

# *Beyond Our Expectations*

**A report of the experiences of  
involving service users in  
forensic mental health research**

**by**

**Alison Faulkner**

This is a report of the experiences of four research projects funded by the National Forensic Mental Health NHS Research and Development programme. Each of them involved users of forensic services in different ways. The aim of this report is to capture those experiences and to enable others to learn the lessons about involving service users in forensic mental health research.

### **Acknowledgements**

This has been an amazing opportunity, and first and foremost, thanks are due to the National Programme for Forensic Mental Health R&D for making it happen. Everyone spoke with enthusiasm and passion about the value of involving service users in their research, or, in the case of the service users themselves, of the experience of being involved. Thanks are due to all of the people I met whilst carrying out this piece of work: to Tina Cook and Pamela Inglis (thanks for your delightful hospitality), to Doug Macinnes, to Keith Halsall (who gave me a sometimes painful insight into the experience of being inside a forensic service) and to Tina Coldham, Paul Godin and Jacqueline Davies. And thanks to Steven, James, Gary, Chris, James, Conrad, Jacob, Eric, Steve for sharing your experiences with me. I hope I have done them justice.

*Alison Faulkner*

**A note on risk.** By virtue of the fact that they are living in or using forensic mental health services, it is likely that the service users involved in these projects have committed an offence in their past that might have been of a dangerous or violent nature. This was not a current concern of the projects and the potential risk posed by the service users was taken care of by the services concerned (for example, by providing staff escorts or occasionally, by not permitting them to attend meetings). The focus of the projects, and of this piece of work, was not on the risk posed by individuals involved in the research projects or by forensic service users in general, and consequently it does not feature in this report.

The research upon which this publication is based has been supported by funding from the National Programme on Forensic Mental Health R&D. However the views expressed in this publication are those of the authors and not necessarily those of the Programme or the Department of Health.

# Contents

Part One: Introduction	4
Part Two: An outline of the four projects:	6
1. Development of a Questionnaire to Measure Service User Satisfaction Within In-Patient Forensic Services - the Forensic Satisfaction Scale; <b>Dr Doug MacInnes</b>	
2. Forensic Service Users' Research Project; <b>Keith Halsall</b>	
3. Understanding research, consent and ethics: a participatory research methodology in a medium secure unit for men with a learning disability; <b>Tina Cook</b>	
4. Engaging Service Users in the Evaluation and Development of Forensic Mental Health Care Services; <b>Paul Godin</b>	
Part Three: Learning the Lessons	12
Part Four: Conclusions and Recommendations	19
Reports and further reading	
Appendix List of questions	22

## Part One: Introduction

In recent years, and particularly since the publication of the *Research Governance Framework for Health and Social Care*, in April 2001, there has been support and encouragement for public involvement in research from the Department of Health. The organisation INVOLVE, a national advisory Group funded by the Department of Health, exists to promote and support active public involvement in National Health Service, public health and social care research. The NHS Research and Development funding programmes have adopted different approaches to service user involvement, predominantly encouraging it through their funding criteria. Other funders, too (such as the Joseph Rowntree Foundation and the National Lottery) have made the involvement of service users in research a criterion for funding.

The National Programme for Forensic Mental Health Research and Development (NPFMHR&D) has a history of involving service users in the work of the programme, and of encouraging potential grant holders to involve service users in their research. To date, they have

- developed a service user involvement pack,
- involved service users as members of the advisory committee,
- engaged a service user review panel,
- ensured user involvement in research through the application procedures and report monitoring.

In April 2002, the Forensic Mental Health Programme invited expressions of interest from people with a track record of research into user involvement, to produce an expert paper on user involvement in forensic mental health research. This piece of work was undertaken by Alison Faulkner and Brigid Morris and published in 2002. The authors reviewed the existing situation regarding service user involvement in forensic mental health research, with reference to mental health research generally and user involvement and representation within the forensic mental health services. They concluded that there was considerable interest in the subject, although little evidence of service user involvement in anything more than audit and evaluation at that time. Furthermore they pointed to the difficulties of gaining access to forensic mental health services and service users, associated with the need to maintain security, confidentiality and the protection of individuals.

In 2003 the National Programme funded four research projects, all of which sought to involve service users in different ways. In 2006, I was invited to interview the researchers and find out what difference(s) it had made to them to involve – or work with – users of forensic mental health services. With the forthcoming disbandment of this specialist R&D funding programme, it becomes more important than ever to ensure that the lessons learnt from this innovative practice are analysed and recorded.

The aim was to write an accessible report which would aim to:

- provide a synopsis of the main findings from each of the projects;
- summarise the lessons learnt regarding service user involvement in forensic mental health research;
- identify good practice;
- propose recommendations for the future of user involvement in forensic mental health research.

## Methods

I drew up some initial questions (see Appendix A) based on previous experience (Faulkner 2004; Faulkner and Morris 2003) and contacted the four principal investigators by email in the first instance. Subsequently, I interviewed two researchers over the telephone, and met and interviewed the others in person. In addition, although it was not in the original project brief, I was fortunate enough to be able to meet some of the service users involved in two of the projects. These are the people I spoke to:

Project 1: Doug MacInnes (PI\*)

*Development of a Questionnaire to Measure Service User Satisfaction within In-Patient Forensic Services - the Forensic Satisfaction Scale*

Project 2: Keith Halsall (PI) and Tina Coldham

*Forensic Service Users' Research Project*

Project 3: Tina Cook (PI) and Pamela Inglis (researchers) and five service users: Steven,

James, Chris, Gary, and James. (also members of staff accompanying the service users)  
*Understanding research, consent and ethics: a participatory research methodology in a medium secure unit for men with a learning disability*

Project 4: Paul Godin (PI) and Jacqueline Davies and four service users.

