City Research Online

City St George's, University of London

Citation: Banongo, E., Davies, J. & Godin, P. (2006). Engaging service users in the evaluation and development of forensic mental health care services: a peer reviewed report to the funders. London, UK: City University London.

This is the unspecified version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

Permanent repository link: https://openaccess.city.ac.uk/id/eprint/3612/

Copyright and Reuse: Copyright and Moral Rights remain with the author(s) and/or copyright holders. Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, unless otherwise indicated, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way. For full details of reuse please refer to City Research Online policy.

City Research Online: http://openaccess.city.ac.uk/ publications@citystgeorges.ac.uk

Engaging service users in the evaluation and development of forensic mental health care services

This report about a fmh funded project has been written by:

Mr Eric Banongo (service user researcher),
Ms Jacqueline Davies (research fellow and lead research on project),
Dr Paul Godin (principal investigator and lead researcher on project),
Mr Jacob B Thompson (service user researcher),
Mr Conrad Lohneis (service user researcher),
Mr Collins Denys (service user researcher),
Professor Mike Floyd (research project advisory group member),
Mr Steve Fuller (service user researcher)
Professor Bob Heyman (research project advisory group member),
Ms Lisa Reynolds (research project advisory group member),
Dr Alan Simpson (research project advisory group member)

Credit for the success of the research undertaken by the team belongs to all of its members, and to our sponsors who bravely decided to fund and support the project. Undoubtedly, deficiencies will be identified in the writing of the report, which the lead researchers take full responsibility for.

Disclaimer
The research upon which the following 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

Abstract *page 4*
Executive Summary *5*

1. Introduction **8**

1.1. Aims of the project 8
1.2. Methodology 8

2. Method **10**

2.1. Preparation stage 10
2.1.1. Service user involvement at the bidding stage
2.1.2. Putting a bid together
2.1.3. Setting up recruitment
2.1.4. Ethical approval
2.1.5. Research Project Advisory Group (RPAG)

2.2. Establishing the team 13
2.2.1. Pen profiles of project team members
2.2.2. Recruitment of SURs to the project team
2.2.3. Recruitment interviews
2.2.3.1. Service users were keen to explore issues
2.2.3.2. Keen on the other benefits of participation
2.2.3.3. The money
2.2.3.4. What about the women?
2.2.3.5. Reluctance to participate
2.2.3.6. Barriers to participation
2.2.4. Relationship with professionals

2.3. Shaping the research 29
2.3.1. The research question
2.3.2 Capacity building

2.4. Doing the research 34
2.4.1. Doing the analysis
2.4.2. SURs' involvement in doing the research

2.5. Dissemination 36

3. Findings **39**

3.1. Process findings 39

3.2. Findings about SURs' evaluation of forensic mental health care 40

3.2.1. How and why the experience of using forensic mental health care services is fundamentally bad?
3.2.1.1. Comparing institutions
3.2.1.2. The therapeutic relationship
3.2.1.3. Allocation of blame
3.2.1.4. Labelling and Stigma
3.2.1.5. Religion
3.2.1.6. Cultural differences
3.2.1.7. Medication
3.2.2. How things could be better
3.2.3. Moving on

4. Conclusions **50**

References ***54***

Tables

Table 1 Weeks of paid work for SURs Page 19
Table 2 Weeks attended by RPAG members 19
Table 3 Success of recruitment methods 20
Table 4 How time was spent in the meetings 30
Table 5 Meeting based capacity building 32
Table 6 City Mental health department seminars 33
Table 7 Output so far

Appendices

1. The original call 55
2. Recruitment flyer 59
3. Press release 61
4. Recruitment poster 62
5. Minutes of all project team meetings 63
6. Reflexive and creative writing by SURs 110
7. Capacity building session on focus groups 121

Abstract

In a year long participatory research project, funded by the NHS National Programme on Forensic Mental Health Research and Development (fmh), seven service users were recruited to lead an evaluation of forensic mental health care, with the help of academics and advocates of service user involvement (known as the research project advisory group [RPAG]). In keeping with the principles of participatory research, service user researchers (SURs) were maximally involved in all stages of the project, acting as both researchers and subjects in producing and analysing their own data.

After a capacity building period of learning about research, the SURs chose to address the following three research questions:

- ◊ *'How and why is the experience of using forensic mental health care/ services fundamentally bad?*'
- ◊ '*How can forensic mental health care services be improved*?' and
- ◊ *'How can forensic mental health care service users move forwards from the experience of being in forensic mental health care?'*

In reflexive writings and focus groups about their experiences, and in an interview with a health service policy maker, SURs sought answers to these questions. In short, findings revealed that some institutions, regimes of treatment and service providers were seen as better than others. In essence, what is widely regarded by forensic mental health care service providers as good practice was appreciated by SURs. However, they also identified ingredients of the poor interpersonal relationships they had endured with those that cared for them (such as dishonesty, lack of compassion and trust). SURs also pointed to social stigma and their difficulty in gaining employment as major barriers to their ability to move forwards in their lives, wishing for help to deal with both.

Though SURs led the project (setting the research questions, gathering and analysing data, and disseminating findings), they were considerably supported by RPAG members, particularly by the lead researchers and main authors of this report, who describe at length the processes and particular challenges of undertaking participatory research in this uncharted area.

In the process of encouraging the SURs to be actively engaged in the process of researching their experiences of forensic mental care, it was striking to the lead researchers how uninvolved SURs felt they were in genuinely open discussion about matters of treatment, such as medication. SURs seemed to be constantly second guessing and suspicious of what clinicians were up to. As the active involvement of service users is now regarded as desirable and helpful in research, perhaps it also time to similarly regard the active involvement of service users as desirable and helpful in policy development and practice delivery.

Executive Summary

A group of seven service users of forensic mental health care were recruited to participate as researchers in a service evaluation project. They were employed as service user researchers (SURs) by City University, supported by a research project advisory group (RPAG), of academics and advocates of service user involvement, who acted as a resource to the SURs for them to carry out a research project to evaluate services.

The seven SURs each stayed with the project for four to nine months, contributing their time, experiences and ideas to developing the research. To different degrees they undertook reflexive writing about their experiences, took part in focus groups and their analysis, interviewed a policy maker, contributed to writing the project report and the organisation of posters and presentations about the process and findings of the project.

The protocol and ethics for the project only allowed for SURs to be employed for three hours per week. In addition to this restriction, SURs limited their involvement yet further.

Yet the project was closer to the lead researchers' hopes for the best than their preparations for the worst.

The project produced useful findings in two major respects. First, as one of four pioneering projects in the involvement of forensic mental health service users in research, it has provided useful findings about the processes and problems of undertaking such research.

Secondly, the rich qualitative data generated by the service users, 'mining [their] own experiences' (as one SUR described it) produced a detailed picture of how forensic mental health care was/is for them. Their reflexive voices offer insights and understandings that could be usefully employed by policy makers and practitioners to improve services.

With regard to the former, the lead researchers stress the following key points as findings about the process of undertaking a user involvement project in forensic mental health.

- Securing the involvement of service users of forensic mental health care has its own unique challenges. Not only are forensic service users reluctant to identify themselves, but also they are very reticent to explore their experiences of the services they have received, as it indivisibly involves a re-evaluation of their past and a challenging exposure of themselves.
- The project showed that recruitment could not be done simply through advertisement or through key-workers suggesting to their clients that they might like to take part. The lead researchers had to actively seek out potential recruits and encourage them to join.

- Though community psychiatric nurses and other mental health care workers played a vital part in recruitment, with the best of intentions, they sometimes imposed pressure on the clients to participate.
- In recruitment, it became apparent that some interviewees might have preferred to be engaged in such a project on a more individual basis. Therefore, future research in this area might be done that is not dependant upon a group of SURs meeting regularly. Although the group dynamics were valuable, individual projects would have produced something different.
- Past experiences of research and treatment regimes shaped recruits' expectations of what the proposed project would entail, which discouraged many from taking part.
- Service users were attracted to join the project for a number of reasons, including a desire for self-improvement and to inform the improvement in service delivery.
- Despite many difficulties, it was possible to recruit a group of SURs to collectively work together and successfully complete a research project in which they were substantially involved. Furthermore, their participation stretched to the point of them undertaking analysis of their own data and dissemination of their findings. Other participatory research studies in the area of mental health care evaluation have stopped short of involving the service users in analysis, for example Schneider et al. (2004).

With regards to the findings generated by the SURs, based largely on the reflexive consideration of their experiences of using services, the following may be concluded in relation to the research questions they set themselves.
The SURs had first tried to establish how and why the experience of using forensic mental health care/services is fundamentally bad. Data revealed that they had different experiences of a range of services, such that some institutions, treatment regimes and professionals could be recognised as better than others. Those that operated progressive practices, such as addressing service users by their name rather than by a number and involving service users in the appointment of staff, as experienced in private medium secure units, were preferred.

SURs were also concerned that the relationship they had with staff were often far from therapeutic. They described staff as frequently lacking trust, loyalty, honesty, compassion and any respect for patients.

In discussion about specific unpleasant events they had experienced (involving violence, attempts at making complaints and seeking help), SURs considered where blame should be allocated. In so doing they apportioned blame to organisations, staff and other service users. Though it was recognised that their behaviour could be challenging for service providers, SURs too often found the behaviour of staff challenging and wished that they might be more understanding of the people they cared for.

Services were seen as sometimes insensitive to religious and cultural needs, with some staff seen as racist (in various directions).

Lastly, SURs expressed concern about major side effects of psychiatric drugs and their questionable therapeutic value.

SURs second research question was: '*How can forensic mental health care services be improved*?' SURs thought the greatest improvement could be made to services by ensuring therapeutic relationships between staff and patients. Perhaps more than anything, they felt staff could be more open and honest with them. On many occasions SURs demonstrated that they had often been uncertain of staff's true intentions and purposes as SURs attempted to second-guess what staff were up to.

In their interview with a policy maker, SURs indicated that they wished for services to be more accountable and for services to help them overcome the social stigma they faced. In particular, they suggested service users needed help to find employment inside the health service and beyond its boundaries.

SURs' last research question had been: *'How can forensic mental health care service users move forwards from the experience of being in forensic mental health care*?' Discussion about this question revealed that at times, within secure provision, they had felt like they were deep within a hole from which there was little chance of getting out. Facing a system that they regarded as often unjust, hostile and otherwise unhelpful, they felt that it was easy to despair. While services attempted to develop skills, providing IT and other courses, once the SURs were in the community they found it difficult to form relationships and gain employment because their past loomed over them casting a shadow of stigma. The limited involvement of some service users in the project, either declining to participate or withdrawing, was often couched in terms of wanting to move on from their careers as forensic mental health service users. Others saw participation as useful to them in moving on from where they were currently, and hoped that by showing that they could undertake a study they would help reduce the stigma which was holding them back.

