not just on one's own behalf but for the benefit of others, is a strong influence on self-worth. It is not just service users for whom this is important, for example, staff have voiced similar opinions about how the work of the ISG connects with their idea of what their professional discipline is all about, including notions of helping, caring and promoting self- determination and responsibility. For many staff, their routine work in secure services does not necessarily or consistently hold out opportunities to put these professional ideals into practice. In this sense, many staff can feel somewhat alienated form their own sense of self as a person who makes a positive difference in other people's lives.

ISG members have been reportedly less successful in bringing the positive features of the ISG culture back home into the daily reality of secure units. It is unrealistic to expect that the members of the ISG alone assume responsibility for carrying positive culture changes back to their own units. Often, deficits are described in terms of the failings of other staff, or service users, not experienced in the culture of the ISG who represent various forms of resistance to enhancing involvement culture at ward or unit levels. An obvious contrast is made between the ISG and some examples of community meetings. At their worst these community meetings simply exist for staff to impart information to service users, there can be a lack of cooperation on the part of staff and service users and a distinct absence of the sorts of creative approaches to facilitation that are so appealing for the ISG members. Of course, the community meetings take place in a radically different setting.

<u>ISG case: Key learning points</u>

- The community setting for ISG meetings is an important dimension of creating a positive

culture; this is clearly difficult to replicate at ward or unit level.

- Positive attempts to develop a culture of mutual respect that equalise relationships and promote effective and inclusive communication have been successful in the ISG. There is no reason why these efforts at improving the social relations of communication and decision making cannot be reproduced at ward or unit level. Relevant staff and service users may need to be both persuaded of the value of this and socialised into working this way.
- The Regional Involvement Leads are key change agents and culture carriers. These roles ought to be a model for best practice elsewhere.
- The presence of commissioners, including the lead commissioner, is an important aspect of verifying the authority, credibility and influence of the ISG. Such close working between commissioners, provider service staff and managers, and service users ought to be a model for best practice elsewhere, not limited to mental health services.

- The use of creative facilitation techniques and strategies for inclusion are an effective part of the success of the group. These can be continually bolstered. There could also be concerted efforts to improve the quality of meetings at ward and unit levels by wider deployment of such methods. Though this would require the practice of skills in facilitation, these ought to be well within the compass of ward based practitioners. Exposure to the working practices
- of the ISG has a positive impact upon both staff and service users' appreciation of involvement and sense of self. An expansion of high quality communication of the sort experienced in the ISG could widen the impact of such effects at the ward and unit level experience.
- The enthusiasm and skills of certain ISG members could be harnessed by utilising them to
- co-deliver training initiatives aimed at expanding involvement practices, in their own or other units.

Care Programme Approach Standards (CPA)

A significant strand of work to emerge from the ISG and become a focus for i4i meetings has been the work to develop and implement standards for the operation of CPA process and meetings. The ideas were first discussed in meetings convened at Stockton Hall. These user-led standards were finalised early in 2010 and have been rolled out across the region. The successful implementation of the standards has had a profound impact for those service users who take them up thoroughly and go on to organise their own CPA meetings and chair them. The positive impact is appreciated by both service users and staff. For service users, some of the observations in the previous section which link involvement activity to positive impact on recovery, efficacy and self-esteem are also evident in this context.

The standards themselves are written in plain language, and were put together over a series of meetings, drafts and redrafts. The CPA standards are also accompanied by a pack that offers a range of supportive information, including a meeting planner, checklist, invitation and an explanatory leaflet and DVD that were also co-produced with service users (see below). The standards stipulate a number of ways and means by which the service user can be placed at the centre of the CPA process and gain a degree of control over the proceedings. These include:

- Excepting for exceptional circumstances the service user should be involved in all of the CPA meeting
- Maximising service user choice about the room for the meeting and who sits where.

This includes the opportunity to check out the venue and its layout in advance.

- Working together with named nurse to organise timely invitations to the meeting and administrative support for the service user to send out invitations in their own name.
- Changes of date or cancellation of meetings will only take place following discussion with the service user.
- A plan for the meeting is drawn up in collaboration between service user, care co-ordinator and named nurse.
- Independent advocacy support is promoted and available throughout the CPA process.
- Service users are involved in all report writing in advance of the meeting.
- There is the opportunity to attend the nearest ward round or MDT meeting before the CPA
- meeting to discuss issues that might arise.
- Service users have the opportunity to present their own viewpoint in a format of their choice, verbal or written.
- Service users have the choice to chair their own meeting or nominate a care team member to take this role.
- Service users have the opportunity to meet the various members of the CPA meeting informally before the meeting starts.
- Service users have choice over a number of aspects to do with the meeting arrangements: how and when people enter the room; the seating arrangements for different people; how reports are to be presented and in what order; how and when to respond to reports and matters arising from them.
- It is expected that authors of reports should make every effort to attend in person.
- Time will be taken at the end of the meeting to agree an action plan (with timescales and responsible people identified), the date of the next meeting, and identification of who needs to attend. There should be a short break for the service user to gather their thoughts before moving on to future planning.
- Following the CPA meeting the service user will be involved in reviewing the final report and will be able to incorporate different points of view if necessary. The date at which the report needs to be complete will be stated.
- The process of reviewing the report should be inclusive and respectful.
- There is a commitment that all reports are written in accessible language.
- Paper and pens must be available for everyone at the meeting.

- There is a commitment to civil and respectful communication at all times in the CPA meetings.
- Adherence to these standards will be evaluated by the service users and carers via a questionnaire at the end of the meeting.

It is a matter of choice whether service users take up all the opportunities made possible by the standards, and not all have maximised these for themselves. For instance, some simply do not wish to chair their own meetings. Efforts to make sure service users have the opportunity to make use of the standards, even if they choose not to, has been made a measurable CQUIN target.

The work to develop these CPA standards is of interest in the context of involvement practices because it addresses some key principles of control, autonomy and self-determination. The focus upon the CPA process is important because one of the prime issues for service users detained in secure settings is the pace by which they can progress through the system towards discharge or transfer to a less restrictive setting. Many of the complaints that service users have in secure care services involve objections to slow progress through the system or feeling powerless in the face of seemingly impersonal bureaucracy. The CPA process is a key aspect of the administrative bureaucracy of mental health services and, as such, is an important place to start to intrude choice and entitlements for service users and make the process itself more transparent and open to influence.

For those service users who make the most of the opportunities afforded by the CPA standards there is a reported strong sense of empowerment and enhanced agency in the process. Interestingly, satisfaction with the application of the standards is apparent even if the service user does not get all that they wanted from decisions taken in the meeting. That is, the improved process is appreciated over and above the outcome. This has been reported to the research team in terms of feeling more trustful that the process is fair, and that this is reassuring that progress will be made eventually. Whereas, previously, it could feel hopeless that anything would change from one meeting to the next and there was less understanding on the service users part as to what they could be expected to do to improve matters.

Practitioner staff were also appreciative of the standards, often feeling that their existence helped improve cooperation in other aspects of care and treatment. They also reported seeing service users grow into the role of taking more charge of their CPA meetings and how this could be seen to have a knock on effect in terms of confidence and self-esteem. Managers were positive about the fact that a commitment to implementing the standards was linked to CQUIN targets and this helped support the initiative and demonstrate its importance.

CPA Standards: Key learning points:

- The successful implementation of the CPA standards affirms the value of the ISG and i4i meetings in that these involvement practices have demonstrably resulted in important and significant changes to policy and working practices.
- Having user-led standards is an important mechanism for opening up choice and transparency in service delivery. It assists service users to achieve a greater degree of control, autonomy and agency and is an important dimension of enhancing wider involvement and cooperation.
- There is an appreciation of the process which is somewhat independent of whether specific demands are met within any one meeting. The existence of the standards promotes trust that the overall process is being played out fairly.
- Linking the implementation to CQUIN targets is largely appreciated within services and helps demonstrate the importance and value of the initiative.

Women's involvement

We explored women's involvement with a focus mainly upon the development and implementation of services at Garrow House, York. The case of Garrow House is interesting because the service was set up in the first place on the basis of an involvement initiative and care has been taken to make the idea of involvement central to how the service is delivered.