*Engaging Service Users in the Evaluation and Development of Forensic Mental Health Care Services*

\*Principal Investigator

I took notes at each interview and meeting, and subsequently wrote up these notes for the purposes of writing this report. In addition, I collected any reports and documentation available on each project, and read them to ensure that I knew the formal as well as the more informal stories I was collecting from people. In reaching my presentation of the lessons learnt from the projects, I was careful to be systematic in my appraisal of the information. Although this could in no way be described as a research project in its own right, I placed the information gleaned from the conversations and meetings into a table from which I could draw themes and issues across and between the projects.

In this report, Part Two provides a brief outline of each project with its findings and a summary of the ways in which service users were involved. Part Three examines in more detail the experiences of researchers and/or service users of the process and outcomes of being involved, their views and feelings about the projects. Part Four presents some conclusions and recommendations drawn from this piece of work, about the involvement of forensic mental health service users in research.

## **Part Two: Background to the Four Research Projects**

The aim of Part One is to give a brief outline of each project, with a summary of its findings and of the ways in which service users were involved, as a context for Part Two. These outlines do not do justice to the detail and rigour of these projects, all of which will be producing (or have already produced) reports to be placed on the National Programme for Forensic Mental Health R&D website: <http://www.nfmhp.org.uk/research.htm>

### **Project One: Development of a Questionnaire to Measure Service User Satisfaction Within In-Patient Forensic Services - the Forensic Satisfaction Scale - Dr Doug MacInnes**

#### 1. An outline of the project

This project had two main aims: firstly, to develop a questionnaire to assess levels of satisfaction with forensic inpatient services, and secondly, to ensure that active user involvement took place throughout. In many ways this was the most conventional of the four projects, in that it had clear research aims and methods and an outcome in the form of the FSS (Forensic Satisfaction Scale). The project engaged focus groups to develop the pilot questionnaire and then a combination of questionnaire methods and statistical analysis to arrive at the final version.

#### 2. Findings

The first stage of the research involved a series of five focus groups to assess service user views about the themes and issues important to service users in assessing their satisfaction with the services. These were analysed and checked back with the groups to produce seven themes:

Staff interaction	Finance
Rehabilitation	Safety
Milieu	Gender
Communication	

These themes were then used to form the basis of the pilot questionnaire (Forensic Satisfaction Scale or FSS): a 95 item scale. This was completed by 63 participants from the same forensic units. They also completed another satisfaction scale (the Verona Service Satisfaction Scale or VSSS). Statistics were used to examine the satisfaction scores, the differences between the two scales and any differences in responses between different groups of service users. Factor analysis was used to test the relationship of the questions with the original themes and to guide development of the final questionnaire. The final questionnaire has 60 items. Analysis found good consistency for four of the themes: staff interaction, rehabilitation, milieu and communication.

#### 2. Service user involvement

Three service users were involved as part of the project team throughout the project, from inception to dissemination. 'Professionals and service users worked collaboratively throughout the project proving that service user involvement in research is achievable in forensic mental health services' [REF]. Service users participated in developing the research

protocol, agreeing the study design, in identifying and inviting participants to take part in the project, in the data collection, in the data analysis, and in writing up and disseminating results.

## **Project Two: Forensic Users' Research Project – Keith Halsall**

### 1. Outline of the project

This project was highly innovative in that the principal investigator, Keith Halsall, is himself an ex-user of forensic mental health services. He sought to discover the concerns of forensic service users through user led research, using action research methods. The objectives of the project were:

1. To address the concerns of users of forensic services, by the hitherto seldom used method, in forensic services, of user led research.
2. To produce a value for money, relevant, well researched and important document.
3. To involve service users at all stages and recognise their contributions with remuneration.
4. For the research to improve the quality of mental health services for users of forensic service users. To improve their health, their rehabilitation and potential for happy lives.
5. To disseminate the results effectively, in order to provide value for money, and make good use of the contributions of all concerned.

Two male and one female service user researchers, skilled in interviewing service users, were involved in carrying out the project. Interviews and focus groups were carried out in both the male and the female units of the forensic service under investigation. Non-participant observation methods were also employed. The researchers were reflexive in their approach, which meant that they gave consideration to the way in which they worked and reflected on their own participation in the research process. Following the interviews and focus groups the team drew up a questionnaire of 21 items to ascertain the men's research priorities. Finally they designed a short questionnaire of four items to find out the service users' views of the research itself.

### 2. Findings

The research found eight main themes of concern to the men: the quality of nursing, boredom, (too much) psychiatric medication; illicit drug use within the unit; food; peer support; desire for freedom; and a positive comparison of this unit with others. Implicit in the findings was a need for more emotional support. The few women were very much more appreciative about the care and treatment they were receiving in their specialist unit. They also had concerns about the availability of culturally appropriate food and boredom. Both men and women appreciated being involved in the research and found it useful.