In view of these findings the lead researchers make the following recommendations:

That anybody attempting to undertake further participatory research in forensic mental health should be prepared to meet the challenges we have outlined. They should understand service user's reticence to become involved. Once service users become involved, tolerance is required to accommodate the limits they place on their participation. We also suggest that it is important, for the integrity of the research, that it remains separate from service provision and therapy.

This participatory research project has involved overturning traditional conventions of research, to usefully involve SURs in service evaluation. As the SURs' demonstrated that they lacked knowledge about their service provider's intentions, the lead researchers increasingly felt that the type of change being initiated in this research project might also be usefully employed in service provision. Greater openness, honesty, transparency and inclusion of service users in the production of forensic mental health might well help users feel more positive about the services they receive.

1 Introduction

This research project needs to be understood within the context of government policy requirements to involve service users in research and development (DoH 2001, 2002). Following a NHS National Programme on Forensic Mental Health Research and Development (fmh) expert paper, *User Involvement in Forensic Mental Health Research and Development* (Faulkner and Morris 2003), fmh sponsored this research project as one of four pilot studies to promote service user research involvement.

A primary intention of the project was to help give voice to a considered and reflexive view of forensic mental health care services from the perspectives of service users; a view that is often muted, (mis)understood and dismissed within the context of the pathologies with which forensic service users are identified. The project was based on the belief that the voices of forensic mental health service users can offer unique and valuable insights about the services they receive. Through their active involvement in the project, service users were encouraged to articulate their understandings of service provision in the context of their past and present lives.

The project has produced useful findings in two major respects. First, as one of four pioneering projects in the involvement of forensic mental health service users in research, it has provided useful findings about the processes and problems of undertaking such research.

Secondly, the rich qualitative data generated by the service users, 'mining [their] own experiences' produced a detailed picture of how forensic mental health care was/is for them. Their reflexive voices offer insights and understandings that could be usefully employed by policy makers and practitioners to improve services.

1.1 Aims of the project

The main aim of the project was to enable service users to research forensic mental health care, drawing particularly on their reflections of personal experiences of a spectrum of mental health care, from that received in prison to that received in the community.

As far as possible, the project aimed to enable service users to lead and conduct the project. Service User Researchers (SURs) were employed as casual employees of City University to direct and undertake the project. Other members of the project team were known as the research project advisory group (RPAG). RPAG members, from City University and one person from the Revolving Doors Agency (RDA), acted as a resource to the SURs, enabling SURs to know about and practise research, and to direct and undertake the project.

Through dissemination of information about the project and its findings, the research team aimed to inform the development of practice and policy in the area of forensic mental health care.

This project also aimed to enable users to engage in creative, meaningful and fulfilling employment that has enhanced their self-esteem and future prospects for employment.

Lastly, as one of a few novel pilot studies involving forensic mental health service users in research, an aim of the project was to test out a proposed methodology, to determine its feasibility in undertaking such research and to inform future research in this area.

1.2 Methodology

Though this project should be understood as arising out of recent government policy towards user involvement in the research and development of health care, in turn, such a policy must be understood within the context of a developing respect for 'participatory research' (otherwise referred to as user involvement in research).

The importance of participatory research in recent years is evident in the many forms it has taken: participatory action research, co-operative inquiry, action inquiry, etc. Without going into great detail about the many varieties of participatory research, it is worth stating that it is best understood as a set of principles, rather than a set of rules, aimed at producing research that has potential to inform improvements in service provision and, more generally, to emancipate disabled/marginalised people (Zarb 1992).

A central tenet of participatory research is that it should transform traditional social relations of research production that alienate and disempower the researched (disabled and marginalised people) (Oliver 1992). Oliver asserts that within traditional research, people without power appear as passive research subjects, subordinated and alienated by powerful academics and clinicians who produce knowledge, which often adds to their subjects'/patients' disempowerment. Therefore, Oliver argues that disabled and marginalised people need to be meaningfully involved in research, actively taking control of its means of production to produce knowledge that would emancipate or otherwise improve their disadvantaged position. Finkelstein (1985) conveys this sentiment of opposition to traditional research in the slogan 'no participation [in research] without representation'.

This core value of participatory research is often stated independently of Oliver's Marxist terminology, in the general principle that service users need to be involved in all stages of research. As Faulkner & Morris (2003) state in the fmh expert paper on user involvement in forensic mental health research:

> *…we define 'user involvement' as the active participation of forensic mental health service users in any or all of the stages of research, from defining priorities for research, through commissioning, designing and carrying out research, to the dissemination of results.* (2003: 3)

With this principle in mind, the RPAG emphasised to the SURs recruited to the project that it was they that were to direct and carry out research, with the RPAG members putting their knowledge and skills at the SURs disposal.

In certain ways SURs did take control of the project, putting their unique stamp upon the direction and output of the research. Furthermore, SURs identified tangible benefits that they had acquired as a result of taking part in the project. In this account (written largely from the position of the lead researchers [Paul Godin, principal investigator, and Jacqueline Davies, research fellow]) of the method and progress of the project we describe the involvement of SURs at each of its stages to evaluate the extent to which they were able to exploit the opportunity available to them.

2 Method

This section describes the stages of the project in considerable detail to enable others wishing to undertake future user involvement research to learn from our experience. To judge the project's merit as a venture in participatory research, this account gives particular consideration to the degree to which the SURs were involved in each stage.

2.1 Preparation stage

In 2003 fmh invited outline applications from groups or individuals to undertake a research project which addressed the concerns of users of forensic mental health services, demonstrating appropriate involvement of users at all stages (see appendix 1).

2.1.1 Service user involvement at the bidding stage

The lead researchers approached NACRO[1], WISH[2] and RDA[3] to collaborate as partners in the project. These voluntary organisations were invited to participate in writing the proposal, nominate representatives for the advisory group and suggest individuals who used their services as core researchers in the project. NACRO executives read the draft proposal, encouraged the City researchers to continue with the bid, but did not offer to collaborate. WISH,

[1] The National Association for the Care and Resettlement of Offenders (NACRO) is Nacro is a criminal justice charity in England and Wales that aims to improve responses to mentally disordered offenders.

[2] Women In Special Hospitals (WISH) is a charity devoted to improving the lives of women in the forensic mental health care system.

[3] Revolving Doors Agency is a charity that works to improve the lives of people are caught up in a damaging cycle of crisis, crime and mental illness.

after some initial enthusiasm, decided they could only collaborate if there was a clear focus on women. Ian Moran[4] and Pete Fleischmann[5] of RDA agreed to collaborate throughout the project. Their role is discussed below alongside RPAG members. The lead researchers attended CMHF[6] meetings and City University's mental health seminars to discuss their research ideas with service users.

2.1.2 Putting a bid together

The guiding idea of the principal investigator was to facilitate an open and flexible research project in which service users of forensic mental health care could participate as both researchers and, through reflection of their own experience, provide valuable data about what services are like (on the receiving end).
Although suggestions were made about how the research would progress, it was emphasised that the service users would make the final decision, once recruited.

The outline was advanced for funding in October 2003, subject to gaining ethical approval that was obtained in April 2004.

2.1.3 Setting up recruitment

In preparation, the lead researchers had several meetings with a City University human resources (HR) officer to arrange how SURs would be recruited and paid. Agreement on approaches to advertising, interviewing candidates, collecting references and getting them onto the payroll were organised. Guidance was taken from *A Fair Day's Pay* (Scott 2003) to ensure employment was ethically and legally appropriate. Though regulations about permitted earnings for people on state benefits are complex, as a general rule, they may earn up to £20 per week without having their benefits affected. Therefore, we set this as our basis for payment to SURs, assuming that they would undertake, on average, three hours work per week for this amount of payment. This careful preparation of how SURs were employed was important to the Medical Research and Ethics Committee (MREC) in giving approval.

2.1.4 Ethical approval

The MREC application form was drafted at the end of 2003 and beginning of 2004. The lead researchers wrote that the details of the research objectives could not be specified until the SURs were recruited. However, suggestions of what data were likely to be collected were specified. We proposed that SURs might first collectively reflect on their own experiences of receiving services. They might then wish to compose their own biographical accounts of these experiences. These accounts could be enhanced with interviews with

[4] Ian Moran is the research and evaluation lead and link worker for RDA
[5] Peter Fleischmann was the RDA service user consultant who went on to be a researcher with SURE (Service User Research Enterprise)
[6] The Critical Mental Health Forum is a group of mental health service users, carers, professionals, academics and others who are critical of current theory and practice in mental health services. http://www.critpsynet.freeuk.com/Flier02.htm

relatives, friends, advocates and professionals involved in their care. Finally, we proposed that they might wish to interview service providers and policymakers. While this left scope for a number of approaches, it did not allow for user focused monitoring, by which SURs would interview batches of other service users about their satisfaction with the services they are receiving (an approach that some SURs expressed an interest in practising).

The ethics form required us to specify how patients would be referred to the project. The lead researchers were keen to avoid clinicians choosing who should be included (as this would infer that the project was being clinically led and controlled), but equally wanted advice from a key worker whether it would be safe for individual service users to participate in the project. A normal process of job references, in this case from a key worker, was agreed. The South London MREC reviewed the initial application for ethical approval on 14th April 2004, and asked for clarification on some points a week later, focusing on recruitment and employment issues.

2.1.5 Research Project Advisory Group (RPAG)

This group was made up of seven academics from within City University, who were registered mental health nurses and/or advocates of service user research and two service users from RDA.

City University RPAG members worked on numerous drafts of the proposal to fmh, the MREC form and protocol for the project. Membership and role of the RPAG was set out in these documents. The RPAG met together in mid January 2004 to discuss an advanced draft of the ethics form. The minutes from the meeting outline discussion on how SURs will be recruited, how the RPAG will act as a resource, reporting on the study, how ethical dilemmas will be addressed and future activity of the RPAG. Nine people invited to be members of the RPAG, including seven City University School of Nursing representatives (three from the mental health nursing department and four from the health care research unit) and two RDA members. Two invitees who sent apologies to the initial meeting dropped out and the RDA service user consultant who attended was replaced by Chandra Fowler (Service user Co-ordinator) at subsequent meetings. Representatives of the RPAG have attended the team meetings throughout the project, often in equal numbers to the SURs, making presentations for capacity building, listening to and recording SUR discussions and at times participating. RPAG members working within City University have maintained ongoing dialogue amongst themselves about the project and how best to act as a resource to the project's SURs.

To conclude, with regard to service user involvement, at the preparation stage the only formal service user involvement in the formation of the bid and ethics proposal was with Pete Fleischmann of RDA. However, we (the lead researchers) discussed our intended with many service users that we met at a variety of venues, such as seminars and CMHF meetings.

2.2 Establishing the team

Having established the RPAG, SURs were then recruited to the team. The research proposal stated an intention to recruit approximately ten SURs living in the community to the project. Such a sample of service users in the community provides two clear advantages. First, although some were subject to restriction orders or supervised discharge, they were free to meet as a group and not restricted by the barriers of a secure environment. Secondly, the service user researchers of the study were able to offer accounts of their past experiences of living in secure environments, their present experiences of living in the community, and be able to reflectively consider their progression from one to the other.