The establishment of a new Women's High Support Service is described in greater detail elsewhere[84]. In brief, this came out of work predicated on national and regional policy and strategic developments resulting in a project under the auspices of the Forensic Catchment Group in collaboration with Calderdale Women's Centre: the *Women's Involvement Project*[2]. This project undertook to survey the views of women service users by a number of different methods and use the results to inform collaborative planning for a new service. An important starting point was a view that current arrangements for service provision were in many ways inadequate, were failing to fully meet women's needs and were beset with blockages to the system of moving women out of secure settings. The crucial commitment from the start was that women service users would be involved in consulting on the issues, designing the building and informing the eventual service model.

Garrow House was thus set up with a strong ethos of making concerted efforts to more appropriately meet the particular needs of women detained in secure settings, to involve them thoroughly in their

own care and treatment, have an emphasis on relational security and respectful communication, work towards service goals of recovery, self-determination and instillation of hope, and smooth transitions towards discharge into the community. Staff were selected carefully and inducted into the service ethos and model of practice before any service users were admitted. There is a full complement of multidisciplinary staff who ensure that the involvement demands for a range of specific activities and therapy be available are lived up to. There is consistent application of good practice in clinical supervision. A key post in the unit is a dedicated involvement worker, who similarly was in post prior to the unit opening and is an active member of the ISG and other regional involvement initiatives (including the reference panel for this project). The whole process was supported from start to finish by one of the regional Involvement Leads. The high profile involvement of members of the Secure Services Commissioning Team linked in with DH objectives and ensured the development of new approaches to women's services were expressed authoritatively enabling commitment and sign-up from relevant stakeholders.

Our study revealed high levels of appreciation amongst service users of both the process of involvement in setting up Garrow House and of the quality and approach taken in the delivery of the service. This was often contrasted with very negative experiences of institutional care elsewhere. This chimed in with the experiences of Fiona who was part of the research team and poignantly felt that a facility such as Garrow House would have made an appreciable difference in her own history of engagement with secure services (in another region), and almost certainly would have shortened the time she had to spend in secure services. The staff were impressive in their allegiance to the notion of involvement within their practice and the wider model of care and its relational ethos;
their values were readily apparent in their accounts of working collaboratively within the service.
The visibility and support received from the Involvement Lead was remarked upon positively. The

value of having a specific person to lead involvement within their team was valued but staff invariably expressed their own personal commitment to involvement. There was a healthy understanding of key gendered issues in the care of women in secure settings and appreciation of progressive means by which to support individuals with complex histories including serious self-harm.

Women's Involvement: key learning points

- Garrow House is an impressive development and arguably a beacon for best practice for the care of women detained in secure settings. The relational service model appears to be a most helpful means of providing effective care and treatment. This connects with a well- developed understanding and appreciation of gender issues and self-harm.
- The fact that the service was developed and designed on the basis of a thorough involvement process is itself an indicator of best practice.
- The service has unarguably benefited from the opportunity to be very selective in putting together the care team in advance of admitting service users.
- The role of the Involvement Lead and other involvement of the commissioning team was crucial in supporting developments and establishing the authority of the project.
- Having a dedicated involvement worker on site is important in ensuring that a positive culture of involvement is consistently supported and that the involvement role is not diluted by other commitments.
- The women service users who participate in involvement activity experience a number of positive effects and these contribute to the sense of recovery (these are of a piece with those previously outlined in relation to the ISG experience).
- A systematic approach to clinical supervision for the staff is applied and appreciated by the team.

The filming projects

A number of films/DVDs have now been made across the region as part of the wider involvement activity and promotion of different involvement practices and initiatives. Specific DVDs have been made to promote the *My Future Plan* and the *CPA Standards* initiatives. Other filming has produced information resources for specific units, for example secure services for individuals with learning difficulties at Amber Lodge. The latter films are of use to prospective service users considered for referral into the unit or for family members who would benefit from understanding more about

their relative's care environment. They can also be used in terms of staff induction, or in staff recruitment, showcasing the respective units to prospective job applicants. The films have been produced in collaboration with external personnel from the Film and Media department at the University of Bradford and SHOOT Productions who were engaged by the Secure Services Commissioning Team. The production approach has involved service users in the different stages of making the films and has also paid careful attention to issues of consent and protecting anonymity for participants where necessary.

Service users and staff have been involved in planning content and doing the actual filming and contributing to the editing process. Those involved have been taught how to use the equipment and learn about different ways to develop ideas in movies, or conduct interviews to support the content. They have decided what the key messages are which they want the film to express, and have reviewed cuts of the film to see that this is achieved effectively. The process concludes with celebration screenings which preview the film for others in the service. The intention is that participants receive copies of the DVDs, for instance to share with their relatives or for the service to show to new people. Everyone involved is issued with a certificate to mark their contribution to making the film.

Those service users and staff who were involved in the different filming initiatives were appreciative of the involvement aspects of the process and the opportunity to learn new skills or just have fun with the process. For many, the fact that the process results in a tangible output, the film, which is clearly of high quality has been a source of pride and achievement. The opportunity to work with outside people with expertise in film was also appreciated. For some participants, the filming project connected with a wider interest in film. More critical points of view were also expressed, some staff and service users were unaware that such films existed, raising questions about the degree to which they were being made use of in practice. Some of the people who had been involved in the production of particular films could only vaguely recall the process or had lost touch with what was happening with the films; they could not recall if they had their own copy nor knew how they might get one. For some, this was not too much of an issue because the filming had been incidental to wider involvement practices which had carried on. Some felt disappointed that they had had a one off chance to get involved in this way but would welcome further opportunities to carry on with such filming initiatives. Others expressed the salient view that some of the films were prone to date quite quickly, as they were overtaken by service developments or further involvement innovations. These participants suggested that there was a need to continually review and update the material.

Filming projects: key learning points

- Artistic endeavours like filming are a very good way of framing and supporting involvement and can tap into people's talents or build valued skills. This has a concomitant impact upon confidence and esteem as remarked upon in other involvement contexts.
- The use of user-made films can be an effective way of adding to the diversity of communication resources in units, complementing written information or substituting for it for people who have difficulty comprehending the written word.
- The external facilitation of the filming projects was a valued part of the process but may have contributed to the 'one-off' feel of this involvement for some participants. There may be a need to build capacity amongst staff so that the filming can be carried on, especially as content becomes dated.

Making sense of involvement

Analysis of the interviews and focus groups resulted in the articulation of ten major themes which span the different case studies. We have titled these themes as follows and will present in summary form in turn using illustrative quotes from individual participants:

- Appreciation for the Involvement Strategy Group
- Bringing it all back home
- Not just about me
- It's the talk!
- Involvement as a basis for recovery and wellbeing
- Emotional impact of involvement work
- Safety and security first, involvement second
- Supportive staff and context

- Commissioning for involvement

- Accessibility of involvement practices and messages

Appreciation for the Involvement Strategy Group

> *What we say is always listened to, there is always someone to write down the views of the service users … I think it definitely makes a difference* (service user)

There is an enormous amount of goodwill for the Involvement Strategy Group voiced by participants. This group is valued strongly for a perceived high degree of influence. The ISG is recognised as a direct channel to the regional commissioners and also into networks of national policy making. Numerous participants report tangible evidence that people having their say has made a real difference to practice and policy. The presence at the meetings of lead commissioners was highly valued and symbolic of the degree to which people felt the involvement was real and meaningful. The affection within which the group is held is also related in strongly relational terms. The various relationships between participating staff, service users and commissioners are very much valued and contrasted with more critical accounts of problematic relationships elsewhere.

Almost universally, members of the ISG appreciate the opportunity to meet with fellow service users and staff from other units and share experiences, success stories and disappointments about involvement. This networking leads towards refinements of strategy and tactics for involvement within the group and influences the demands that can be made of one's own service on return:

> *There are so many times, like over the issue of mobile phones … it was great to hear what was happening on other units and the success they have had … it hasn't happened yet on our unit but it is good to know and be able to say that other units allow this* (service user)

The setting is important – both in terms of being a non-secure community venue with good facilities and also in terms of the creative and inclusive facilitation practices and organisation of the meetings. The work is designed to maximise participation by all and build upon the strengths of the alliance model of involvement, bringing together staff and service users to contemplate and deliberate on involvement goals. At the local unit level, the journey to the ISG meetings means that small groups of staff and service users often share the same vehicle, further potentiating a continuation of discussions or preparation and always affording the opportunity to strengthen relationships.