### 3. Service user involvement

As stated above, this project was different from the others in that the principal investigator was an ex-user of forensic services; his co-interviewers on the project also had experience of using mental health and/or forensic services. They carried out a pilot in the women's service and then carried out 11 individual interviews and 6 focus groups in the men's service.

The researchers were careful to take the progress and findings of the research back to the service users regularly, to ensure that they were genuinely reflecting their views and experiences. This included taking the final report back for comments.

## **Project Three: Understanding research, consent and ethics: a participatory research methodology in a medium secure unit for men with a learning disability – Tina Cook**

### 1. Outline of the project

The aim of this project was to develop and evaluate a framework for engaging residents in a medium secure unit for people with a learning disability with the nature of research, consent and ethics in participatory research. The research sought to:

- identify the key processes that enable men with complex learning needs to understand: the nature of research, consent, the ethics of research, the possibilities of research, how research findings can be used, and dissemination of research.
- produce two sets of information: one for people with learning disabilities on ‘research, consent and ethics’ written by the research participants and another for those who research with people with learning disabilities on the principles for gaining informed consent.
- add to the current small body of knowledge on supporting informed consent to research and dissemination of research with people with learning disabilities and offending behaviours.

The researchers, Tina Cook and Pamela Inglis, met with the men on a number of occasions to discuss and find ways of understanding some of the key terms used in research. In order to demonstrate aspects of research to the men, they invited a local service user group to make a short DVD about research. This was shown at each meeting. Together they found different ways of explaining and understanding research terms, both visual and verbal, and kept meticulous records of what took place at each meeting. These notes were read out at the next session, and pictures were used as part of the records.

In this medium secure environment, the men were obliged to be accompanied by staff escorts. As a result it was a specific intention of the research that some members of staff also became engaged in the project, both to help the men with their research work and in their own right as researchers and learners. Staff help was particularly important for those who found it difficult to understand the research and the discussions that took place at the meetings. It was important to be able to go over the information again and again, and to present it in different ways.

### 2. The findings

The team found different ways of presenting and understanding research terms together. The box below gives an example from one of the meetings. Their experience is going to be written up in the form of guidance for people with learning disabilities about research and for researchers about involving people with learning disabilities in research. A central theme is the concern about obtaining genuine informed consent. Emerging findings from the project include the fact that this collaborative approach is more likely to identify practical and usable findings, issues that can be directly applied in the forensic setting or research environment.

**Consent:**

1. consent is a difficult word, it might be better to say agree or disagree.
2. it is about choosing whether or not to take part in research,
3. and choosing what information is shared with others.
4. The information we need to make a choice and that it should be understandable.
5. that one of the first questions we should ask is what is research and why do you want to do the research.
6. If we say no to research we may be treated differently.
7. It is sometimes hard to say no.

### 3. Service user involvement

This was a complex participatory project; the team worked together to find ways of understanding research as an activity as well as understanding key research terms, such as ethics, informed consent and dissemination. Four of the men subsequently registered at a local University to obtain work-related credits.

## **Project Four: Engaging Service Users in the Evaluation and Development of Forensic Mental Health Care Services: Paul Godin (PI) and Jacqueline Davies and team of service users.**

### 1. Outline of the project

This project aimed to engage service users in evaluating forensic mental health services throughout the research process. In acting as both researchers and researched in producing and analysing their own data, they carried out what they came to refer to as ‘mining our own experiences’. The researchers recruited people to the project who had used a wide range of different forensic services; at the time of the research they were living in rehab. wards, hostels and flats. As a result most of them had greater freedom to attend meetings outwith the forensic settings than service users in the other three projects. They met regularly as a group, initially with an agenda and minutes, although this structure did not continue throughout. In most meetings the men shared their experiences of different forensic mental health services, whilst some meetings took the form of research training, for example on focus group methods. They devised the questions for the focus groups which they conducted with themselves:

1. How and why is the experience of using forensic mental health care/services fundamentally bad?
2. How can forensic mental health services be improved?

3. How can forensic mental health care service users move forwards from the experience of being in forensic mental health care?

In addition, they interviewed a policy-maker and analysed the data produced together with the members of the advisory group.

## 2. Findings

Whilst the findings of this project reflect the assumption in the above questions that forensic services are ‘fundamentally bad’, the researchers and service users were able to make comparisons between services about good and bad practice. The men talked about the negative attitudes of staff including incidents of abuse, the difficulty of feeling any hope for the future, a lack of honesty and trust between staff and patients in services, insensitivity to religious and cultural needs, racism, and a concern about the effects of (too much) psychiatric medication. In answer to questions about improving services, they identified a need for therapeutic relationships between staff and patients, in particular with regard to trust and honesty. They talked of the need for services to help them to overcome the social stigma they faced, and to help them find employment. They also talked about the lack of hope and the despair they felt when living in forensic services... *‘felt like they were deep within a hole from which there was little chance of getting out’*.

## 3. Service user involvement

Service users were recruited through a number of methods, coming together as a group for the purposes of this research. In some ways, since the service users were both researchers and researched in this project, it was equivalent to doing research *on* research and hence has some similarities with Project Three. Researchers talked of ‘blurring the boundaries’ between researchers and service users. The service users shared their experiences of forensic services, and gained research training, eventually devising the questions (see above) and then carrying out the focus groups with themselves. They also took part in the analysis and the report writing. The service user researchers were also invited to attend the University department’s research seminars, an opportunity that they clearly appreciated. They took part in disseminating the findings, contributing to the report and accompanying DVD and speaking at conferences.