In practice seven service users became core members of the project team to be regarded as the project's SURs. Though five SURs lived in hostels and flats in the community two SURs were in-patients of a local medium secure unit that allowed them leave to attend meetings. Between them all, they had experienced using the full range of forensic mental health care services in prison, young offenders' institutions, special hospitals, private hospitals, secure units, hostels and community supervision. Furthermore, the SURs came from varied ethnic backgrounds with a mixed level of educational achievement. We make this point about the diversity of the group of SURs to address the virulent accusation, often made by service providers, that views of any group of service users becoming involved in research or policy making are likely to be unrepresentative of 'ordinary patients', as they are declared to be atypical (Crawford and Rutter 2004). This attitude is very apparent in two of the three reviewers' comments about this report (see appendix 7).

Towards the end of the project all team members (RPAG members and SURs) agreed to provide the following pen profiles of themselves to provide a human picture of the project team members. Conrad, a SUR, worked hard at collecting these from SURs.

2.2.1 Pen profiles of project team members

Alan (RPAG member)

I left school in Somerset at 16 with few qualifications and fewer ideas what to do. Too shy to be the rock singer I wanted to be and crap at football, I worked in a shop, a factory and a tannery before I trained as a mental health nurse.

I went to Sussex University in Brighton to study social psychology at 28, so I could fit it in with bringing up my two sons. Then, very broke, I went back to mental health nursing and worked on wards and in a day hospital, then as a research nurse in drug and alcohol addiction for over 3 years in London.

I went back to Brighton as a Community Psychiatric Nurse (CPN), working with people with mental health problems who were homeless. Also did a two-year training in counselling during this time and worked as a volunteer

counsellor in the NHS. After over three years intensive, demanding work I was asked to run a research project.

Bitten by the research bug, I was overjoyed when the NHS funded me to do a PhD and conduct research for three years. I looked at how CPNs worked with other members of the Community Mental Health Teams to support people with severe mental illness in the community, which got me interested in teamwork. Then, nearly four years ago, I was offered a job as a Research Fellow at City University where I work on various projects to do with mental health services and completed my PhD.

I have a longstanding interest and belief in the importance of service users having much more say about the way services are provided and have really enjoyed working alongside a group of people that I have come to like and respect for their quiet determination to improve their own lives and the lives of others.

Bandit (SUR)

Hi I am Bandit.

What I enjoyed in this project was gathering data, the methods I have learned about from my time spent with the team. I am now applying this to the way I go about my life.

The next thing I must stress is for someone who walks into a hospital for the first time. They should know that it's all just like prison. It shows no sense of care on to that someone, and if that person is a weed smoker then it's a whole new ball game. I mean with the media making statements the weed leads to or is the main cause of people going mad. Then also the stigma is very high in people, not just in hospital but also in the community.

What I have learned from this project is being able to put what ever bad or good thing happens down on paper or to talk about it without getting set off or fed up like I use to. Taking notes, sitting and thinking while listening was good, as we analysed the data.

The seminar meetings that we went to were also good. I enjoyed them all and learned a lot from going to them. Yes, I would like to state that I do strongly agree that there is strong insensitivity towards the black culture. I do also agree that there is a lot of racism going on in the Hospitals by staff of black onto black just due to where you are from. Then there's the white staff on to you due to you being black. Also there is the heavy reliance on medication and staff's poor interpersonal skills.

Well it's time for me to say let more of these projects like this take place and you will see what area you need to take a step up in to let patients feel someone is caring for you and that you are not just locked up and so on.

Bob (RPAG member)

I feel young some days, and not so young on others. I love playing chess (badly), playing the violin (very badly indeed), listening to opera, walking the streets of London and the countryside, eating curry and visiting wild tropical places. I am married and have three children, all adult now, and leading their own lives in very different ways.

Oh yes. I knew there was something else. I work at St Bartholomew School of Nursing and Midwifery at City University, mostly doing research as well as a bit of management. I like to listen to people's stories about their health, particularly about how they manage health risks. I then try to tell stories about their stories.

Conrad (SUR)

I, of course, see my self as God. Perhaps not the God (the Ultimate Creator) but definitely a God – I mean doesn't everyone?

I'm quite intelligent and quite articulate – I can be quite annoying when I put my mind to it. I like a good argument although often (for the sake of argument) I pretend I don't. I am very, very nosey. In the sort of zombie cat range, really.

I found the groups enlightening – it's the fact of confirmation. This is what really goes on, and here are some of the reasons. Other people's stories are fascinating: Steve's joy at his new diagnosis meant he could not be treated and so released, was a real eye opener. Denys's, 'no fights we're sensible' approach will certainly change my behaviour should I be readmitted. And as for Bandit – his confusions over his own motives and what he was due – and wasn't, helped me understand my own periods of mental desperation better.

So a profile of me, of the group, of the spirit of the group. Learning, expressing and finding common threads and expressions which enlighten one or other aspect – too gushy, OTT, just ok then. It worked. We worked the experiment worked. Now there needs to be attempts to validate it's results. More groups along the line need to be set up. They work, and they provide unique insights into both illness and the system.

This group was part off the rebuilding of my confidence. I found it very helpful in keeping me well and giving me focus and directions. It also showed me a new path to travel with my writing.

Well guys – that's all folks!

(Have you heard the one about Mother Superior in heaven?)

Denys (SUR)

About me, I'm six feet two inches tall. I am dark in colour, I've done mostly every thing a person would do during their life. My biography is just basically

about myself explaining why people like myself have had such a hard time from an early age. In growing up with an attitude of positivity in succeeding, my ambitions are in working towards the future and also in securing it for not only myself but generally everyone in my family.

Now, I've always dressed nicely in my appearance; and, at the end of the day, I believe cleanliness is godliness, and I'm always clean, no matter what. My appearance is important to me, and it makes me feel that other people around me feel important because of my appearances. So that works for me.

I work part time every Thursday in Market Research as a part time service user. I enjoy the work I do for City University, especially our Meetings, Seminars and the input we made from something basically experienced. While in hospital, being treated in some cases for nothing wrong, being there without any chance of being released. Now that I'm an ex-patient and a Market Research Service User, I'm in the position now to change things within the Mental Health Act and try to bring all the bad things to an end.

In the NHS, ill treated patients, because of my capabilities overcame the problems within and I am now trying to propose how to make it better. Anyway, back to the thirty nine years of age and basically I'm just writing fairly the things about myself for the moment, concentrating on what's happening now with the seeing as there's been a big change in my circumstances in how to move on.

I've been working all my life and, believe you me, it can only get better before it surely becomes worse.

I live comfortably in a new place, which I'm still decorating and I'm just starting another part time job with a company called ACCESS who work computers.

My life is basically a good one, really forgetting all of the rubbish I've done in the past. Which made me look like a very bad person but I'm over it hopefully. So is everybody else. OK that's me Good bye.

Eric (SUR)

I prefer to refer to myself as Eric for the purposes of this research. I am a single male, aged 33 years and Black African by ethnicity. My faith is Roman Catholic. I attend Church on Sundays whenever I can but don't call myself very religious.

My first experience of mental ill health was at the age of 25 in 1977. At the time I was diagnosed as Affective Disorder. On my 3rd and current admission I was diagnosed as Schizophrenic. After a thorough assessment and review, my diagnosis was changed to Schizoaffective.

With regard to hobbies I am interested in going to the cinema to watch blockbusters and romantic comedies. I love African music and classical music such as Handle, Beethoven and Mozart. I have a keen interest in Computers,

especially web designs and electronic publications. As for sports I love swimming.

By qualification I have a Higher Diploma in Marketing. I would like to pursue further study in Marketing to degree level and if possible join the Chartered Institute of Marketing. With regards to Mental Health, I would like to get involved in further research in Mental Health as a service user. I believe this will enable me to make a contribution to the process of improving services as a whole. I am also a member to a Service User Advisory Group on Research at the Academic Unit in Newham Centre for Mental Health.

Jacqueline (research fellow and one of the lead researchers on project)

I have been a researcher for over ten years, working part-time when my children were younger and now working full-time. I have undertaken academic research in education and healthcare settings, though my mum thinks I do market research. My main project in the last five years has been on risk management and rehabilitation in forensic mental health care.

At 18 I left Huddersfield to study history at university but returned north in the holidays and spent my summers working at Storthes Hall mental hospital as a domestic assistant. This experience did not inspire me to become a clinician, and I spent the next few years working as a P.A. in wealthy corporations. Ten years on from my first degree, I studied psychology at Birkbeck College and soon after started my research career after briefly exploring work in the voluntary sector.

Outside university based research I have done paid and unpaid work with youth groups. I was employed briefly as a youth worker at a special needs youth club before it burned down. Now I am involved with the Woodcraft Folk, an inclusive organisation welcoming all young people. This is an activity I find more satisfying than supporting football teams.

Lisa (RPAG member)

My background is in mental health nursing. I trained at Birmingham University. After a brief stint in acute mental health care I have worked in forensic mental health services.

I have been working as a mental health lecturer within the School of Nursing and Midwifery at City University since 2002. My specialist area is forensic mental health although I also get to teach people how to make a bed and brush their own / each other's teeth. Last year I went to South Africa to teach forensic mental health and also undertook some research whilst I was there. But I didn't see any lions.

I do not intend to grow up and become an old married woman. To this end next year I am going to start doing my PhD. I intend to regress and start sending my washing home to my mother and recommence collecting beer

bottles. Oh and also do some ground breaking research, which will make me really famous; in-between watching daytime TV chat shows. Don't tell Bob…

Paul (Principal investigator and lead researcher for project)

I am fast becoming an old married man (rather grumpy sometimes) with two kids in the process of leaving home for university. Like all good Essex men, I support Arsenal.

My working life has been a game of two halves. In the first half (fifteen years worth), I began employment as a ward orderly in Goodmayes Mental Hospital. I then went on to train as a 'Registered Mental Nurse', as we were called then. After working for a number of years on acute wards I then drove a 2CV around Essex, working as a CPN. My last job in the health service was as a manager, planning the resettlement of patients from closing mental hospitals in north London to Enfield.

From 1990, to the present, I have been teaching sociology to nurses at City University School of Nursing (previously known by other very lengthy names). I have worked on a number of research projects investigating aspects of mental health care since the 1980s, including a PhD study of the history community psychiatric nurses. I have enjoyed working on this project, not least for the lively discussions that we have had each week in team meetings.

Sheriff (SUR)

I am 27 years of age. I live in London, which makes me a Londoner. I have mainly lived in East London but my place of birth is South London. I used to live with my mum (just behind the medium secure unit, where I am admitted for suffering from paranoid schizophrenia).

It has been the worst experience of my life, since my admission to the hospital but I had always used this downfall of me being in the hospital to benefit my future. I am currently undergoing GCSE math at FE College, following on to Diploma in Mechanical Engineering. My goals are to complete my diploma and to go onto degree level. My aim in the future is to start up my own business repairing cars.