Service users consistently rated the ISG high on the ladder of involvement; many perceiving the quality and experience of involvement at these meetings to be a true partnership.

Bringing it all back home

Whilst the ISG and other collective meetings held away from service settings are most valued, various participants questioned the grass roots impact of this collective involvement activity. That is, they called into question whether the commitment to involvement and the extensiveness of its practice was thoroughly enough translated into ward level activity. Even within units, a difference between the quality of involvement in collective meetings, such as unit involvement forums, and ward based routine practice was critically noted:

> *Trying to make sure that everybody gets their voice heard on a ward like this can mean that often the meetings get quite heated and then we have to step in and sort it out* (staff)

> *The community meetings here can be good, but mostly they are boring and not everyone wants to go. They are definitely different from the bigger meetings [ISG]. Sometimes it is just the staff letting us know what is what* (service user)

Ward based community meetings were more often than not singled out for critical commentary. Typically, perceived staff attitudes and/or obstruction of involvement were remarked upon to explain these discrepancies. In this sense, the notion of variable staff support (see below) would appear to be crucial.

That said, there were numerous examples of effective involvement practices at ward and unit level also cited and particular satisfaction with the positive impact of the CPA standards. Some issues of implementation are reported associated with the context of different levels of security: medium versus low security units, for example, or wards with a concentration of vulnerable individuals, for example around self-harm, within units. The issue appears to be one of consistency of application of involvement practices across units and within units.

Some units have achieved excellent systems to support involvement at grass-roots level. Some of these good practice examples emphasise relational aspects of care and relational approaches to security. In some places these practices appear to closely resemble features of therapeutic communities. Garrow House in particular is an excellent example of this and has also in place very

thorough systems for staff clinical supervision with attention to the emotional labour of their work and a well thought-out understanding of gender and risk in the progressive care of women who present with complex needs and how to support staff of different gender in this context. This unit was designed and staffed on the basis of strong user input into the planning, and was exceedingly selective in staffing the unit from scratch, including the facility for a dedicated involvement support worker and a range of disciplines on site. Many of the support worker staff are relatively well educated for their grade-point and possess skills in creative approaches to community living. As such, Garrow House is well placed to support effective involvement, and a culture of participation is obvious throughout the unit and reflected in the narratives of staff and service users.

Stockton Hall has a well established system of ward representatives feeding into unit-level meetings. On the whole this is supported and facilitated by off ward staff, notably from social work and occupational therapy, and there is a felt need to more thoroughly inculcate these practices across the wider team, particularly ward-based nurses.

The Humber Centre reported some difficulties in consistently achieving 25 hours of meaningful activity for service users, but are working hard to address this. This unit has made some notable innovations on the involvement front, including the establishment of a *laughology* group and a joint service user-staff football team. The latter enterprise has resulted in interesting connections with the local professional football club. The former has also resulted in associated activity to create a service user-led space for activities using participatory methods to plan and furbish.

Not just about me

Many of the service user participants state that their affinity for involvement is not merely because they can see benefits for themselves (see below). They suggest that a significant motivator to get involved is a desire to make a difference not just for themselves but for others detained in the system:

> *This is all about helping other people stuck in the system. I spent years moving through very slowly. I wish we had all this involvement when I first started. It has really helped me now, but I wish it had been around then. When you are in one of these hospitals the most important thing is getting out, or knowing you have a chance of getting out. I'm out now. I carry on with the involvement stuff to make a difference for those who are still in* (service user)

Arguably, being able to contemplate the value of involvement in such unselfish terms connects with

other analyses of user movement activity, both confirming that forensic mental health involvement is not so different from involvement elsewhere in this regard, and that service users in secure contexts can access a positive identity as people who serve the interests of others in direct contradiction of some of the more negative stereotyping of this client group. Many service users stated that their commitment to involvement activity would continue, and in some cases already has, after their own discharge from secure services; reinforcing the implicit value and reward this work brings but also the desire to continue to make a difference for others still detained in the system and those who will come after them.

It's the talk!

> *This is what we are trying to achieve, making the case for involvement amongst ourselves and spreading the message about involvement as wide as possible. You can only do it by having conversations with people, persuading them, listening to what they have to say, and then coming back with more persuasion … you have to be convincing … you have to be prepared to listen and think about objections and reply with a better argument* (staff)

One of the most interesting dimensions of the discourse of participants in this study is the extent to which they value the conversations they have with each other in a context of involvement and the degree to which they associate this talk with driving forward a sense of empowerment and achievement in the process. This theme is strongly linked to other positive commentary about the relational dimensions of involvement, but is also distinct in suggesting that the talk itself is crucial in driving involvement forward. At times, the fact that this was felt to be the case was reflected in an almost poetic articulation of viewpoint in this regard, though the value of each other's communication in the act of involvement was not necessarily dependent upon relative powers of expression; raw experiences and associated live emotions would be just as significantly influential as any neat turn of phrase and the expectation within meetings would be that all present speak as clearly as possible. Interestingly, participants in the study were also appreciative of their opportunity to tell us their stories of involvement, and it is this sharing of stories which is a central feature of the extent to which involvement in groups such as the ISG was appreciated.

The importance of communicative acts was summed up in the words of one interviewee, who was being pressed to say exactly what it was that he valued in his experience of involvement. Evidently struggling himself to put into words what was immanent in his consciousness he eventually spat out: *it's the talk*! The fact that this participant felt his answer to be self-evident and obvious was a big part of his frustration at this juncture in the interview and his eventual succinctness in reply; he may

very well have added the word 'stupid' for an aphoristic connection to the famous observation on the economy at election time.

Many service user participants observed that one of the effects of participation in involvement initiatives such as the ISG was that they then felt more able to engage in constructive talk with their care teams. Interestingly, these service users were able to articulate the type of communication they valued in their care team. Care team practitioners would be appreciated if they were respectful of different opinions and willing to take time to listen. Importantly, the service users did not necessarily frame an ideal communicative encounter in terms of having their demands met; rather they valued the process by which their concerns were attended to and placed most value on receiving meaningful explanations for any care and treatment decisions:

> *You don't always get what you ask for. All I am after is a proper explanation and the chanceto put my view across* (service user)

Nevertheless, service users and staff noted that communication, and competence at communication, improved for people then they were more likely to be able to present their views on care and treatment and hence more likely to achieve influence over these.

Involvement as a basis for recovery and wellbeing

> *If patients can give their view about what recovery is, you know, then that is crucial information for the care team*, commissioners *… and ultimately about letting people go, discharge from hospital* (service user)

Both staff and service users felt that service user participation in involvement practices had a beneficial effect upon well-being and recovery. Typically, this would be expressed in terms of a positive impact upon individuals' confidence and self-esteem. Confidence would flow from being part of meetings that led to tangible results and being encouraged within the process of these meetings, which afford multiple opportunities for positive affirmations of individual and collective contributions:

> *I used to be nervous and would hang around in the background … now you can't stop me. I chaired my own CPA the other day and it was fantastic. Everyone let me know what a good job I had done… it felt a bit weird at first but now I'd say everyone should be in charge of their*

own meetings (service user)

In tandem with increasing levels of esteem and confidence would be enhancements to skills, especially communicative skills which are improved in the act of becoming involved in groups such as the ISG; these enhancements to skills being honed in the participatory approaches deployed in the course of these meetings such as discussing in small groups, feeding back to the larger group, chairing meetings, undertaking presentations etc.

Staff and service users also reported that a growing culture of involvement at unit level coupled with the impact upon confidence and skills could also help improve the extent to which service users become adept at navigating the system; making the most of care-team meetings and CPAs or individual encounters with health professionals, for example. The sense of being part of a collective that does indeed make a difference is also a powerful motivator and influential for people's sense of worth and well-being. This notion of 'doing good work' is also linked to the aforementioned attachment to the value of involvement on behalf of others, not just oneself. Ward based staff also reported examples where the activity of a ward representative service user would be of positive benefits for other services users, helping them to see the benefits of involvement:

They can see that there is more to their treatment programme than sitting there, getting up, taking meds and going to bed (staff)

Involvement activity can take many forms, but, invariably it makes demands upon participants' energies and capabilities; more often than not these efforts are implicitly rewarding and the sense of having an important focus and keeping busy is also a positive contributory factor. One or two individual service users reported taking on prodigious amounts of involvement work, attending numerous meetings of different sorts or helping to facilitate ward community meetings. Others had been remarkably influential in supporting or initiating the development of highly creative programmes of involvement (one such example being the mixed staff and service user football team at the Humber Centre).