## Summary

Each of these projects was unique and innovative in its own way, as can be seen from the outlines above and their respective research reports. Nevertheless, there were some strong common themes, both from a methodological perspective and in relation to research findings. Project Two, led by Keith Halsall, was the only user-led project and Project Three, led by Tina Cook, the only one carried out with people with learning disabilities. Projects One, Two and Four all had something to say about the nature and experience of forensic mental health services; projects One and Two had sought the views of people outside their immediate project teams. Projects Three and Four both took their research team as their primary source of research data, engaging people in a process of personal exploration as well as of further understanding and sharing of experiences; the group process therefore was of primary importance. Part Three of this report explores the more substantive themes to emerge from the four projects.

**Table One: The Projects in Brief**

	<b>Project One Doug MacInnes</b>	<b>Project Two Keith Halsall</b>	<b>Project Three Tina Cook</b>	<b>Project Four Paul Godin</b>
<b>Location</b>	Three forensic units in the South East	Medium secure unit S.E.	Medium secure unit for men with learning disabilities in N.E.	Community, S.E.
<b>Brief aim</b>	Formulation of a questionnaire to establish satisfaction with services (FSS)	User led research into people's views about services	Exploration of ways of explaining and understanding key aspects of research	Exploration of the group's experiences and views of services
<b>Methods</b>	Focus groups, interviews, questionnaire development.	Focus groups, interviews, questionnaire.	Participatory action research: group work, video, visual images	Group work, focus groups
<b>Key Findings</b>	Staff interaction Rehabilitation Milieu Communication Finance Safety Gender	Quality of relationships with staff, boredom, psychiatric medication, the use of illicit drugs; desire for more freedom, food, & positive comparisons.	(not reported as yet)	Relationships with staff - lack of trust & honesty, racism, concern about psychiatric medication, lack of hope for the future.
<b>Outputs</b>	FSS questionnaire, report, conference presentations, user-led presentations to user groups	Report, presentations at conferences	Practical guides to explaining research, presentations	Report, DVD, presentations at conferences, further articles planned.

All reports will eventually be placed on the FMH website: : [www.nfmhp.org.uk/research.htm](http://www.nfmhp.org.uk/research.htm)  
 At the time of writing, Projects One and Four have reports placed on the website.

## Part Three: Learning the Lessons

The lessons learnt from these four projects have been divided into three main categories: the benefits of service user involvement, the challenges to involvement and the facilitators to involvement. In addition, there is a fourth category which I have included in order that we can hear the views and experiences that forensic mental health service users expressed about the services themselves. There were such strong common themes in this last category that it seemed vital to include them.

Firstly, however, it seems important to acknowledge that all four projects achieved what they set out to do. They did involve users of forensic mental health services in their research, albeit in different ways and with different aims in mind. This at least shows us that it is possible. That it was also a powerful and positive experience for nearly all of the researchers and service users is also a significant lesson: one researcher said it was '*one of the most enjoyable pieces of research I've done*'; another that the service users had exceeded expectations. A service user involved in one of the projects said '*if I had the chance, I'd do it all again*'; another said the experience had been '*unremittingly positive*'. It was also hard work and, as we shall see, there were some significant barriers to involvement as well as achievements to emerge from it.

### 1. The Benefits of Service User Involvement

One of the key questions that people (primarily researchers) ask about user involvement in research is: 'Does it make a difference?'; they may doubt the value of user involvement, or, more seriously, believe that it compromises the quality or rigour of research. Those of us who believe in the value of user involvement often find ourselves defending it without a great deal of 'evidence' to support our views. Consequently, one of the questions in my mind in carrying out this piece of work was whether or not these researchers felt that involving service users had changed the research for the better (or worse) – whether, from their point of view, service users had increased, or indeed compromised, the quality of their research.

However, there are broader issues to consider: what were the benefits for the researchers themselves, for the service users who were involved, for the services, staff and wider community of (forensic and other) service users. The discussions pointed to another major benefit: in raising awareness of the issues faced by and the capabilities of forensic mental health service users, these projects were contributing to challenging stigma, both within and beyond the forensic services.

#### **Benefits for the research**

The researchers all believed that the involvement of service users had resulted in significant benefits for the research itself.

- **Data collection:** Two of the projects (One and Two) involved service users in collecting data from their peers, whether through interviews, focus groups and/or questionnaires. Researchers in both of these projects gave the view that involvement resulted in better quality data and/or the opportunity to engage more or different people in providing that

data. For example, one said ‘*people were more relaxed with us, more honest*’. In Project One, the service users were responsible for publicising the project around the wards and engaging people in it; as a result, it was felt that the project engaged some people who would not normally take part in research.

Where the approach taken was both qualitative and reflexive (projects Three and Four) the researchers felt that the research produced data that was both rich and insightful.

Researchers in both projects felt that their approach enabled them to gain in-depth knowledge and information that would not have been possible without the active participation of the service users concerned. Project Four gained considerable insight into the men’s experiences of different services through a process they came to refer to as ‘*mining our own experiences*’.