Anonymity & authorship

Pen profiles were not received from Chandra, Ernest and Steve. All SURs were given the opportunity to use a pseudonym of their choice for the project report.

However, even without identification by name, much of the data, particularly the SUR's written pieces, rendered them identifiable. Thus, after the report had been reviewed, we again alerted SURs to this point to ensure that they were happy with the level of anonymity that the report afforded them.

The issue of authorship could have benefited from greater consideration. Though it was agreed to let the lead researchers write the document, with other team members commenting on it once it was written, it was later realised that we had neglected to properly consider the issue of who were the authors of the report. Though the lead researchers had done the bulk of the writing, the SURs had authored major pieces within the report, namely their pen profiles and pieces of creative writing (see appendix 6). Therefore, SURs were asked whether they wished to be named authors (either by their own name or a pseudonym) of the report. These two issues were discussed in the post project meetings that were organised to prepare for the November presentation with SURs signing forms to indicate their preferences on both issues.

Attendance of project team members

The attendance of the seven core SURs who worked on the project for four to nine months is shown in (table 1).

Table 1: Weeks of paid work for SURs (3 to 6 hours each week)

	2004							2005																											
	O		Nov			De		January				Februa				March				April				May				June								
Con																																			
Stev																																			
Ern																																			
Col																																			
Band																																			
Eric																																			
Sher																																			

Funding paid for Jacqueline, Paul and Chandra (on a pro rata basis) to devote time to the project. Other RPAG members gave their time freely to the project when they could. The table below illustrates the attendance of RPAG members.

Table 2: Weeks attended by RPAG members

	2004							2005																											
	O		Nov			De		January				Februa				March				April				May				June								
Paul																																			
Jacq																																			
Lisa																																			
Alan																																			
Bob																																			
Mike																																			
Chan																																			

2.2.2 Recruitment of SURs to the project team

An advertisement, inviting people to participate was first posted on the City University website, as this is routine practice for all job vacancies that arise within the university. Secondly, invitations were circulated within RDA, the CMHF in Central London, and assertive outreach and community mental health teams in inner and outer North East London. Presentations were made separately to groups of service users and health care professionals and leaflets designed for service users were distributed (see appendix 2). Thirdly, recruits were sought through Health Trust and other newsletters using a press release (see appendix 3). Table 3 shows the progress of recruitment timetable.

Table 3: Success of recruitment methods

Contacts	Website June 04	RDA & CMHF Sept 04	Community teams (Jul-Nov 04)	Hostel residents Nov 2004	Press release Nov 2004
Paid SURs	-	-	6	1	-
Other FMH service users	1	-	2	5	9
Non forensic service users		-	1		5
Psychology students	4				
Useful contacts	outreach team	-	hostel teams & residents		mother of FMH service user

The press release was included in the East London Trust and Kensington & Chelsea MIND publications. We received approaches throughout the first half of 2005 from Kensington & Chelsea. The lack of participation by these respondents was partly due to our delay in getting a press release out and may have been partly due to the distance that Kensington & Chelsea service users needed to travel to get to team meetings.

The four SURs recruited in late 2004 discussed recruitment with RPAG members and two tried to encourage other forensic mental health care service users they knew to join the project, without success. Otherwise SURs played no other part in recruitment.

2.2.3 Recruitment interviews

In all, contact was made with at least 30 mental health service users. The most enthusiastic gave as their main reason to participate as a wish to undertake research that would improve services. Applicants were also keen to engage in a worthwhile activity away from clinical settings, develop a CV that would lead to other opportunities and earn some money. Some potential recruits were unable or unwilling to commit time to the project for various reasons that the lead researchers can only speculate about. Perhaps the payment offered was not a sufficient incentive. Some were seemingly unwilling to discuss a past that they wanted to put behind them. Below are

details from field notes about why people were, or were not, keen to participate.

Field notes were made about each contact. Our first service user application was through the advert on the City University website, from a woman who had been in a medium secure unit (MSU) in the 1990s. A friend of hers, working at City, had noticed the advertisement and brought it to the service user's attention. The lead researchers set off to meet her at her home. In the interview, she explained that she thought there was a lack of support to prevent people entering and re-entering forensic services. She was also concerned that bad staff and bad organisations pushed users to (re)-offend. She was keen to earn £20 a week, to the point that she may have been more interested in what we wanted her to do than setting her own agenda. She arranged for us to meet her outreach worker and get a reference. However, she then chose not to participate in the research as she had always contested her conviction and compulsory detention, and felt that participation implied an admission of guilt.

Below is a summary of the reasons why service users wanted to participate or not participate and barriers to their participation.

2.2.3.1 *Service users were keen to explore issues*

Ideas developed in initial interviews were in line with the key themes that emerged from the project's data analysis. The service users wanted an explanation for the lack of counselling support both inside and outside hospital that they thought would help service users employ their time more productively and avoid a revolving door syndrome. In recruitment interviews, a service user talked of manipulative guards in special hospitals and another of disrespectful staff who goaded service users into violence in medium secure units. From the early stages of the research, it became apparent that service users used the word 'staff' in a rather ambiguous way. Generally it was used as a synonym for the front line workforce (nurses or prison warders) though sometimes it might also include other professions involved in their care.

Cultural insensitivity in services was a driving concern for SUR Ernest and also a Muslim interviewee. The latter person was concerned that in the local MSU the prayer room was inadequate and that there was no Imam provided for the growing Muslim population. He complained that while the mental health services were prepared to pay for Christian priests, they were not prepared to pay for an Imam.

2.2.3.2 *Keen on the other benefits of participation*

When recruiting, we advertised participation as an opportunity to join a research project, voice concerns and influence policy. We also offered around £20 a week. (see appendix 2 & 4). Denys agreed to participate because of benefit of up to £80 a month, the university based employment and possible reference to help him get on a university IT course.

About half those spoken to focused on the financial benefit. The money will be discussed below. Several of the people who contacted us expressed a need to be valued by others, and something to fill their time. One applicant who had very little to do with his time wanted help to find something to replace weekly project meetings where he met with peers.

Meeting other service users, particularly women, was of interest to some of the men who contacted us. In recruitment interviews we were asked if there were women in the group. Those asking proposed that women had a different view to put forward. Recruitment mix will be discussed below.

2.2.3.3 *The money*

Twenty pounds was a priority for about half the people we spoke to, both those who did and did not become members of the team. While the woman referred to above asked what she had to do to earn £20 this was not everyone's response. Those on disability living allowance (DLA) told us that they could earn over £70 per week without compromising benefits and suggested we should be paying more. One potential recruit, who chose not to join the team, said that he would participate without payment to ensure that his DLA benefit remained unaffected. One person who did attend four sessions chose not to ask for payment as he did not want to become a full member of the team.

After a long day of unsuccessful recruiting, the last person we spoke to was Bandit. We presented the project to him in terms of money, job record and reference. After signing-up Bandit, we were sceptical about whether he would turn up to meetings as he had been oversold the benefits of participation. We thought perhaps that *he merely agreed to buy the encyclopaedia just to get us off his doorstep.* However, he turned out to contribute a great deal to the research and was prepared to withdraw from the project when he found it difficult, even though this meant he would lose the income that it gave him.

2.2.3.4 *What about the women?*

Sensitive efforts were made to recruit women. Five women service users contacted us of whom two had no forensic experience. One woman made several appointments to visit us but never arrived. We did visit a woman in West London who gave us an extensive recruitment interview and said she would join. When told that she might be the only woman, she said that she would enjoy that, and that she preferred talking men rather than women. However, one of her stories about how bad it was in the MSU was that male patients had harassed her. One night when she had locked her door before going to sleep, a nurse had unlocked her door, mistakenly thinking s/he was locking it. She woke up to find a male patient lying on top of her. It is possible that she did have reservations about being in a male dominated group.

2.2.3.5 *Reluctance to participate*

Time commitment to the project. While some recruits had little to do with their time others were very busy. One SUR engaged in mutual support with family and friends, voluntary work at the church, trying to get employment, an Open University degree and creative writing. The West London woman

explained that her time was limited as she was attending a college course four days a week and had a primary school aged child to care for. One man interviewed in a hostel worked five mornings a week as a gardener. Although he expressed some interest in joining the team, he was not sure he would have the energy or finish his main job in time. One SUR was late most weeks as he had a music class before the slot that suited most others. Two service users who would probably have made good recruits, preferred employment pushing trolleys at supermarkets that they obtained shortly after their recruitment interviews. Trolley pushing work, arranged through Shaw Trust[7], paid around £100 a week, providing longer term employment and allowed service users to move on from their past experiences in a more normal form of employment.

Not enough money As mentioned above, better earnings could be obtained and for a longer term. In some cases, those who signed up with us had been unable to get jobs elsewhere.

Method of payment One of the challenges for service users was getting paid. They were asked to have a bank account, a national insurance number, a birth certificate or passport, a tax code and a reference. Some non-participants may have been reluctant to get a reference from a key worker or GP, but this was never said. One service user who attended a single meeting dropped out because he would have to visit his mother to get his birth certificate and he saw that as an impossible task. The method of payment may have been a problem for several. The gardener, mentioned above, seemed reluctant to have an official record of his payment as his existing work may have taken him near the limit he was allowed to earn before his benefits were affected. While some already had bank accounts, others had to set them up to receive payment. Two SURs never managed to sort out a bank account and the university HR department kindly, but reluctantly, provided cheques each month. Another SUR had no national insurance number at the beginning of the project, but with help from the HR department was eventually able to obtain one. This formal method of payment was seen as a way of reinforcing the idea that SURs were engaged in a proper part time job. Cash in hand payments would have been demeaning (a token payment for work of little value). However, the formal payment method might have discouraged some participants.

Putting the past behind you Not everyone wanted to rake over their past. For our first woman, raising her MSU experience of ten years ago drew it to her current key worker's attention for the first time. However, the main reason she gave for her non-participation was that, by including herself in the group, she would be admitting to her offence; something she had always denied. One recruit withdrew from the team after three (unpaid) sessions, coming only once more to a seminar, because he did not want to share his experiences with others. He had left special hospital only weeks before and was clearly still very angry. He said that he didn't '*owe the system anything and it doesn't*

[7] Shaw Trust employment is a charity that specialises in finding disabled and disadvantaged people the opportunity to work.

owe me anything'. One of the SURs who had recently moved from an MSU to supported accommodation said when he was first approached that he was not ready to undertake research, possibly because the experience was still too raw.

Bad previous experience of research Recruitment interviews revealed that service users had plenty of previous experience of being researched within hospital, where they were a captive population of potential research subjects for trainee psychologists and nurses undertaking research projects in pursuit of professional qualifications. This was generally experienced as mildly negative. One service user living in a hostel residence talked about once being let down by a researcher who after making initial contact with him had promised to carry out an in-depth interview with him but then failed to contact him again. We tried to emphasise the crucial difference of this project that invited them to become actively involved and move beyond them being mere research subjects. This idea was not always fully appreciated or believed by applicants. Ernest expressed reservation about engaging in the project as he told us that he had previously been engaged in a user involvement project that he felt had got 'watered down'.