Conversely, some individuals struggle to strike a balance between their capacity for this work and the amount of commitments they take on. On occasion, staff reported concerns that some individuals might need to be counselled to take on less involvement work, in case it was too taxing of their personal resources or, for at least one service user, seen to be something of a distraction away from important clinical work. Key staff would see it as an important part of their role to talk through different levels of commitment with service users, for example whether they were well-placed to

take on a representative role, or indeed, counsel against taking on extra responsibilities if it was felt this would be too much for them.

Service user representatives at meetings such as the ISG see themselves as having an important role in influencing practices and policy in secure care. One point emphasised is the need to impress on managers and commissioners what the various features of recovery are for people so that the most appropriate care packages can be provided and, ultimately, this progresses people through the system:

> *As far as I'm concerned that's mostly what my job is … representing service users and speeding up the whole process… getting people through the system faster by getting them involved in their own care*(service user)

Emotional impact of involvement work

Participants' retelling of their experiences of involvement were quite often replete with the emotional flavour of this work and its consequences. Efforts in involvement can be both taxing and rewarding, frustrating or fulfilling. The tangible successes of various initiatives in the region, right up to influencing national policy work, were related with pride; an emotion that was often mentioned with regard to individuals' participation leading to a sense of real achievement for self and others. On occasion service users told of the sheer hard work associated with involvement, sometimes attending boring meetings, sometimes becoming worn out trying to persuade others of the value of the work. One service user expressed intense irritation that some staff and service users couldn't grasp the importance of a particular initiative he and others had worked hard on, and contrasted this with the good feelings when people showed more positive interest:

> *It can feel like you are wasting your time … I had to listen to a lot of negativity during the pilot from other service users … you know, 'what the (expletive) is this for' …. It does get you down, I'm trying to help them you know … and then, some staff thought it was (expletive) brilliant … that picks you up* (service user)

For service users, the chance to engage in involvement activity, especially away from the secure environment at the ISG and i4i meetings, was an escape from the tedium or oppressive features of life in secure care. There is also the opportunity to meet and form relationships with others from different units, and, indeed, alter significantly the relationships with care staff from one's own unit, effecting changes in sense of self and identity, all of which can have a positive impact at the

emotional level. At a more superficial level, but equally appreciated, are the opportunities for humour and banter afforded within the easy-going atmosphere of some of the involvement forums, generating a range of positive emotions and enjoyment of the proceedings.

Staff who were committed to supporting the involvement initiatives felt that this activity contributed positively to their own sense of job satisfaction and experience of work, in some cases counteracting a largely negative experience of working life in secure units or reconnecting them with a wholesome view of themselves as someone who makes a constructive difference in the lives of people under their care. This latter point touches on the issue of whether aspects of mental health care can be alienating for both staff and service users, and whether alienation from a positive view of oneself as a caring, progressive practitioner is most likely to present itself when service users are subject to compulsion and incarceration in secure units wherein the potential for conflict between service users and practitioners is more acute but, perhaps, models of involvement offer one possible remedy from these negative feelings via effective co-operation towards agreed goals.

Some of the supporters and promoters of involvement initiatives remarked that they often present the rationale for staff engagement in involvement, especially with recalcitrant staff, using a sort of appreciative approach that taps into the emotional side of things and the associated potential for job satisfaction and fulfillment in their work:

> *Find out what they do have a passion for … they might be cynical about particular things, especially when you mention recovery or involvement, or choice, personalisation or meaningful activity. But when you say to them 'why did you come into the job? What do you enjoy when you come into work?' you can get into a discussion and by the end of it … you have actually met, together* (Involvement Lead)

Supportive staff and context

> *It's as much about support as anything else* (service user)

> *All the staff are interested and involved … thoroughly committed … the staff come up with some good ideas sometimes, yeah* (service user, reflecting on i4i meetings)

Both service user and staff participants pointed out the importance of involvement practices being supported by appropriate staff. The flip side of this observation was that unsupportive staff could

undermine the scope and effectiveness of involvement. This theme also included commentary on the context of involvement within different provider units and the extent to which different care systems or configuration of services supported involvement initiatives. Some of these observations were focused upon perceived differences across professional disciplines associated with degrees of participation in involvement and support for involvement practices. At its simplest, there is a perceived contrast between ward-based staff, typically the nursing team, and other disciplines, usually located externally to wards, with most support for involvement felt to be enacted by the non-ward staff. Similarly, the extent to which principles of involvement have insinuated themselves into all aspects of routine care was felt to be limited in some areas rather than others; with, for example, some psychiatrists criticised for 'old-school' attitudes towards participatory approaches and involvement in clinical decision-making, most obviously over issues such as medication or leave. Critical commentary in this regard, would usually locate a lack of attachment to involvement in the personal values of the practitioner or a sense that such practitioners would view too much involvement as opening up the service to untoward risk. The fact that some staff give voice to such concerns explicitly is covered under the particular theme titled 'safety and security first, involvement second'.

Despite strong views on perceptions of staff attitudes for or against involvement, the actual territory in this regard is complex, and resistance to involvement can come from service users as well as staff if trust is lacking:

> *We need to get away from the 'us and them'* (service user)

At the level of clinical decision making, a number of service users were critical of their psychiatrists for a relative lack of interest in democratising decisions about, for example, medication changes. That said, a small number of psychiatrists were interviewed in the study, and all of these were keen supporters of the notion of involvement and could see the benefits of involving service users in key decisions about care and treatment. The CPA standards were seen by many participants as one route to making improvements in this regard. There were also well-articulated reflections on good practice in involvement demonstrated by ward nurses and support workers and who were clearly committed to greater degrees of democracy and involvement in decision making, including over leave and medication. Some staff were seen as resistant to change, voicing opinions such as 'this will never work', yet participants reported instances where even the most cynical of staff could be won over by demonstrations of the value of involvement; even up to the point where the previously resistive are transformed into *champions* of involvement in their service.

The need to extend best practice in staff support for involvement across all disciplines and workplaces was acknowledged by those staff identifying themselves as supporters of involvement. To some extent, this uneven evidence of support from staff was a source of frustration for these evangelists for involvement but many were also able to demonstrate an understanding of how such differences might occur and the implications for remedies. At least one solution recognises that a seeming lack of support for involvement could, at least in part, reflect differentials in workplace autonomy across groups of staff, often also associated with constraints on abilities to devote significant amounts of time to activities seen as additional to one's typical role. In units where the visible support for involvement was associated with staff in particular disciples, Social Work or Occupational Therapy for example, these staff also saw it as their responsibility to do more to encourage ward-based staff to take on this role, rather than simply condemn them for not doing so. Service users recognise that involvement is best supported by all disciplines and service users collaborating:

> *It is important that everyone works together and for everyone to have their say* (service user)

Safety and security first, involvement second?

This theme reflects tensions between involvement practices and concerns with the management of risk. Clearly, there is a significant imperative of risk management and public protection underpinning the very existence of secure mental health services. Notwithstanding this, the relationship between degree of involvement for individual service users and the risks that they pose to themselves or others need not be conceived as in a singularly one-dimensional relationship. For some staff, without necessarily arguing with general principles of involvement, especially as they might apply in non-secure mental health services, there are significant limits to the extent that involvement can be enacted uncritically within a secure environment, and that this equation becomes more acute as one travels up the different levels of secure care. This view was put strongly by one Charge Nurse in a medium secure unit:

> *On my ward it is safety and security first, involvement and anything else come second to this.* (staff)

Conversely, other staff and service users make the argument that increasing levels of involvement, participation and ways of working that emphasise therapeutic alliance should make shared knowledge of risk more likely, improving the service response to its effective management and,

ideally, encouraging service users to become more aware and responsible for their behaviour and, hence, limiting their own risk:

> *If you give people more choices it goes hand in hand with them becoming more able to exercise those choices responsibly … in the long-run I think this makes people more responsible. Yes, I'd say if we promote autonomy, on the whole we minimise risk* (staff)

For some staff, who hold the latter view their work in involvement initiatives makes a positive contribution to their sense of self and role, and adds to their fulfilment in their work. One staff participant reported that his involvement in involvement work had rescued him from becoming burnt-out in his role, opening up new vistas of job satisfaction and countering a previously cynical view of innovation and change.