- **Analysis and report writing:** Again, researchers from Projects One and Two felt that the analysis and interpretation of the data benefited from service users being involved. Each could point to ways in which they had altered their own perceptions of a finding or the way in which something was described in the report. One example was given in Project One: when ‘safety’ did not emerge as a major theme, the researcher questioned this but was assured by the service users that safety was not a major issue in this particular unit. In Project Three service users have been doing the analysis – deciding which are the important themes and which have fallen by the way side. In Project Four the service users were again actively involved in the analysis of their own group discussions and the work they undertook with members of the advisory group and the interview with a policy-maker. The service users also contributed to the report and the DVD produced to accompany it.
- **Outcomes:** Project One produced a questionnaire to assess satisfaction in forensic services: the Forensic Satisfaction Scale which is being used in several other forensic settings in England, Wales and Ireland. Project Three has yet to publish its outcomes, but they will be producing an accessible guide to explain key research terms to people with learning disabilities. Projects One, Two and Four have all provided valuable insight into the lives of people using forensic mental health services, insight that should inform the development and delivery of services in the future. The value of this insight into the experience is perhaps to appreciate the central role of relationships of staff and the themes of trust and hopelessness that predominate in the discussions. (See 4. Findings below).
- **Terminology:** It was felt that involving service users in the research improved the use of terminology with research participants in various ways: the language used to explain the research to others, and the wording of questionnaires was made more appropriate and accessible. This was, of course, the primary aim of Project Three: to explain research terminology in ways that would be accessible to people with learning disabilities – in such a way that fully informed consent could be obtained.

### **Benefits for the (non-service user) researchers**

From the start of this piece of work, it was notable that the researchers were all enthusiastic, often passionate, about their experience of taking part in this research. As referred to earlier, one described this as ‘*one of the most enjoyable pieces of research I’ve ever done*’.

- **Learning to share power and control:** Researchers in all four projects spoke in different ways of learning to share power and control of the research process with the service users. This was not always easy, but it was a vital part of ensuring that the project was genuinely collaborative. In Project One, the team devised a democratic way of making decisions (see below) and the researcher confessed he had at times been voted down when he believed he was right! Aspects of learning to share control involved

working at a slower pace, being prepared to take time over things, particularly in the early stages; being prepared to compromise about how the research was done, what questions were asked; and generally blurring the boundaries between ‘researcher’ and ‘researched’.

- **Enjoyment, satisfaction:** Nearly all of the researchers talked with enthusiasm about their projects, that it had been a satisfying, even enjoyable, process.
- **Insight, understanding:** This was an explicit aim in most of the projects: that the research should benefit from the added insight or understanding afforded by involving service users. One researcher in Project Four described her experience of previous research in forensic settings, where she felt that the views and experiences of service users were barely touched: *‘I felt there was another story to be told’*. She felt that the approach taken by this project had enabled these stories to be told, and thus enabled her to understand a great deal more about them.

### **Benefits for the service users**

The service users I spoke to directly (from Projects Three and Four) were also enthusiastic about their involvement in the projects. They described many benefits, primarily talking about learning skills and developing confidence as well as learning to work together in a group and developing trust and respect for each other.

- **Learning skills, developing knowledge:** Service users had received some basic grounding in research skills and some had also received knowledge-based training (in Project Four service users had attended University research seminars). In Project Three, the sessions had all focused on explaining research terminology, which some had made great strides towards understanding. In this project also, some wished to move on to explaining their learning to others, and four were working on achieving credits for Accredited Work-based Learning; the CPD module at level three gives them 10 credits at A level standard.
- **Working with others:** Both of the projects based on working together as a group (Three and Four) had resulted in benefits for the service users in this respect. One person said he had learnt to talk about his experiences without getting angry. Another said *‘learning in a group is quicker and it’s more fun’*. Service users in both projects talked of the value of building trust and respect as a group, and of recognising that each had something to contribute. In Project Four, the group valued finding shared experiences and the opportunity to reflect on these together had been a powerful learning experience for them.
- **Confidence:** In all of the projects, people mentioned gaining confidence as a benefit for the service users. For some this was based on a sense of achievement and for some it was a result of meeting and being with other people. The latter was particularly significant where people were living in the restricted environment of a medium secure unit.
- **Stepping stone to work:** In Project Three, four of the service users were registered at the University for accredited work-based learning. In Project Four, three of the service users talked of the value of the project being a ‘stepping stone to work’. For one in particular this has become a reality. He spoke eloquently about how the project had given him payment, a commitment to regular hours and had made him known to the tax office. He is now self-employed and living in the community.

### **Benefits beyond the project**

- **Raising awareness, challenging stigma:** For all of the people I spoke to, one of the key themes to emerge was the importance of raising awareness about the potential these projects could reveal within the lives of people using forensic mental health services. It

was important for all of the researchers to be able to reach a wider community of staff working in forensic services, researchers and policy makers beyond these services and even society as a whole, that people are capable of far more than we often give them credit for.

- **Staff:** Project Three highlighted the potential for these projects to have benefits for members of staff in forensic services. Since the service users were accompanied and supported by individual members of staff, these staff members were also able to learn about research if they wished to. Both researchers and staff said that they might make more use of this opportunity if they were to do a similar project in the future. In addition the project raised the awareness of some members of staff about the capabilities and the potential of the service users involved. One member of staff said of the service users: *'they have excelled... we underestimated the people here'*.