Many interviewees thought the project might be like occupational and group therapy that they had previously experienced. Another hostel resident compared our invitation to others he had heard over many years in his patient career from nurses, occupational therapists and psychologists to join the ***'grOOp!!'.*** As with others we spoke to, he was unclear what the purpose of the group/project was, and whether it had some covert therapeutic intent.

Misunderstandings about the project Our initial approach to potential recruits was largely through their CPNs, some of whom saw an opportunity to get their clients involved in something that would be approved by the Home Office. One CPN included participation in the project into someone's care plan. The service user's brief attendance was therefore not entirely voluntary and may have contributed to his withdrawal. The same CPN encouraged someone else on his caseload to visit us who, although giving a detailed interview about his experience as a Muslim in an MSU when we met, did not attend any meetings. Some applicants and SURs thought they were signing up to be our research assistants, giving out questionnaires and interviewing other service users on our behalf. When we said that we anticipated something more reflexive and involved one applicant withdrew, and another SUR became less involved, eventually describing the project as lacking structure.

Location of the group City University, in the centre of London, was well placed for this project, for a large proportion of people that have used in-patient forensic mental health care services live in the London area. Furthermore, all the SURs had 'freedom passes'[8]. However, at least two potential recruits did not have such a pass and this contributed to their non-

[8] A freedom pass allows free travel on London transport for people with a disability (details about freedom passes can be found at: http://www.freedompass.org)

participation. One applicant from Kensington & Chelsea had to catch at least two buses as he could not afford to travel by tube. For a number of West London contacts, East Central and East London were a long way to travel. One hostel resident did not want to go to our seminars in East London. His key worker confirmed that he had 'paranoia' problems with certain areas, but there could be more real problems connected with his offending past. At least two SURs did not want to go near MSUs or other places they had received care. The West London woman was concerned that to get to our main office from the nearest tube station she would need to walk through a tunnel.

Ill health SURs limited involvement (lateness, irregular attendance, failure to undertake homework) was undoubtedly due to SURs sometimes feeling too mental unwell to be more fully involved in the project. Limiting health problems were cited as barriers to getting to the meetings. Mental illness was seen to be something that prevented service users undertaking a range of tasks. One SUR informed us that he wanted to but could not find himself a woodwork group because he had a mental illness. For some applicants, alcohol problems were particularly difficult around Christmas when the project was really getting off the ground. One Kensington & Chelsea contact asked if his diabetes would be an excluding factor. He chose not to attend, possibly because of the refreshments provided at the meetings. Multiple health problems of forensic mental health service users meant that they had difficulty getting to meetings. One SUR informed us that he had memory and learning disabilities, which appeared to make him struggle to organise getting to meetings. In the winter he missed several meetings when he was physically ill, unable to manage his resources and could not contact us because he had failed to pay his phone bill. When he returned he was much thinner. Although meetings started at 3pm or 4pm SURs reported not being up in time because of depression, the effect of depot injections, and nocturnal lifestyles.

Exposure in a group of peers and professionals Not everyone we spoke to wanted to share their experiences publicly. While some were happy to talk in their recruitment interviews they withdrew from talking in front of a group of service users. One hostel resident declined to join the team, but offered to give a one-to-one interview with one of the lead researchers. A service user, recently discharged from high security hospital, attended briefly. Though very articulate when speaking to the lead researchers he was virtually silent in the group. Bandit withdrew from the project in March after he was repeatedly challenged by one member of the group in what Bandit regarded to be an un-collegiate way.

2.2.3.6 *Barriers to participation*

We invited everyone we spoke to who had experience of forensic mental health care to provide a reference from a key worker or GP. Those who provided a reference were invited to join the team. We had references for all seven SURs of the project. There were people for whom we got a reference who subsequently chose not to participate, and others who expressed an interest, but then did not provide references. Whether getting a reference was difficult for any of the applicants was not discussed, and how far this was a barrier is unclear.

We defined having experience of forensic mental health care as being in high security, medium secure or prison services. Some of those who contacted us (four women and two men) had only experienced acute services.

Participants had to be at liberty to attend our meetings. We had two SURs who were still in-patients within a low security ward of a local MSU. A nurse escorted one of these men each week to the meeting. Although he was usually on time, his occasional late arrival and twice when he was unable to come was explained by a lack of nurses on the ward. The nurse escort brought him to the meeting and waited outside until the meeting finished at 5.30pm, or when the meeting was followed by an open seminar, the nurse joined everyone for the seminar. The ward manager assessed the situation early in his participation and came as the SUR's escort to the end of project dinner.

It was agreed in the protocol, ethics application and at recruitment that any concerns that might arise about the health and behaviour with SURs would be discussed with them and then with their key workers who had provided a reference. If SURs missed several meetings (or dropped out), the lead researchers, and other team members, contacted them to check they were OK. At no time were professionals contacted about concerns with SURs. CPNs did ring the team leaders to ask if all was OK, one nurse rang explaining that he needed to 'tick a box'.

2.2.4 Relationship with professionals

As was seen in table 3, it was through community teams that the lead researchers were most successful in recruitment. In Summer 2004 we visited four community mental health teams. We presented our intentions, answered questions and provided them with A4 leaflets (see appendix 2) for them to discuss with their clients and distribute where they thought was appropriate. Forensic psychiatric nurses within the mental health trust in which the university undertakes teaching and professional development produced the greatest number of contacts including service users living independently, in low secure settings and hostels.

The three Forensic CPNs we were most aware of helping us arranged and facilitated up to four meetings, each with potential recruits. We learnt in these meetings that for some cases, service user engagement in our project would look good with the Home Office and the nurse was keen to sign his client up, partly because it allowed him to tick a box on his regular response to the Home Office. However, the nurses were also keen to provide worthwhile activity for their clients and increase their income. When we visited the hostel to see one of the Forensic CPN's clients the hostel manager was keen to capitalise on the opportunity and arranged for us to present our research to service users at two supported houses, with the service providers in the background.

In all cases, where we approached the service providers for a reference, the reference was given. The service providers generally were interested in what we were doing and what they were giving a reference for. However, the reference was essentially signing a pre-prepared reference, which was in some cases done with an illegible signature and no description of the signer. Only in one case (the woman recruited from the website advertisement) did the nurse spend time clarifying her client's forensic status and giving advice about signs of relapse for the candidate. This nurse had to look into records that predated her relationship with the service user and was surprised to see her forensic past. It may not have been good for their relationship to unearth these details and may have contributed to the website woman's withdrawal from the project.

One psychiatrist in the office of an assertive outreach team was openly interested in our research. When we visited for an arranged presentation, all the other team members were out 'saving lives' and the psychiatrist was our only audience. He looked through his list of patients on a whiteboard in the office and suggested the most likely candidates. He agreed to give them leaflets and one did contact us and became a SUR.

When recruiting through press releases and therefore contacting service users before contacting service providers, the latter were often unhelpful. When one service user contacted us, I (Jacqueline) asked to get a reference from his key worker. I rang his outreach team and both his social worker and nurse spoke to me briefly. They agreed that I could meet their client at the outreach offices. However, when the service user failed to turn up and a second meeting was required the service providers said they were busy and did not want to be involved further. Eventually a reference was obtained from a drugs and alcohol counsellor, but the service user never came to a research meeting.

On the whole there was little contact with staff after the recruitment stage, except for the one nurse discussed above. One nurse who had kindly suggested four of his clients for the project contacted us a few times to ask if those on his case load were attending meetings. It became apparent that at least one of these men may have felt obliged to attend and was not truly a volunteer. As previously mentioned, the service user in question had 'participation in our project' included in his care plan. His nurse had also asked us to fax information to the psychiatrist of one SUR from his case load. Although the nurse probably had the good intentions and the best interests of his clients, his communication tested our concerns about confidentiality.

One SUR who still lived in a low secure unit required an escort under Home Office regulations. Early in the project the ward manager came and assessed the safety of the service user being in the meeting, with three registered psychiatric nurses on the RPAG, and the ward's nurse waiting outside. It was agreed that this was acceptable to the service user's multi-disciplinary team. Over seven months about a dozen different nurses escorted this SUR, including the ward manager.

Methodological criticisms about the recruitment of SURs

Mental health service user research projects are sometimes criticised for being carried out by people who are also academics or otherwise possess a high degree of personal capital and are therefore regarded as unrepresentative of most service users. Though one of the SURs was undertaking a degree none of the SURs of this project had previous carried out service user research. With their varied and extensive experiences of forensic mental health care (we thought) it would hard to accuse the SURs of this project as being unrepresentative of forensic mental health care service users as a whole. Yet this is exactly what two of the reviewers of the report did (see appendix 7). We were accused of bias in our recruitment methods, dissuading fair-minded forensic mental health service users from joining the project, attracting only those (presumed by the reviewers to be a minority) that were dissatisfied with themselves and their experience of forensic mental health care to take part. Accordingly, the reviewers that identified this putative methodological flaw seemingly felt the findings were invalid and unworthy of consideration or comment.

Regarding this criticism as invalid, we addressed it in our response (see appendix 8). However, it is worth here outlining our objection to the reviewers' criticisms by making some elementary points about sampling and qualitative research to persuade the reader that our methodology was sound and that our findings were trustworthy and do deserve attention.

First, an attempt to gain a strictly representative sample from the population of people that have used forensic mental health care services (as though we were conducting quantitative rather than qualitative research), as the reviewers suggest (paying particular attention to gather a representative mix of people that positive, negative and indifferent experiences of forensic mental health care services), would have been impractical. How could we know the balance of views within the population prior to our pioneering study into this area? Furthermore, had we attempted some sort of randomised or stratified selection of the population of forensic mental health care service users, then (as in our recruitment experience) the majority of selected people may have declined to participate. How then would we have coped with such non-response? Had it even been possible to recruit a strictly representative sample of forensic mental care service users, supposed by the reviewers to contain people that thought the services did not require any change, then what, other than payment, would be the motivation for them to be actively involved in the project? As Telford and Faulkner point out:

> *One of the strongest motives for* [mental health] *service users to become involved in research is the desire to bring about change and improvements to services and practices; a wish to improve their own lives and the lives of others.* (2004: 552).

Secondly, we should point out and emphasise that this project was a **qualitative** research study and should be judged as such. Qualitative studies are concerned far less with establishing how many people of a population experience or think one thing or another, but rather with the detail of what they experience or think. For this reason qualitative research is less concerned

with the representative nature of a sample and more concerned with what richness of data that the sample might yield. Thus qualitative researchers typically employ different strategies of sampling, than those used by quantitative research (see Patton (1990) for a detailed account of sampling in qualitative research). Furthermore, unlike quantitative research the sample size is not crucial to the trustworthiness of the findings, which are about what exists rather than how much of it exists. Therefore, it is surprising that one of the reviewers makes the following inappropriate judgement about the project's research findings: 'The low numbers of users included preclude its value for qualitative analysis although they have attempted to conduct a thematic analysis of the issues' (see appendix 7).