Commissioning for involvement

> *If it was going to be something that people take notice of it needed to be driven by commissioning* (staff)

This theme observes the relationship between the commissioning process and involvement practices. To some extent this involved a narration of some of the local history of the development of involvement in the region, the appointment of two Regional involvement lead workers within the commissioning team, the establishment of the Involvement Strategy Group and the consequent involvement work streams and particular involvement initiatives. All of these elements were presented as essentially flowing from the work of the Commissioning team, with key individuals named as having a leadership or facilitation role in various innovations or as having on-going relationships supporting involvement across the particular units in the region. In addition to this, it

was felt that previous efforts to develop involvement initiatives were quite easily frustrated, and this was less likely to be the case with the authority of the commissioners behind it:

> *It gives the message to both service users and providers that involvement is important. To service users it gives the message that what they say is going to be listened to and that they get the opportunity to get involved in making some of those differences … and for managers and providers it is driven through the contracts … 'we have got to do this now' … and for clinicians on the ward … people think, we have been frustrated because we have wanted to be doing some of these things for so long and its only now we are actually getting a chance … (Commissioner)*

Both staff and service user veterans of the ISG and other meetings reported that the high visibility of senior commissioning staff in the setting up and running of the groups, their readiness to listen and take on board participants' views, and the way in which subsequent action was demonstrably brought back to the group were all influential in persuading people of the value of the meetings. Amongst service users there was a sense that the presence of commissioners and managers indicated the seriousness with which involvement was regarded:

> *You'll get general managers moaning to commissioners and you think yes, I'm part of something here … you get insights into the way things work.. the whole CQUINs and QIPP programme and such things*(service user)

For many of these ISG members, their initial disposition towards the ISG was ambivalent at the very least, and it was the progressive way that the commissioners and involvement leads conducted themselves and the proceedings which was conclusive in bringing people with them and promoting the value of the involvement work and strategy.

A mixture of positive and negative viewpoints was offered on the link between commissioned involvement initiatives and funding for services. The overwhelming majority valued the extent to which development and support for involvement was strongly associated with commissioning arrangements and the practices of individual commissioners. This would be typically expressed in terms of demonstrating the seriousness, importance and value of involvement and participatory practices. Furthermore, opportunities to influence the commissioning agenda for involvement directly through the ISG and share best practice across provider units via the work of the i4i groups,

and hence be well placed to meet CQUIN targets, was very much appreciated. More critical perspectives were concerned with concerns over the extent to which various involvement standards could be achieved within different units with different levels of security or whether the interests of statutory or independent sector providers were dealt with equitably.

The established forums for shared learning about best practice in involvement and the means by which this impacted upon funding via CQUIN arrangements was described as an essentially co-operative set of relationships. This was reported as in tune with participants' inclinations for how best to achieve innovation and entirely within the spirit of the wider goals of involvement. As pointed out previously, one of the key features of the work of the ISG that participants most valued was the sense in which the group brought people from across the region together, opening up possibilities for shared learning about involvement and other practices and strategic thinking based upon what had worked or not worked in other places. Extending this philosophy and practice of co- operation to developments designed to address CQUIN targets and drive up quality comes naturally to participants, yet is apparently contrary to some of the principles of competition which clearly underpin broader government policy regarding commissioning. This seeming contradiction was noted positively by a number of participants, who both valued opportunities for co-operation and saw co-operative practices as more compatible with their own personal values and vision for health care services in general.

There were some notes of caution raised over the relative lack of service user influence at national level policy framing, and that the adoption of good practice around shared pathways development, for instance, at a national level might be not so inclusive of effective user involvement as the Regional work to initially develop these ideas.

Accessibility of involvement practices and messages

This theme reflected a sense amongst participants in involvement initiatives, especially the ISG, that issues of accessibility were more often than not well attended too, and that on the whole involvement practices were sufficiently supported to enable full participation of a diverse group of service users. The visibility of efforts to promote accessibility is part of the appreciation of the ISG and to some extent extends the sense of solidarity and togetherness within the group:

> *To steal a phrase I feel we are all in this together … it is great to see the deaf guys and the guys with learning disability taking an active part … it must be hard for them, it is up to us to be patient … there is one bloke (name) who really struggles to get his words out clearly, but*

he is always willing and the staff help him, I wish I had some of his energy (service user)

That said, there were still instances where interviewees remarked upon opportunities to pay closer attention to accessibility issues and there was a felt need to continuously keep a high level of awareness of these such that unconstrained participation was always maintained.

There was a refreshing degree of support for accessibility strategies and techniques amongst participants who did not feel that they themselves suffered any impairment that would impact upon their level of involvement or participation. This translated into an expressed view that the process of involvement was better for all if efforts were taken to include people with say learning difficulties or hearing impairment, even if this meant that proceedings were slowed down. The fact that these efforts were being made added to participants' feeling that they were taking part in something that was worthwhile and congruent with the overall aims of the involvement process: for everybody to have their say and for this to be heard and acted upon.

Connecting with the *bringing it all back home* theme, some participants felt that more care could be taken by staff to render feedback from the ISG and other policy documents more accessible, especially in a context of learning disability. One of the few criticisms of the ISG arrangements related to the extent that numbers of service users were effectively excluded from attending because of their leave restrictions.

<u>Making sense of involvement: key learning points:</u>

- There are multiple lessons that flow from the appreciation of the ISG, these have been largely covered in the review of the case study (above).
- There is a need to pay further attention to how best to implement involvement practices across the board which effectively 'bring back home' to unit and ward level the best practice elements of the ISG. These tie in with the user-led recommendations for future practice (below).
- Service users in secure settings are capable of expressing a commitment to involvement that is regarding of others rather than self-serving. This is an interesting contradiction of some negative stereotypes of detained service users.
- Mutually respect and equality in a context of communication is a crucial feature of effective involvement activity. Getting the setting conditions right to optimise the quality of 'the talk' is an important aspect of opening up the space for involvement conversations and democratising decision making.

- Active participation in involvement initiatives can make a significant contribution to
- individual's recovery journeys.
- Involvement and work to promote involvement can generate strong emotions. Positive emotions help drive the initiatives. The management of negative emotions ought to be part of how best we can support individual practitioners through the 'emotional labour' of involvement work. Some staff and service users may take on too much and risk burning out or becoming over-stressed.
- Staff who embrace involvement practices can open up new avenues of job fulfilment for themselves.
- The support of a range of staff at ward and unit levels is important for the consistent uptake of involvement practices. There are complex factors at stake which can reflect working patterns and the organisation of the work of different disciplines. Knowledge of these complexities can assist in developing development strategies or staff training to further promote involvement.
- Scepticism about the value of involvement can be expressed in terms of threats to security and safety. An alternative view is that more thorough involvement practices can make risk management more meaningful and effective.
- The Regional Involvement Lead posts are an important driver of change and a model for best practice elsewhere.
- The involvement of senior commissioning personnel is crucial to raising the profile and credibility of involvement initiatives and their strategic importance. Making this part of the contracting process is typically well-received.
- National level strategy work could learn from the practices of the ISG and/or make use of this forum to ensure that tokenism does not prevail in national level meetings.
- Cooperation between service provider units works to drive up standards as part of the broader commissioning process and this is congruent with the ethos of involvement.
- Participants in meetings appreciate efforts to be inclusive and accessible, even if this slows the pace down.
- A consistent approach to backing up strategy meetings with accessible information down to ward and unit level is desirable.

- Need to explore possibilities of increasing opportunities for effective involvement in strategic meetings for those service users with more restrictions on their leave arrangements.
- CHATNET is one means by which accessibility concerns can be attended to and the reach of the ISG can be extended.