## 2. Challenges to Involvement

- **Time:** Time was unquestionably the biggest challenge for all four projects. All could have done with more time to complete, primarily due to the early stages of engaging people, getting to know people and building a sense of trust and understanding. In a couple of the projects, entering a secure environment presented its own challenges in this respect: shift changes or unforeseen events might mean that staff or service users were not available on the arranged days necessitating a return visit. However, Project Four also faced challenges at the recruitment stage, finding it difficult to engage people to become involved.
- **Project funding (i):** A shortage of funding was an issue for three of the four projects. To some extent this was connected with the additional time needed for the research. Whilst three of the projects were cushioned by the resources of the establishments they worked in, Keith Halsall was working alone and could not rely on this kind of back-up. This highlights some inequity in the funding for isolated researchers compared with researchers working in Universities and other establishments.
- **Project funding (ii):** There is an issue here for both commissioners and researchers in considering what is feasible within the funding available. However, careful consideration does need to be given to the funding made available for this type of research; it takes more time and money to achieve quality research taking into account the extra demands of service user involvement.
- **Payments and fees:** Most of the projects suffered at the hands of bureaucracy when it came to making payments to service users as researchers and participants in the research. One issue was the requirement to pay into a bank account, which some people did not have access to. Another was the painfully slow payment of fees and expenses, which could take weeks and even months. In a couple of cases, it is likely that this contributed to people dropping out.
- **Access and communication:** Access and communication were significant issues for projects working with people living in secure environments. Even after initial access had been successfully negotiated, it was often difficult to get messages to and from the service users inside, and to arrange meetings or groups from outside. Members of staff who took on a liaison role were immensely helpful in this respect (see below).
- **Staff:** Members of staff were significant in their ability to facilitate or hinder the research projects. A couple of projects spoke of the positive contribution of some staff who had become personally interested in the research; however, the opposite was also true. Some

staff could adopt a powerful gate keeping role and make it difficult for researchers and service users to communicate or to engage with each other and the project. In addition, a couple of the projects were unable to achieve privacy of the research from staff whether from practical or (predominantly) security reasons.

- **Support & supervision:** The issue of research supervision was raised in particular by Keith Halsall, and is undoubtedly influenced by his lone researcher status. Adequate support was also a significant issue, as it is for anyone who has their own personal experiences relating to the research they are undertaking or the environment in which they are working. It is important not to underestimate the potential emotional impact of re-entering this environment.
- **Literacy:** A couple of the researchers mentioned the challenge presented by the fact that they had underestimated the literacy needs amongst users of forensic services. This was an issue both for working with service users as co-researchers, and for service users as participants in the research. It seems that the important issue is not to make assumptions about people's literacy – whether positively or negatively.
- **Gender:** Most of the people involved in the four projects as service user researchers and as research participants were men. Although this reflects the population of forensic mental health service users, it has been a challenge for some of the projects to work with or gain the views of women. However, Project One reached female participants, both in the focus groups and the survey; a key issue for these women concerned the potential of some male service users to be abusive or threatening. No significant differences were found in their responses to the questionnaire. Project Two worked with a small number of women in one service, and found that the issues for women did seem to be quite different. It is for a future project perhaps to look at this in more depth.
- **Endings:** One of the difficulties noted by service users in Project One was that when the project came to an end so also did their research role. It proved difficult to obtain ongoing funding to develop the study or maintain the interest of the service users concerned.
- **Peer review:** The researchers in one project felt that their final report had been severely and unjustly criticised by reviewers. They felt that the reviewers did not understand the nature of the research methods they had adopted. They included some reference to this in their revised report and wished to use the comments as further data for analysis, but were unable to do so as the reviews were regarded as confidential.

### 3. Facilitators to involvement

- **The services and the staff:** All projects spoke of the value of gaining the support of both services and frontline staff. The former was more important at the start, and the latter during the work in progress. Researchers spoke very positively about the way in which some staff had become involved and helped both themselves and the service users. Where researchers needed to enter a secure environment each time they had a meeting, group or interview, staff were vital in enabling this to happen and helping with practical arrangements.
- **Taking time to build up trust:** This was vital to both the work with service user researchers, and to gaining the interest and involvement of service users as participants. In a couple of projects, it was felt that spending time on this helped to reach different and often excluded service users in the research. One of the projects took place on neutral territory: they were able to meet in the University rather than in one of the forensic services and they felt this helped to build up trust between them. Having ground rules

about confidentiality also helped in this process: being assured that what you say is not going to be fed back to staff was of key importance to people feeling free to give their views and talk about their sometimes painful experiences.

- **Choosing your research topic:** Several of the researchers felt strongly the value of researching something of personal and current relevance and significance to service users. They felt that asking a reasonably simple question such as ‘What is it that concerns you now?’ or ‘What do you find helpful?’ was more likely to engage people. In Project Four, the service users decided to ask three main questions of themselves, all of which were focused on past and present experiences of services.
- **Being involved from start to finish:** It was considered more likely to engage people in the research if they had some input into the project from the start, initiating it or devising the questions. Researchers felt this gave people more ownership of the project and led to a greater commitment.
- **Payment for work done:** Researchers believed in the importance of paying people or rewarding people appropriately for work they had done, as did the service users in Project Four who gained a sense of value and worth from the experience of being employed as researchers on the project.
- **Food, refreshments:** all of the projects mentioned the value of providing food and refreshments for meetings and visits; this varied from chocolate biscuits to Caribbean meals. Food is a simple way of rewarding people, but it also seemed to act as a facilitator in bringing people together as a group or community, helping to build trust between service users and researchers, or the researchers and the researched.
- **Negotiating differences:** it seems likely that in a group of people with different perspectives there will be differences of opinion. In Project One, they developed a democratic voting system for managing this situation and on occasions the researcher or supervisor were voted down. Similarly, in Project Four, the researchers thought it important that the service users were not outnumbered in the group and consequently able to override the opinion of the researchers on occasions.
- **User-led research:** the two researchers in Project Two both felt that it had been enormously powerful for Keith to be able to say ‘I have personal experience of forensic services’. One of the values of this, they felt, was that it gave some people who lived without much hope, the opportunity to see that someone had moved on and was able to live and work in the community. Another important benefit was that they felt it enabled service users to relax and to be more open and honest about their views and experiences.