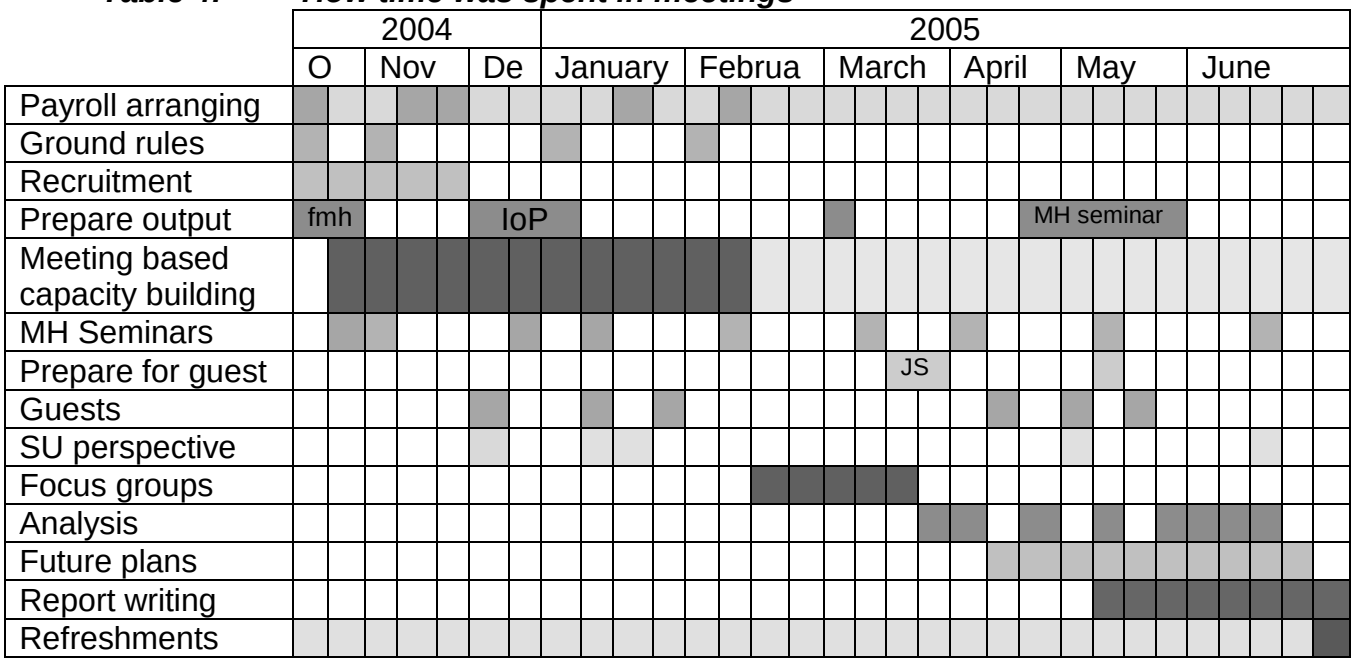
Thirdly, that the data were produced by people who were motivated to express their views about the services and wanted to influence change should be regarded as a strength. Indeed the sample could thus be said to have had 'intensity', which then provided rich information about people's experience and thoughts about using services, from people that felt they had something, rather than nothing, to say about forensic mental health services.

Lastly, it should be recognised that the SURs' research data contain a rich level of detail about how a group of service users experienced and thought about the forensic mental health care they received. It should not be dismissed on the grounds that it might be unrepresentative. The degree to which the SURs' experiences and thoughts are widespread amongst the entire population of forensic mental health service users, should be judged by comparison to other emerging studies in this area and by service users reading the report who might (or might not) feel what Carr and Kemmis (1986) term a 'shock of recognition' when reading the SURs' experiences and thoughts, acknowledging them to be similar to that which such readers may have had.

2.3 Shaping the research

Once the RPAG members had been joined by SURs recruited to the project the team then had the central task of deciding what research they were going to conduct and how they were going to do it. As the table below indicates this took until mid February to achieve, though other tasks were also attended to in this time. From then onwards meetings focused more upon the production of data, its analysis and plans for its dissemination.

Table 4: How time was spent in meetings



The above diagram gives an overview of what was done in meetings. More detail can be found in a full set of all minutes of all project team meeting in (appendix 5). Discussing pay issues was an ongoing issue. The HR officer visited with the group five times, as well as spending time with individual SURs. Ground rules were discussed in the introductory meetings, when the group increased in size, and then again in February when the group was ready to start generating data. How to recruit more SURs was discussed in early meetings.

Dissemination also featured as a priority to be attended to from the early stages of the project. One of the first tasks to be done was to prepare a poster for the fmh conference in early November 2004. The task of preparing for the Institute of Psychiatry (IoP) conference, Three Bridges presentation in March and the forthcoming November 2005 Mental Health seminar were woven into the programme.

The first meeting was on the 1st October 2004 when three SURs met with three RPAG members. The meeting began at 12.30 with lunch and was followed by a visit to the HR department. It was agreed to meet two weeks later at 3pm before the next monthly mental health seminar at the East London site of City University. However, six RPAG members, including the RDA member, but no SURs, attended the next meeting. Two SURs arrived an hour late, just in time for the seminar, and seemed unaware that time of the meeting could not be changed to manage their late arrival. The lead researchers decided not to reconvene the group until the next seminar in a month's time in order to concentrate again on recruitment, for the group could not survive on only three SURs who might be absent or late. Paul and Jacqueline also concentrated on preparing the poster for an fmh conference presentation, with the help of Conrad, who was profoundly apologetic about being absent for the second meeting. Attendance was problematic

throughout the project. The SURs suggested starting late in the afternoon to allow for their other activities and preferences. We arranged most meetings for 4pm in City of London, the latest we could practically begin. However, to attend the 4pm seminars, we chose to meet at 3pm and frequently the majority of the SURs arrived only for the seminars.

However, SURs engaged in the open seminars, asking thoughtful questions in a large lecture theatre. Over the first four months, members of the RPAG gave overviews of research, examples of their own research activity and drew attention to the work of others. Guests were added to this capacity building programme: Keith Halsall and Ian Light, both service user researchers. Other service user researchers who spoke to the team were Chandra Fowler, the RPAG member from RDA, Diane Hackney, whose presentation was postponed due to illness in December and Diana Rose who spoke as part of the main mental health seminar programme. Other guests who visited were Laurence Pollock who interviewed the SURs for a piece in Mental Health Nursing (Pollock 2005), Jim Symington, a director of National Institute for Mental Health in England (NIMHE), who was interviewed by the SURs and Sue Spiers, from fmh, who came to discuss the final report. When Laurence Pollock interviewed the SURs they had not predicted the very good questions he asked and articulated very few appropriate responses. Before Jim Symington and Sue Spiers visits the team discussed how the interviews might go and prepared their questions and answers. For Jim's visit, SURs agreed how they would present their project to him and who would ask what questions, which on the whole went extremely well. Despite this, when one SUR was twice asked whether he would like to ask a question by the SUR chairing the interview, the former smiled and said '*not really'.*

2.3.1 The research question

The early meetings were largely spent building the research capacity of the SURs, such that they could make a decision about what they wanted to research. The essence of their research questions came fairly quickly to the group and remained relatively stable. They wanted to demonstrate that services were bad for users and understand why they were bad and how they could be improved. Furthermore, they wanted to find an answer to the question of how they could move on from having used forensic mental health care to improve their lives.

There was considerable discussion about the form of the first of these research questions. The RPAG members, questioned whether the question prejudged the findings (see minutes of 2nd & 9th December 2004, appendix 5). However, the SURs firmly insisted on maintaining the way they had framed the question. Thus, in the spirit of participatory research, it stood in this form, only to be strongly criticised as 'biased' by the reviewers of the first draft of this report (see appendix 7)

2.3.2 Capacity building

The level of research experience and knowledge of the SUR recruits was unknown before the project began. It was assumed by the RPAG members

that service users were likely to have limited knowledge and that some time would need to be spent introducing a range of research methods. However, within a short time frame and small budget the lead researchers had to produce some research findings and a report, not just run a research-training module. In the first month of the project, the SURs showed that they had some ideas of research, largely gained from being subjects within research projects of junior doctors, trainee psychologists and nurses undertaking minor research studies for their professional training. This gave SURs an awareness of research methods. They described what they knew about questionnaires, double blind experiments and hypothesis testing.

In response, we embarked on a programme of capacity building (see table 5 below). The first session of this programme was spent looking at the differences between quantitative and qualitative research (18th November). This was followed by a number of examples of research projects undertaken by the RPAG team and service users.

Table 5: Meeting based capacity building

18th November	Overview of research methods Summary of quantitative and qualitative, including looking at Rosenhan (1973)	Bob Heyman
25th November	Schizophrenia and Employment: A Nuffield sponsored study (Floyd 1984)	Mike Floyd
2nd December	Another fmh service user led research project	Keith Halsall
9th December	MSU risk management and rehabilitation research	J Davies
6th January	Preparing Dissemination *Getting the Score on MSUs*	P Godin
13th January	Overview of service user involvement in research/training and policy making (based on Rose (2001))	Alan Simpson & Ian Light
20th January	User Focused Monitoring in Bristol (MIND)	C Fowler
27th January	Experiencing an interview	L Pollock
10th February	What is a focus group? (based on Krueger & Casey (2000))	Godin & Davies
28th April	What is a focus group? (based on Krueger & Casey (2000)) (again). Plus: Guidance on analyzing a transcript	Godin, Davies & Simpson
5th May	Talk from a Service user researcher Postponed from February.	Diane Hackney
19th May	Visit by Sue Spiers to discuss content of the report.	

This programme was complemented by the School of Nursing's Mental Health Department's seminar programme (see table 6). When in February 2005, about half way through the programme of meetings, it was agreed to undertake focus groups, the lead researchers presented an outline of the methodology, based on recommendations of Krueger and Casey (2000) and

Webb and Kevern (2001) [see appendix 9]. Throughout the focus groups, the RPAG provided support by reminding the SURs of the research questions they had chosen, and to think about what was both positive as well as negative about using forensic mental health care services and how they could be made better. When transcripts were ready for analysis they were distributed to the SURs and the RPAG again talked about the process of interpreting the data before and during the process of analysis.