Service User led recommendations

The emergent findings of the research were discussed at a number of ISG meetings. A special meeting of the ISG was convened towards the end of the project to allow the group to influence the recommendations of this report. The ISG members took part in workshop activity to decide upon their priorities for the future focus of involvement initiatives. To this end they came up with an agreed list of priority areas as follows:

- Food/dining experience
- Access to telephone and internet
- Leave
- Increased and enhanced involvement at unit/ward level
- Transitions – moving on and between secure services and the role of care teams
- Ward round standards, similar to the available CPA standards
- A focus on individual care and individual therapy
- More focus on activities
- More family or carer work

In the course of deciding these priorities the ISG members also developed a *wish list* of other matters they would want to pay attention to. These included:

- A need to prevent services losing sight of the *My Future Plan* initiative. To re-energise this and clarify where it fits in with the shared pathway work.
- Wanting services to concentrate more on stipulations of CQUINs or contracts.
- To avoid losing momentum with different initiatives because of turnover of staff or service users. Sometimes previous initiatives can be lost sight of with the efforts to focus on other 'newer' initiatives.
- Would like to develop systems for mandatory 'joint training' to promote involvement facilitated by staff and service users involved in the ISG.
- A desire to make the most of CHATNETs potential.
- Address issues of uptake and shared good practice especially for smaller units.
- Make involvement a significant aspect of developing portfolio of recovery tools.

At this workshop the ISG members concluded by giving some thought as to how to make sure their priorities were addressed fully. They derived this strategy of things to do to make sure this happens:

- Undertake a regional project to ask service users what their current experience is? What is good, what not good? Who should be involved?
- Develop a questionnaire/survey by a core group of people.
- Organise a focus group supported by and run by neighbouring services – for staff and service users/family and carers. That is units audit each other's, rather than their own services.
- Make the most of opportunities to present and share experiences and practice when developing standards.
- Review and make use of the shared pathway experience.

Discussion

The findings of this study represent a substantial affirmation and appreciation of the process and impact of involvement initiatives across the Region. The experiences of the range of participants in the interviews and focus groups confirm a highly positive view of involvement and the various activities that have taken place and continue to be supported. The Involvement Strategy Group and the Regional Involvement Lead personnel in particular are most appreciated. The ISG appears to be a unique forum for the facilitation of involvement focused on secure care services compared with other regions of the UK. The means by the involvement initiatives are both led by the Commissioning Team and integrated

to the process of commissioning is also overwhelmingly valued. The participants were more critical of the extension of involvement practice thoroughly at unit and ward level, suggesting further work is required to optimise the comprehensive uptake of involvement practices across the board. That said, the various units we visited were welcoming, made strenuous efforts to facilitate access to participants, and most were able to showcase significant examples of local good practice and both staff and service users who are strongly committed to supporting involvement. Furthermore, it was clearly the case that key staff, including the Regional Involvement Leads, are aware of these issues and continually and creatively facing up to them.

For many of the participants the most often reported *critical incident* they recalled in their own accounts of the involvement initiatives was their initial (and other) encounters with one of the Regional Involvement Leads. Another oft cited key moment was the impact of meeting like-minded individuals from other secure units at an Involvement Strategy Group meeting. These moments were typically reported in terms of big personal impact, and it could be a sort of epiphany. For some, there was a significant turning point where suspicion or scepticism about the value of involvement was overturned on the basis of these encounters. The organisers and participants in the ISG and associated forums are deserving of much credit for their contribution to these meetings The scale and quality of involvement at the ISG appear to be unmatched elsewhere in UK mental health services, let alone secure services. The fact that the Commissioning Team have invested significantly in this and other structures and personnel to support involvement, and that this commitment is sincerely expressed at all levels of leadership, is an important feature of the success of involvement practices in the Region. Linking co-operative networking practices to the setting and mutual achievement of CQUINs targets represents an important innovation in driving up quality. This is very much valued by participants in the study, notably service managers, and in our view is a commendable deviation from the devotion to competition that appears to drive commissioning practices in other contexts.

The observations of the emotional flavour of involvement work demonstrate both the positive rewards of a job done well and the hard work that constitutes trying to make involvement a reality in secure service settings. There are multiple benefits for participants in involvement. Staff can gain more reward from their work and sustain a valued professional identity in terms of supporting individuals to progress through the system and feel one makes a positive difference in this endeavour. Effective involvement maximises cooperation and can reduce tension and conflict in caring relationships, which in turn reduces stress in the job. Service users obtain numerous benefits from participation in involvement initiatives, and these can connect with their recovery and sense of well-being. Involvement work also offers a challenge to negative stereotypes of secure service users, opening up the possibilities to gain more positive sense of self and agency within important

contexts, not least clinical decision-making. Such considerations are most obviously at work where services have concentrated on developing service ethos and practice models which emphasise involvement and relational principles. Garrow House is an excellent example in this regard.

The importance of communication and relationships in underpinning effective involvement were crucial features of many of the participants' accounts. We turn now to discuss these issues in the light of some of the theory and previous research flagged up earlier in the report.

One of the few previous studies of service user involvement in secure care services[60] confirms the rather pessimistic view of Hodge[67-69] that the quality of communication or empowerment on offer within psychiatric facilities is somewhat limited. When this happens the idea of involvement is devalued. Interestingly, these authors work with the theories of Jurgen Habermas, a philosopher who was most concerned with the empowerment potential of communication itself. He sees communication as the basis for actually changing things (see above). For Habermas[65, 66] the most important thing is that communication should not be restricted by differences in power between people. He was also concerned that communication should not fail because of a lack of mutual respect or a failure to connect if people see each other as different. The theme in this study that emphasises the importance of *the talk* is of interest in the light of Habermas's ideas. It suggests that the efforts taken to support and organise for involvement in the region have to some extent overcome the sort of objections about limited communication that previous critics have raised. That is, the conditions for more effective communication, leading to tangible change have successfully been put in place. This is best exemplified in the reflections on the Involvement Strategy Group, less so in regard to routine ward-based involvement or community groups. That said, a small number of staff remarked upon the desirability of democratic models of practice that could be implemented at ward level, such as therapeutic community approaches. Arguably, a crucial feature has been the emphasis placed upon staff and service users working together in alliance as part of the involvement process. As the research team were continually reminded in this project: it is not *service user involvement*, it is just *involvement*. This observation connects with Habermas's stress on the relational dimensions of effective communication for change, with staff-service user relationships central to the appreciation for involvement expressed by participants in this study. It also brings to mind the recent work by Richard Sennett[85], who makes the case for co-operation. For Sennett, it cannot be taken for granted that co-operation will happen, it must be worked at to be sustained and achieve full value.

Our findings suggest that service users want to be involved in decisions about their own care and progress through the system. An important aspect of this is the wish to be more fully involved in

decisions about key issues such as medication or leave. There is some evidence that service users feel least able to be fully involved in decisions about medication. Given that best practice should seek to maximise patient involvement in medication decisions, and that this is seen to make for better concordance with treatment plans, then this must be seen as disappointing. Successful involvement in medication decisions can take advantage of a person's own knowledge of what types and dose of medication have helped most in the past. This can be an important route to empowerment. Previous research of ours which studied advocacy report similar findings[86, 87]. In one of these, accounts provided by black men linked the impotence of disempowerment with the actual emasculating effects of medication. We suggested that advocacy could be a way of addressing this by intervening in medication decision making. This could have the effect of both empowering the individual service user and making a positive difference to the experience of medication, perhaps reducing distressing side effects. Hence there was the possibility to re-introducing 'potency' in different ways[88]. Arguably, directly improving involvement in clinical decision making ought to have the same effect.

When thinking about differences between care teams and their readiness to get to grips with involvement it might be useful to think about different forms of place and space. Some commentators point out differences in what they call social space. A social space includes features of the built environment and the quality of relationships between the people who are there. Clearly, different secure mental health settings will be different sorts of social space[89].

In an interesting study by Quirk and colleagues[90] different types of encounter between psychiatrists and service users were observed when they were discussing changes to medication. A key aspect of this was the extent to which the practitioners attempted to either negotiate or put pressure on service users to comply with their decisions. Three different types of conversation were noted. Some were described as *open*. In these, there was a free discussion of options and the service users would be fully involved in the decisions that were taken. Neither party would try and impose their view on the other. The opposite approach would involve the psychiatrist pressurizing the service user into accepting what was felt to be in their best interests from the practitioner point of view. In the middle where conversations were it was clear that the doctor had a prescription in mind and a cooperative patient was gently led around to accepting this. In terms of our study, it must be the case that effective involvement practices ought to make it possible that more discussions about important clinical decisions are shifted towards the more open form of communication. Arguably, this is evident in participants' experiences of the successful implementation of the CPA standards, especially where service users achieve a degree of control over the proceedings.