#### 4. Themes from the findings

There was considerable overlap in the themes to emerge from Projects One, Two and Four regarding service users’ experiences of forensic services. Findings from the quantitative methods used in Project One (clustered themes of staff interaction, rehabilitation, milieu and communication) are borne out and given more depth by the themes arising from the qualitative approaches used in Two and Four. However, the findings from Project Three are quite different due to the nature of the project and cannot be combined with the other three projects (see below).

- **Hope & hopelessness.** The projects shed light on the fact that many people living in secure forensic services are living without hope. Some are unable to see the way out of their situation or to have any hope for the future. In some settings, it would seem that

people were not getting help with dealing with this, or with the profound effects of guilt felt by some. In other settings, the presence of caring and helpful staff, and a clear focused rehabilitation programme, were able to give people hope.

- **Relationships with staff.** In three of the four projects, people spoke with some passion about the need for more caring and therapeutic relationships with staff, a need for more honesty and trust. They often felt suspicious of staff motives and several could point to examples of abuse. One person advocated the psychological testing of new staff to screen out people who may have a tendency to misuse their power.
- **Clarity about rules:** One of the issues underlying the above was a lack of clarity or honesty about the rules and regulations, about the things that you could do to win trust or gain greater freedoms.
- **Basic needs:** Users of forensic services are preoccupied with concerns about their basic needs. Issues that recurred were: food, access to different levels of freedom, boredom, a sense of a life beyond the services that might involve somewhere to live and a job.
- **Gender:** There is some suggestion that we may be in danger of losing the voices of the women who are living in forensic mental health services. Project One successfully reached women and did not find significant differences in their views about the services involved. Conversely, Keith and Tina (Project Two) suggested that the women seemed more vulnerable and more reluctant to share their views and experiences than the men in the same setting. However, they were more appreciative of the care and treatment they received than were the men. More work needs to be done to ensure that women have the same opportunities as men to be involved in research (if they wish to), perhaps through working with such organisations as WISH (women in special hospitals).
- **Race and racism:** Several of the service users spoke of racism within forensic services – racism between people from a range of different racial and cultural backgrounds. One service user in Project Four said he would like to be involved in research in this area.
- **Drugs:** Project Two found that illegal drugs were a major issue for people in the settings they were visiting. It seemed that drugs were easily available which made it difficult for those who were trying to come off them. This was confirmed by service users in Project Four, but less so by Project One where the main drug of concern was cannabis and participants did not view drugs on the unit as negative or threatening.
- **Project Three:** This project found that the men with learning disabilities were well able to participate in their exploration of research, aided by the use of pictures and a DVD, the use of repetition and the careful use of notes taken at meetings. As with other projects, providing refreshments in the form of coffee and biscuits or cake also facilitated the process of team-building. The project also shed light on the complex issue of people's capacity to give informed consent. For example, a person with good literacy skills may not necessarily have the capacity to understand the meaning or implications of what he is capable of reading. Emerging findings include the fact that this kind of collaborative research is likely to produce directly practical and usable findings: outcomes that can be applied in the forensic setting or research environment.

## Part Four: Conclusions and Recommendations

### Conclusions

There are some significant conclusions that I would like to draw attention to here. First and foremost, the four projects have shown that it is possible to involve users of forensic mental health services in research. They explored some different ways of achieving this and encountered some significant barriers or challenges, but they were all successful in what they set out to do. What was also clear from talking to the researchers was the degree of passion engendered by this work. Whether this was from talking to and hearing from the service users in more depth than before, from seeing people achieve a great deal personally or from a true sense of working together, all of the researchers reflected a great sense of passion about the work, the people and the need for change within services. The power of this kind of work, it seems to me, is that it has the potential to challenge stigma and to change people's attitudes towards the people living in or using forensic mental health services, both within and (hopefully) beyond the project itself.

Many of the challenges encountered in these projects are common to all research involving (mental health) service users. It takes more time, it takes more money and it takes more thought about such issues as accessible language, research training and support. In addition, these projects faced significant access, practical and communication issues where the service users were living within secure units, which meant that relationships with staff became of vital importance.

However, the benefits to emerge from the projects were also significant: benefits for the research itself, for the researchers, the service users and also for members of staff. I would argue that these projects demonstrate that service user involvement has a positive impact on the findings, the process of carrying out the research and the understanding all of us might gain about people living in forensic mental health services. The benefits to the service users were of particular significance. In a restricted environment where there might be little in the way of rehabilitation or hope for the future, they were able to gain confidence and skills and to reflect on their experiences in a constructive manner.

### Recommendations

Researchers and service user researchers were asked what they would like to tell people or recommend to people planning to undertake similar work.