Table 6: City's mental health (MH) department's seminars

DATE	TITLE	PRESENTED BY
14th October	Reducing conflict on acute inpatient wards	The City Nurse Project
11th November	Does the therapeutic relationship in psychiatry matter?	Dr Rose McCabe
9th December	Young people and substance misuse: is strengthening the family the solution?	Lindsey Coombes
13th January	Fresh findings from research in acute psychiatry	Prof Len Bowers
10th February	Friend or foe? Self harming patient's perception of care	Alastair McElroy
10th March	Medicine-taking decision-making for people with schizophrenia	Glenn Marland
14th April	Supporting acute in-patient mental health nurses to work therapeutically	Roger Evans
12th May	Advanced directives in community mental health care	Chris Flood
16th June	Consumers perspectives on electro convulsive therapy	Diana Rose
All seminars were free, open to all and help at 4pm in a lecture theatre at St. Bartholomew School of Nursing & Midwifery, Whitechapel, London.		

RPAG members also attempted provide instructive support to help the SURs prepare to interview a policy maker and in response to their reflective writings. Conrad, a prolific writer, was already very skilled at writing in a poignant and poetic fashion. Others produced less comprehensible pieces that the lead researchers transcribed and provided advice about improving writing.

Following the end of the project the group met again on four occasions to plan their presentation to the School of Nursing Mental Health open seminar. This process involved the RPAG members helping to consider how they could make an effective presentation of their work. SURs were helped to practice speaking clearly and concisely to make the points they wanted to make in front of a camera. This filmed material will be used in the group's presentation. Hopefully the experience of preparing for and presenting their work, and then fielding questions will be a valuable learning experience to the SURs about how they might present their viewpoint in a way that might inform others.

Clearly the limits of the project limited the amount of capacity building that we were able to undertake. Had the project been longer and bigger with the SURs undertaking more research activities, then we would certainly have had to undertaking more extensive capacity building, possibly through more formal training and individual mentoring to support SURs' research activities.

2.4 Doing the research

Throughout the capacity building period of the project, different research possibilities were discussed. Keeping diaries was proposed and books were given to service users for this purpose. Diary keeping was dismissed but some did bring their books to meetings and made notes in them. Denys gave the lead researchers his book to type up some of his notes however the contents of other books remained private. The introduction of diaries seemed to inspire a number of efforts at creative and reflexive writing (see appendix 6). Some of these pieces were used to promote discussion in the focus groups that occurred in February and March.

Getting hold of their past clinical records was proposed by SURs as a possible research activity. The feasibility and value of doing this was discussed over several weeks. SURs proposed that an examination of these documents could reveal what clinicians had really thought about them, which would then explain the treatment they had received. It was also talked about as something that might bring about closure to their past. However, one SUR feared getting his records feeling that because the process might incite clinicians to act unfavourably towards him. Others also lost enthusiasm for this idea. However, though Conrad declined our help to get his records, he attempted unsuccessfully to obtain them.

Although the lead researchers had hoped that SURs would want to interview those who had cared for them, they were not keen to contact places where they had been cared for, speak to those who had cared for them, or devise interview schedules for us (RPAG members) to interview their service providers. Except for focus groups where RPAG members, drawing on their clinical experiences, suggested how clinicians might respond to SURs' questions and statements and an interview with Jim Symington from NIMHE, there was no research contact with mental health care professionals. The lead researchers had met Jim at the November fmh conference and opportunistically asked him to be interviewed (in his capacity as a policy maker) by the SURs. The SURs welcomed the opportunity and, with help of the RPAG members, prepared questions to ask Jim. The interview was fully transcribed and is referred to later in the findings section.

Once exposed to presentations about user focused monitoring projects in mental health, some SURs expressed an interest in emulating such studies. The lead researchers had already spent some time in explaining that to interview other service users would require further ethical approval and would have to be regarded as a separate project. This had to be re-explained at this stage of the research. SURs enthusiasm for user focused monitoring might

have been associated with a desire to become researchers researching others, thereby avoiding exploration of their own experiences and themselves. SURs seemed very happy to reuse a rather superficial user focused monitoring questionnaire to interview other service users. The lead researchers questioned the value of this. We asked whether a questionnaire of very superficial questions was likely to generate any valuable findings. We were also concerned that the division between researcher and research subject, which had been successfully eroded in our project, would be re-established were the SURs to embark on a user focused monitoring project. Once it was recognised that this activity was not feasibly within the existing project SURs abandoned the idea.

As our lively weekly meetings continued without a decision about how to carry out the research the idea emerged of formalising our discussions about service users' experiences of forensic mental health into focus groups. As outlined above, capacity building then turned to a brief education about the method and practice of focus groups. The lead researchers spent two sessions explaining the principles of the focus group method before then facilitating five weeks of focus groups led by Conrad (on two occasions), Denys, Bandit and Jacqueline (in place of Conrad when he was absent).

It was proposed that the SURs take it in turns to moderate, observe and scribe the focus groups. Although there was an enthusiasm to lead and participate discussions, all SURs claimed that they could not make notes for the use of the project. As a stimulus for focus groups, Bandit and Conrad offered to present something they had already written, and Conrad subsequently wrote more narratives for the group (see appendix 6). Denys started a focus group with a piece of writing that he found influential and subsequently wrote something for use in the group (see appendix 6). All focus group interviews were then transcribed.

2.4.1 Doing the analysis

In March and April 2005 the group began to consider how the focus group data might be analysed. All the RPAG members had backgrounds in the analysis of interview data using grounded theory methods and attempted to enable the SURs to undertake their analysis more through the process of doing it with them than by any detailed instruction of the processes and principles of grounded theory. The lead researchers explained how interview data are commonly analysed by first identifying interesting/ rich points within transcripts. We issued SURs with highlighter pens and copies of the first two focus groups to undertake this task. We explained that analysis could then proceed by the group coming together and sharing with each other what extracts they had chosen from the transcripts as significant, explaining that group discussion could then lead on towards the group agreeing what were rich points within the data and why they were significant. Unfortunately, only two of the SURs attended this first analysis meeting, though this basic lesson in analysis was repeated in the next and future meetings. Over subsequent weeks we pushed ahead with analysis, repeatedly re-explaining what it was that the team had now agreed to do with its focus group data.

SURs were repeatedly given copies of transcripts, highlighters and pens to undertake handwritten analysis at home and then bring to the meetings. Conrad was an enthusiastic analyst, bringing to meetings extensive notes. Two of the SURs highlighted excerpts and made brief notes while others came to meetings ignoring the fact that the task of analysis had been set. Although most members were able to contribute to the discussion on the day, though not always about analysis of the transcript, some SURs occasionally asked what was happening now, why were we working towards an end, and why could the group not just continue indefinitely? The reality was that the project was going to end and that the team were required to produce some outputs. Four sessions were devoted to the analysis of three of the focus groups. Analysis of the last focus group on medication was undertaken completely by the lead researchers.

Further analysis, towards the identification of themes within the focus group data and data that occurred in other group discussion elsewhere in the project, were finally carried out by the lead researchers, using open, axial and selective coding (Strauss and Corbin 1990).

2.4.2 SURs' involvement in doing the research

Undoubtedly the project was successful in enabling SURs to undertake research that could be said to be theirs. Having set their research questions they produced three main forms of data: focus group transcripts, reflective writings and an interview with a policy maker. Furthermore, they then went on to play a significant part in the analysis of their focus group data. Conrad, Denys and Bandit had been inspired to write about their experiences in the knowledge that it would be read and might have some impact on others. Though their well prepared interview with Jim was, perhaps, not as lively and penetrating as those conducted by Jeremy Paxman or Andrew Marr, it was one further step towards realising the ideals of participatory research, for it reversed the power balance of traditional research such that the research subject (a Programme Director at the London Development Centre for Mental Health) was interviewed by people that would have not normally spoken to him as researchers.

2.5 Dissemination

As previously mentioned, the task of dissemination featured throughout the project. The table below summarises main presentation and news features in which the project had been publicised.

Table 7: Output so far

November 2004	Fmh conference	Poster
December 2004	City University Health Care Research Unit In-House Seminar	Oral presentation of poster
January 2005	IoP MSU conference	Oral presentation with powerpoint
March 2005	Three Bridges In-House Seminar	Oral presentation with powerpoint
May 2005	Mental Health Nursing journal	Journalist written piece.

Denys joined us in the audience at the IoP conference, though two others had promised to also attend. A SUR had promised to come with us to make a presentation to the staff of a forensic unit in West London, though failed to turn up.

SURs became familiar with the monthly mental health open seminar. The lead researchers managed to get a slot for the SURs to make their own presentation about their work in the new academic year's programme. Some SURs welcomed the opportunity, making suggestions and making tentative plans for it.

Conrad suggested the title and he and Eric helped the lead researchers towards drafting the abstract (below).

Seminar presentation

Mental Health Department Seminars: 10th November 2005
Forensic Service Users Perspectives on Therapeutic Relationships

This presentation is based on the findings of a DoH Forensic Mental Health (fmh) sponsored research project in which service users explored their experiences of forensic mental health care. Based on data from focus groups and written narratives of reflexive consideration about receiving care, service users will report on how the therapeutic relationship is experienced when a person is: in prison, held indefinitely in hospital or recovering in the community.

How do service users understand the therapeutic relationship that nurses claim to have with their clients when they are subject to: control and restraint, seclusion and enforced treatment?

In answering this question, the presentation will concentrate on issues of trust, compassion, friendship, healing, honesty, collaboration and mutual understanding between service users and those who provide services for them.

To be presented by a team of
service user researchers and research project advisers

Perhaps the greatest achievement of the project in terms of dissemination will be the forthcoming seminar presentation that will give SURs the opportunity to address an audience of mainly nurses about issues of care that concern the SURs from the position of people that have researched the issues.

How the report was received

Before submitting the report for review the summary report was circulated to all SURs and RPAG members for comment. Conrad thought it highlighted much of what the group had been concerned about, Denys called it 'very accurate' but Steve said that it lacked excitement.

The report received a rather mixed reaction from the three fmh reviewers, (see appendix 7). The reviews were discussed by the whole team in the first of the October dissemination meetings. Steve was affronted by the accuracy of his data confirmed a detail questioned by one reviewer. The full time researchers wrote the team's main response to these comments, with a further rebuttal by Conrad's (appendix 8).

3 Findings

As previously mentioned, the project has produced two types of findings. First, it has produced findings about the process of undertaking participatory research in this uncharted area. Secondly, it has created illuminative findings produced by the SURs about their experiences of forensic mental health care.

3.1 Process Findings

Our extensive methods section already provides a detailed account about how this attempt to involve service users in the research evaluation of forensic mental health care was realised. In summary, the lead researchers agree that it was closer to our hopes for the best than our preparations for the worst. Seven service users were recruited to participate as researchers who all stayed with the project for four to nine months, contributing their time, experiences and ideas to developing the project (to different degrees). Above all, they became involved in it to produce a useful research study and have got something out it themselves.

In some respects the SURs limited their involvement. They often failed to turn up and/or arrived late and failed to do the work they had agreed to undertake (analysis of data, preparation for interviewing and writing of pen portraits). SURs were reminded that such limited involvement would inevitably restrict their final output. However, SURs received full payment for the meetings they attended, regardless of whether or not they were late or had undertaken project work. Despite these limits to SURs' involvement, in a series of meetings they completed a research project in which they were substantially involved, formulating research questions and then producing, analysing and disseminating data. Furthermore, the project traversed the oppressive researcher and research subject divide, as SURs were simultaneously both. They were their own, rather than a powerful other's, research subjects.