Again thinking about different types of social space, the different efforts to improve levels of involvement will have an impact. One such effect is to make the daily goings on in secure settings more transparent, so that all involved better understand what is likely to happen and what each other's expectations are. Important here is an open appreciation of how decisions will be made and how this will be communicated. When involvement practices have such an impact it is felt be service users to be associated with changes in staff behavior and attitudes. These are seen to become more respectful and the staff are more empowering in their relations towards service users, though this view is not extended to all staff. The care teams who are good at this were probably those who had a greater commitment to involvement to start with, including working practices that are more open and democratic. Places where there is a motivation from all involved, staff and service users, to make the most of involvement opportunities can be thought of as convergent spaces. In these spaces, positive ideas for change come together. The research team felt that Garrow House was a particularly well-developed example of this.

Not all service settings have this degree of convergence, and factors such as compulsion into care and the need for security and risk to be managed can complicate this. Arguably, such factors are most obviously at stake in secure settings. This might mean that relationships between staff and service users, despite a commitment to improve involvement, may not always be best placed to actually deliver on this. These relations might be better described in terms of contention rather than convergence. This means that the work to support involvement becomes harder and needs to pay serious effort to improving trust between staff and service users. Different perspectives and points of view between service users and staff need not be the enemy of involvement and positive change.

Being aware of tensions or contradictions can lead to the sort of creativity wherein new possibilities can be imagined or brought about[89]. Involvement could have a key role in enabling this if innovative practices begin to highlight such contradictions and promote reflection upon them. This has more chance of working if it starts with a commitment to strengthen practices which support the agency of individual service users and collective attention to rights.

A more critical view of involvement might see it less for its potential for empowerment and more as part of a set of processes that have the effect of pacifying service users, or helping them adjust to the system without too much fuss. This view is informed by the writings of Goffman[91] who used the idea of the confidence trick to make sense of all of the different ways that people adapt to failure or disappointments. Seen in this way, involvement might not really change the system for the better. It

might, instead, work to water down objections or smooth over upsets about the negative effects of being detained. From this perspective, involvement has a *cooling out* function which stabilises the system or returns it to the status quo. This connects with a wider critique of the social control role of psychiatry and psychiatric services or their function in containing public fears of madness associated with dangerousness[92, 93]. The minority of participants in this study who were cynical about involvement practices might be arguably attached to this sort of framing of the issues.

Of course, such critical views need not be the whole story. Given the positive appreciation for involvement in this study and the sincere efforts of many to make progressive and tangible changes within secure settings it would be rash to dismiss the sense of real value. Furthermore, it is worth celebrating the ways in which individual service users can have their agency enhanced promoting recovery and hope at times of significant difficulties in their lives[94, 95]. In this sense, involvement is one way I which the ideals of the recovery movement can be delivered. The impact of involvement, as evidenced in this study, connects with the key recovery principles of 'hope, control and opportunities'. Indeed, secure settings are an important place where control and personal agency can be taken away. So they are equally important places for doing something about this and concerted efforts towards improving involvement have a key role to play in holding out hope for people and opening up opportunities. Instead of seeing involvement as just a way of toning down the impact of a controlling system, we might be better advised to highlight its positive features. A pragmatic position would acknowledge the limitations of involvement but work hard to reinforce the extent to which it can make a contribution to empowering people to become as active as they possibly can in decisions and practices about their care.

Interestingly, the latter point relates neatly with an important finding from the study. For some staff the priorities of risk and risk management are opposed to the promotion of involvement. For other staff and service users, especially those committed to the idea of involvement, this premise is turned on its head. Instead, it is argued that risk management is better served by more effective and extensive involvement. That is, greater degrees of participation in decision making ought to result in better knowledge of risk for individuals, greater co-operation between service users and care teams, and improved concordance with treatments. Along with this, service users could assume greater responsibility to act in ways to minimise these risks. Given the prominence of risk as an organising feature of society as a whole (and its flip side, public fear) the importance of risk management in secure care services, it is not surprising that this is an important focus of staff concerns. The eventual extent to which involvement may be most thoroughly taken up and supported is dependent on developing a challenge to staff attachment to the *safety and security first* mantra. There also needs

to be a demonstration that involvement works without undermining security. In certain respects, the findings of this study suggest that many staff are already persuaded that this is the case and, for them, involvement not only works it also contributes to their job satisfaction and fulfillment in work.

Conclusion

This evaluation has found strong evidence of systematic innovation supporting different involvement initiatives across Yorkshire and Humber. The analysis of interviews and focus groups undertaken with various stakeholders has provided qualitative insights into the different ways in which people understand and appreciate these opportunities for involvement. The emphasis on the importance of communication for effective involvement in these accounts allows us to offer a persuasive rejoinder to previous criticisms of involvement in mental healthcare, where the quality of communication in these contexts was seen as insufficiently developed or supported to make involvement meaningful. That a contrary view can emerge in secure settings is of great interest, as one would expect such places to be most prone to the limiting effects of constrained communication and unequal power relations. The fact that participants in this study could speak of respectful and authentic communication for involvement and that some previously sceptical staff reported epiphany-like moments when they came to appreciate it, is testimony to the efforts of all those staff and service users who have worked hard over a number of years to develop involvement initiatives in the region. The hazard, that for some, involvement practices might appear to be part of a wider system of social control or pacification of dissent is worthy of acknowledgement; not least to be able to address this in staff training but also to galvanise efforts to as far as is possible avoid such an outcome and render involvement properly meaningful for participants.

The region-wide focus for involvement that is the Involvement Strategy Group is a key part of these developments and supports involvement on a scale and at a level of quality arguably unmatched in UK mental health services. Further work remains to be done to ensure comprehensive, consistent and systematic uptake of involvement in all units and down to the level of community meetings and individual involvement in clinical decision making. The user developed recommendations in this report are largely focused upon this task. Some of this will depend upon the achievement of change in the culture of organisations, not least in influencing sceptical staff to appreciate that involvement need not be seen as a threat to effective management of risk and security. The adoption of principles of relational security in some units and especially in women's services, as evidenced at Garrow House, are an important part of this change.

The points of view and recommendations of the ISG have helped inform these conclusions, with a priority being placed upon future strategy to invest in the thorough uptake of involvement initiatives at all levels, especially at the grass-roots ward level. Specific priority issues include: further attention to quality of food and the dining experience; improvements to access to telephone and internet; attention to the processes by which leave is organised and allocated; work focusing on transitions – moving on and between secure services; development of ward round standards, similar to the available CPA standards; more focus on individual care and individual therapy; more focus on meaningful activities; and development of approaches to support families and carers.

The close involvement of the secure services commissioning team, including the most senior personnel, has been crucial in ensuring the commitment of others and improving the quality of services with regard to involvement. It is worth reiterating that many national initiatives in secure services have their roots in the development of involvement in the Yorkshire and Humber region. The importance of the Involvement Lead posts cannot be underestimated, and these could be a model for good practice in other regions.

A number of key learning points have been outlined as they relate to the different analyses of involvement initiatives in this report. The main points are fleshed out in the discussion section and inform these conclusions. All of the learning points could be drawn upon to inform future strategic thinking within the commissioning team and the ISG. They could for example be taken up in training and induction processes. Ideally, such training would involve both service user and staff facilitators, as called for by the ISG participants in the workshop which concluded this research project.

The research team

Rosie Ayub

Rosie was one of the original Regional Involvement Leads for the Yorkshire and Humber Secure Services Commissioning Team. She has now taken the lead role on developing shared pathway approaches to care. She has an interest in creative approaches to group facilitation and has helped ensure that these methods have become part of the work of the ISG. For this project she supported Graham in the planning and facilitation of the ISG workshops that acted on the research and developed recommendations for future priorities

Graham Browning

Graham is an experienced project manager who has led a number of projects for Rethink during the last 5 years. These range from reviews of mental health day services, to development of strategic plans to combat worklessness among people with mental health problems and claiming Incapacity Benefit, to the facilitation of sub-regional strategic plans to combat stigma in mental health. Involving service users and carers has been a central part of each of these projects. Graham has a particular interest in sociodrama and action methods which use dramatic and interactive techniques to explore group relations and develop learning. He was recently involved in a collaboration between Rethink and UClan, with JD, MM and Comensus to develop and support a North West regional service user and carer network called *Collective Voice*. For this project, Graham planned and facilitated the ISG workshops that supported the research and developed recommendations for future priorities, he also contributed to data analysis.