- 1. Ensure adequate resources:** Involving service users in research has implications for both time and money. It is essential to estimate these realistically, paying attention to the time needed to recruit and engage with people and to build up trust at the start.
- 2. Engage positively with staff:** Due to the challenges presented by secure environments, engaging and involving members of staff who can assist with the project is essential. Think about what you and the project can give them in return.
- 3. Provide opportunities for consultation and feedback:** it is important to keep checking back with service users that the research is on the right track, and to give feedback about findings and progress.

4. **Involve people from the start:** If service users can see that they have been able to influence the development of the research, they are more likely to trust both the researchers and the process.
5. **Establish ground rules for confidentiality and trust:** Users of forensic services talk about a lack of trust and honesty within services. Establishing ground rules for confidentiality at the start can help to make their experience of the research project different, and to build up trust with you all as a team.
6. **Ensure good support and supervision:** Forensic service user researchers may have additional needs for research supervision and support, due to the absence of a research environment and a possible lack of research experience, as well as the personal issues involved.
7. **Make people comfortable, reward people:** As with any service user involvement, it is important to make people comfortable and reward people appropriately. Providing food and refreshments can be very welcome and can ease the process. Paying people promptly for the work they have done is vital. However, there are other rewards that can make a real difference, particularly to people living in these restricted environments, such as providing access to educational or employment opportunities.
8. **Address issues of personal and current significance to people:** People living in forensic settings are often living from day to day, and without much thought or hope for the future. Researchers recommended that any proposed research should explore issues of personal and current significance to people in order to engage them successfully in the research.

In addition, Part Three would suggest the following recommendations:

1. **Do involve users of forensic services in research:** The benefits of involving users of forensic services are significant. I will not repeat them all again here, but suffice it to say that all of the researchers remain passionate about the benefits of working with service users in the production of valuable research.
2. **Be prepared to take more time:** over engaging with service users and staff, to slow down the research process to take account of the challenges presented by the forensic environment, such as trust, access, communication and literacy.
3. **Engage with women in forensic mental health services:** It will be necessary to engage with female users of forensic service separately and to seek out their concerns and priorities for research specifically.
4. **Disseminate findings with staff and managers of services:** It is vital to ensure that the findings of these projects reach the staff and managers of forensic services. There may be benefits for them in hearing about what is possible and in hearing about what they too might gain from these initiatives.

## Reports and Further Reading

### Project One

Beer D, Keeble P, MacInnes D, Rees D & Reid L. Development of a Questionnaire to Measure Service User Satisfaction Within In-Patient Forensic Services - the Forensic Satisfaction Scale. Final report to National Programme for Forensic Mental Health R&D. <http://www.nfmhp.org.uk/research.htm>

### Project Four

Banongo E, Davies J, Godin P, Thompson J, Lohneis C, Denys C, Floyd M, Fuller S, Heyman B, Reynolds L, Simpson A. (2006) *Engaging Service Users in the Evaluation and Development of Forensic Mental Health Care Services*. City University / National Programme for Forensic Mental Health R&D. **(Report comes with DVD)**.

Godin P, Davies J, Heyman R, Reynolds L, Simpson A & Floyd M. (*paper submitted to ?*) Opening communicative space: A Habermasian understanding of a user led participatory research project.

Department of Health (2001). *Research Governance Framework for Health and Social Care*. London: Department of Health.

Faulkner A & Morris B. (2003) *Expert Paper on User Involvement in Forensic Mental Health Research and Development*. National Programme on Forensic Mental Health Research and Development. <http://www.nfmhp.org.uk/pdf/UserInvolvement.pdf>

Faulkner, A. (2004) *Capturing the Experiences of those Involved in the TRUE Project: a story of colliding worlds*. Eastleigh: INVOLVE.

Hanley B. et al (2003) *Involving the public in NHS, public health and social care research: Briefing notes for researchers*. (second edition) INVOLVE. [www.invo.org.uk](http://www.invo.org.uk)

Royle J, Steel R, Hanley B, Bradburn J. (2001). *Getting Involved in Research: A Guide for Consumers*. Eastleigh: Consumers in NHS Research Support Unit, available from INVOLVE. [www.invo.org.uk](http://www.invo.org.uk)

**APPENDIX A**  
**Learning the Lessons: Service User Involvement in**  
**Forensic Mental Health Research**  
**List of Questions**

*The aim of this piece of work is to write an accessible report which will:*

- provide a synopsis of the main findings from each of the projects;
  - summarise the lessons learnt regarding service user involvement in forensic mental health research;
  - identify good practice;
  - propose recommendations for the future of user involvement in forensic mental health research.
1. a) *Why* did the researchers wish to do research in this way / b) why did the service users want to become involved?
  2. *How* were service users involved (what part(s) of the process)?
  3. Were any special arrangements made (e.g. training, support) ?
  4. What differences did user involvement make to the research? (*process* as well as *outcome* issues)
  5. How did you all negotiate involvement: e.g. managing differences of opinion, accommodating different views?
  6. Did any difficulties or obstacles to involvement emerge? How were these managed?
  7. Were any additional resources necessary? (over and above a research project not involving service users?)
  8. What were the research findings? Do you think these would have been different if the research had not involved service users – and in what way(s)?
  9. How was the overall experience for you?
  10. What are the key lessons learnt / what would you do differently if starting it again now?
  11. What recommendations do you have for others undertaking a similar research process?

Alison Faulkner July 2006