Joy Duxbury

Joy is Professor of Mental Health Nursing at the University of Central Lancashire and leads the development of and provision for research and education in mental health within the School of Nursing & Caring Sciences. She historically has a background in forensic mental health although her focus in more recent years has been on acute adult psychiatric settings. An avid believer in the promotion of the service user view Joy has conducted extensive research into the role of the patient in the delivery of care. Accordingly the bulk of her research work and publications has been on staff

and patient perspectives on aggression and violence in inpatient services. Joy is a member of the European Research Group on Violence in Psychiatry and leads the mental health research group within the School of Nursing. In this project, Joy helped to support the planning and the data analysis.

Holly Fletcher

Holly has worked in secure services for three years now, and in mental health for eight years. Her role is one of very few dedicated involvement positions and she feels lucky to work in a specialist women's service, Garrow House, with a strong involvement ethos, and focus on relational security and the empowerment of women. This evaluation has highlighted how much good work is happening within Garrow and the region, however, there is a need for this good practice to be disseminated nationally. Of course, there is always more that can be done within Garrow House and the region, and Holly is glad to continue to be a part of this. She is passionate about working with women, promoting collaborative working and pushing for service users to have more choice and autonomy in their lives. Holly feels that the Involvement Strategy Group is organised and facilitated in a truly inclusive and a non-hierarchical way which should be held up as a shining example of good practice to the rest of the country. She looks forward to continue to be involved in all this good work for many years to come. In this project, Holly was an active participant in the project reference panel in Yorkshire and the relevant work of the ISG as it related to the research.

Fiona Jones

Fiona has lengthy experience of using mental health services and has been an active member of Preston Mental Health Service Users Forum. She has latterly volunteered with EmPowerMe (formerly Lancashire Advocacy) a service user led voluntary sector organisation and has also done significant work with national MIND. Recently she has taken up the position of research assistant working on an appreciative inquiry project to develop recovery orientated practices with mental health inpatient teams on Merseyside and this evaluation of involvement initiatives in secure units in Yorkshire. Along the way, she was nominated for Survivor of The Year 2004 and won the Eli Lilly Award for Outstanding personal Achievement and Inspiring Others to Achieve Their Goals in 2006. For this project, Fiona contributed to the planning, data collection, analysis and participated in the project reference panels.

Mick McKeown

Mick is Principal Lecturer in mental health nursing research, School of Health, University of Central Lancashire. He helped to set up and evaluate Comensus, the community engagement and service user involvement initiative in the Faculty of Health. He has published widely, including scholarly papers on different aspects of secure care, mental health nursing, service user and carer involvement and advocacy. Mick supported a service user writing collective to produce the text: *McKeown, M., Malihi-Shoja, L. & Downe, S. supporting The Comensus Writing Collective (2010) Service user and carer involvement in education for health and social care. Wiley- Blackwell, Oxford*. He recently completed his PhD by published work and focused upon staff and service user alliances in a context of involvement. In this project Mick was the lead researcher and contributed to data collection, analysis and working with the project reference panels.

Jolene McVittie

Jolene has been in the system for 25 years and realised over time that things needed to change. Lots of things have already changed so far and she hopes this research evaluation ensures that changes continue to be made into the future. She has been a service user involvement representative ever since this service started up and intends to carry this on in the community in the near future when discharged from secure services. Jolene was involved right from the beginning in focusing on involvement for women in secure services. This included significant input into establishing the Garrow House initiative in York which has pushed involvement initiatives even further forward. She was also one of the original members of the Involvement Strategy Group. For the future, she wants the initiatives that Yorkshire and Humber and the Involvement Strategy Group have been instrumental in developing to be implemented nationally and things to continue to improve for service users everywhere. For this project, Jolene was an active member of the project reference panel in Yorkshire, assisting with planning and the emerging analysis and also participated in the meetings of the ISG that focused on the research.

Sally Rawcliffe-Foo

In the course of this project Sally changed jobs, moving from a practice role to become one of the Regional Involvement Leads. Together with Joanna, she facilitates and supports service users and

staff to work together with commissioners to improve the experience as well as efficiency of services so people feel able to take more responsibility over their recovery. This work is done through the i4i networks, the involvement strategy group and at individual service involvement groups. Service users at these groups and workshops direct the way that services should go, and support this to happen with their experience and pro-active efforts. In this project, Sally was an active participant in the project reference panel in Yorkshire and the relevant work of the ISG as it related to the research.

Simon (pseudonym)

Simon has had multiple admissions to acute services up to 2006 and two admissions to secure services between 2007 and 2010. He has been well since then. He was the lead service user for My Future Plan, CPA Standards and PUPS and is a member of a service user theatre company. He wanted to get involved in various involvement initiatives, including this research project, to help other service users by improving services. He is looking forward to keeping well and staying involved with the Involvement Strategy Group and Forensic Catchment Group. He feels he is in an interesting position having moved out of services because he can reflect more on his previous experiences and use those reflections to find meaningful solutions to strategic problems. He is in a position to feedback to other service users in the community. Being out and doing well affords the opportunity to help service users on the inside with hope and inspiration for their future. This is also of key interest to staff who get to see his progress. For this project, Simon was an active member of the project reference panel in Yorkshire, assisting with planning and the emerging analysis and also participated in the meetings of the ISG that focused on the research.

Helen Spandler

Helen is Senior Research Fellow in the School of Social Work, and an associate of the PsychoSocial Research Unit (PRU), University of Central Lancashire. She has over 15 years experience of research in the mental health field. For example, she undertook research eliciting the views of young people who self harm (Spandler 1996); a national study of independent living and direct payments in mental health (Spandler and Vick 2004; 2005; 2006); a national study of arts, mental health and social inclusion (Secker et al. 2007; Spandler et al. 2007) and an evaluation of a self injury serviced in Bradford (Spandler 2008). Before doing a PhD she worked as a User Involvement worker at Having a Voice in Manchester. Helen is also a respected scholar of the history and organisation of the mental

health service user movement, is a supporter of the Survivors' History Project and authored the book: *Spandler, H. (2006) Asylum to action: Paddington Day Hospital, therapeutic communities and beyond. Jessica Kingsley, London.* In this project, Helen helped to support the planning and the data analysis.

Wayne Turton

Wayne has experience of being a service user in a low secure setting for people with learning difficulties. He has a strong interest in improving the accessibility of services so that they better meet the needs of people with learning difficulties. He has been a unit representative for involvement and regularly attends the ISG. For this project, Wayne was an active member of the project reference panel in Yorkshire, assisting with planning and the emerging analysis and also participated in the meetings of the ISG that focused on the research.

Joanna Wright

Joanna is one of the two Involvement leads for Yorkshire and Humber and has been working in involvement in secure services since 2000. Previously she had a role promoting involvement in research in Leeds. She has had a lead role in placing Yorkshire and Humber at the forefront of commissioning involvement initiatives and takes pride in the fact that many initiatives that have started on this patch have now been taken up nationally. She is also interested in the value of what has been learnt from this process in speeding up similar developments in other specialist mental health services. Joanna feels that involvement in secure settings needs protecting and replicating in other places. She particularly sees the benefits of having dedicated staff to help drive and support initiatives. For this project, Joanna was an active participant in the project reference panel in Yorkshire and the relevant work of the ISG as it related to the research.

Karen Wright

Karen is Principal Lecturer, School of Health, University of Central Lancashire and is course leader for the MSc in Personality disorder, she also maintains a clinical advisory role within an in-patient service. Previous clinical posts include Nurse Consultant in High Secure Hospital care. She is currently involved in a number of research projects with a focus on therapeutic relationships and attitudes

towards violence and aggression. She is course leader for the MSc. Personality Disorder. Her previous role as a mental health nurse within crisis and criminal justice services led her to seek better ways of responding to the needs of those in distress and ways of helping them to recovery. She is co-author of the ABC mental health assessment framework (Wright & McGlen 2008) employed by Lancashire Constabulary. In this project, Karen contributed to planning, data collection and analysis.

Preston reference panel

Throughout the course of the project a number of service users who are active in local involvement initiatives helped to support the work of the project. Some of had significant experience of secure services, others had experience of wider mental health services. People who attended these meetings included Russell Hogarth, Tracey (Milly) Millington, Phil Coombes, Louise Rawcliffe, John Lunt, Ernie Mallen, Graham Hough and Keith Holt.

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