That the project took place in a University, beyond the clinical gaze of health care services, undoubtedly helped maximise the opportunity for SURs to freely participate in the project and contributed towards its overall success. In a culture that stressed learning rather than therapy as its central goal, SURs could be assured that it was in service provision rather than in them that the project sought to effect change.

SURs were able to feel that they were valued members of a team, working alongside academic (rather than clinical) professionals, engaged in a project to evaluate forensic mental health services. Their importance, and that of the project, was underscored by meeting in a newly furbished committee room with refreshments to hand. Unlike many other groups they had been exposed to, primarily intent on bringing about changes in them, the project enabled SURs to produce knowledge that might bring about changes in services. This is not to say the project did not have an effect upon the lives of the SURs. As mentioned, they pointed towards the financial and personal benefits they had gained from taking part. Furthermore, consideration of their experiences of

services they had received indivisibly involved consideration of themselves, which evoked both painful and angry emotions in SURs.

The main lessons that this project taught us (the lead researchers), which we would like to convey to others can be summarised as follows.

First, securing the involvement of service users of forensic mental health care has its own unique challenges. It is very different from researching the user's evaluation of, for example, service in a restaurant or shop. Not only are forensic service users reluctant to identify themselves but they are also very reticent to explore their experiences of the services they have received as it indivisibly involves a re-evaluation of their past and a challenging exposure of themselves.

Secondly, for the reason given above, recruitment is very difficult. It cannot be done simply through advertisement or through key-workers suggesting to their clients that they might like to take part. The lead researchers had to actively seek out potential recruits and persuade them to join.

Thirdly, though CPNs and other mental health care workers were vital in our recruitment of SURs they may unwittingly, with the best of intentions, impose pressure on the clients to participate.

Fourthly, in recruitment, it became apparent that some interviewees might have preferred to be engaged in such a project on an individual basis. Therefore, future research in this area might be done that is not dependant upon a group of SURs meeting regularly.

Fifthly, past experiences of research and treatment regimes shaped recruits' expectations of what our proposed project would entail, which discouraged many from taking part.

Sixthly, service users were attracted to join the project for a number of reasons, including a desire for self-improvement and to inform improvement in service delivery.

Lastly, despite these and other difficulties, it was possible to recruit a group of SURs to collectively work together to successfully complete a research project in which they were substantially involved. Furthermore, their participation stretched to the point of them undertaking analysis of their own data and dissemination of their findings.

3.2 Findings about SURs' evaluation of forensic mental health care

The research findings are reported in relation to the three interrelated research questions that the SURs set themselves at the early stages of the project. The main research question posed by the SURs was: *'How and why is the experience of using forensic mental health care/services fundamentally*

bad?' Corollary questions to this main question were: '*How can forensic mental health care services be improved*?' and *'How can forensic mental health care service users move forwards from the experience of being in forensic mental health care*?'

The following draws on the data that the SURs produced towards answering these key questions. These data comprised of individual and team discussions, the written work of SURs, an interview with Jim Symington from NIMHE and, above all, focus groups and their analysis.

3.2.1 How and why the experience of using forensic mental health care services is fundamentally bad?

'A Very Psychiatric Christmas' (appendix 6) was produced by Conrad to illustrate how bad his experience had been. After reading the piece in the first focus group Bandit summarised his own experience as *It's bad all of it. Bad all the way along*.

Though SURs agreed it to be axiomatic that using forensic mental health services was fundamentally a negative experience, the data demonstrated that this assertion required qualification. As SURs recounted bad experiences of using forensic mental health services they contrasted them against better ones.

> *I wouldn't call what I've had in the first eight years* [medical care] *good – but when I was transferred to* [a private forensic unit] *I was respect. Total. The interaction with staff was brilliant. It was brilliant. And when you are there, the first two weeks was maddening 'This isn't right. They're too nice.' But that is what it's actually like there … you could kick off every day and the respect they have for you, and the rights that you have, you still have …* (Steve)

Some institutions, treatment regimes and service providers were described as being better than others, to the extent that it was recognised that some organisations, treatments and mental health care practitioners could even be described as 'good'. Most noticeably, the various institutions within the range of secure provision were recognised to have positive and negative features that differentiated each from the others.

3.2.1.1 Comparing institutions

Between them the team members had experienced being in special hospitals, NHS medium and low secure units, private provision, prison and acute psychiatric wards as well as receiving community care.

The special hospitals were described by two SURs as brutal places with power structures where you were kicked around and known by a number rather than by your name.

They were seen as places that generated continual tension and conflict between patients and between staff and patients. As one potential SUR explained in our recruitment interview with him:

> *You go in knowing you've done something terrible and you need to come to terms with it and find a way to make sure you never do it again but the environment is not conducive to that, as you are always being antagonised and you are always thinking of that incident when somebody was winding you up half an hour ago* (from fieldnotes)

In special hospitals, and all secure mental health in-patient provision, patients were subject to indeterminate periods of incarceration. This was described as a major concern that caused service users to lose self-esteem, self-belief and, above all, hope about having any future beyond the institution.

In comparison to special hospitals, prison had been a manageable experience where the staff allowed prisoners greater autonomy. Prisoners were only expected to conform to prison rules and were not expected to perform in a way that would suggest improvement in their mental condition.

> *The screws leave you alone and you can have a laugh with them sometimes'*. (Steve)

Furthermore, in prison there was a reassuring clearly defined time limit to one's incarceration. All one had to do to get out was to do time.

However, prison was recognised to be a '*harsh*' regime, particularly by those who had experienced both prison and medium secure units

> *Prison is worse, prison is hell. When you do 23 hours solid, every day … locked behind a door.* (Denys)

By contrast, nurses in health care institutions were thought to be continually observing, judging and reporting on one's behaviour.

> *If you are messing about, and they might advise you 'Don't do that, it will go against you.' – But the nurses, they don't. They just go and say you think this, this, this, 'He is getting like this, he is saying this, he is reacting like this. And we think it will lead to this.' You know! And sometimes, they don't even talk to you about what you are doing. They just leave you.* (Eric)

A private secure unit was described as a haven, with attractive environments, caring staff and good policies that empowered service users by SURs who had also experienced special hospitals and MSUs. The private unit was particularly commended for its emphasis on treating its patients with respect. Bandit recounted experiences of nurses forming caring one-to-one therapeutic relationships with the patients. The inclusion of service users in appointing staff was also recognised as another way in which service users were respected. Yet, despite praise for this institution, SURs described specific

incidents of bad practice taking place within it. In particular nurses were said to have collaborated with each other in telling untruths about the events of incidents that had been officially investigated.

The main inpatient care experienced by the SURs was within MSUs. The individualised care provided here was seen as having less pleasant aspects, as it was often very demanding. SURs felt under continual pressure to perform in therapy sessions, groups, occupational therapy, ward rounds, etc. They felt they were being judged by their performance, and that their future progress to release depended on this. Furthermore, the demands and judgements of the regime were not always seen as fair or helpful. Yet as Ernest said of his time in an MSU (and prison) *'of bad comes good'*, explaining that the environment encouraged him to read his first book and undertake studies, that might have not otherwise have done. Sheriff's pen profile (see above) also conveys a similar desire to turn a bad situation into a better one. Another feature of MSUs, noted particularly by Eric, was that in their control of patients staff adamantly denied their actions to be punitive, a claim that SURs did not regard as very credible.

In-patient care, as a whole, was described as being unsafe in several respects. First, SURs felt vulnerable to what they saw as the unwanted effects of drug treatments that caused them to lose cognitive abilities, energy, sexual and other functioning and often resulted in considerable weight gain. SURs were highly critical of doctors that Conrad described as often taking a '*cavalier attitude*' towards service user's concerns about the side effects of medication and its failure to produce a therapeutic effect. Secondly, SURs complained that they could not secure their personal property in hospital, and that staff dismissed incidents of theft as inconsequential. Though this could be tolerated when admissions were short term, for long term patients this resulted in them being unable to enjoy the security of any personal possessions for years. Thirdly, SURs described being at the mercy of a regime that they felt could not be trusted to act in their best interest.

Some of the above issues about personal security were even more relevant to SURs' experiences in acute psychiatric wards, which were seen as too busy to provide any helpful individualised care. Furthermore, acute wards were seen as chaotic, stressful and unsafe.

Five of the SURs live in the community and are supported by Forensic CPNs and outreach workers. Although pleased to be in the community, they are critical of the support they receive there (see 3.2.3 below).

3.2.1.2 *The therapeutic relationship*

SURs spoke a great deal about how the interpersonal encounters and relationships with nurses and other professionals assisted or impaired their progress towards recovery.

Discussion established that the relationship between patients and professionals was qualitatively different to friendship, yet SURs indicated that they still expected elements of friendship, such as understanding, empathy, trust, honesty, loyalty, compassion and respect, to be present in their

relationships with professions. SURs gave countless examples of these qualities being absent in the staff that had cared for them. SURs often described staff as manipulative, uncaring and wanting to provoke conflict (descriptors that strikingly mirror those sometimes used by mental health professionals in their parlance about patients).

In particular, SURs described their resentment of the greater power of mental health professionals that they thought was used to discredit the patients' voice, such that complaints procedures were rendered impotent as staff conspired in falsehoods against patients.

Apart from such dishonesty, mental health care professionals were seen as being economic with the truth. Most strikingly, SURs expressed the view that professionals rarely shared their thinking about patients with them, such that there could be very little real partnership or shared decision making in care. This was expressed most acutely by Ernest who described his psychiatrist as trying to test his potential aggression by provoking him with

> *"I cannot cure you – you are going to be ill for about twenty years – all the medication can do is keep the lid on it – I got no better news for you". He's playing mind games with you.* (Ernest)

This comment, like many others made by SURs, illustrates an impression they held of staff holding a hidden, undeclared agenda in the prosecution of their work. SURs were therefore continually second-guessing the intensions of staff.

The phrase 'playing the game' was used on many occasions in team discussion to describe the process of relating to mental health care professionals. In a recruitment interview one potential SUR told us how acutely aware he had been when in a special hospital of the expectation of staff on patients to play the game. He had concluded that to do so was not a good strategy, for, to unconditionally agree with a doctor's assessment of you and his/her treatment regime left you vulnerable. He explained that though acquiescing to a doctor's treatment ideology might help you progress, the doctor would then leave and be replaced by a different doctor with a different treatment ideology and assessment of what was wrong with you and what you should be doing to get better. The service user felt that he needed to develop a more durable independent understanding of himself, that he felt conventional mental health services did not facilitate.

Good therapeutic relations were associated with staff who were prepared to be flexible in their approach. One story was of a social worker who brought her dog to be walked by Steve in the grounds of the hospital.

> *My social worker, she had a … Labrador, she used to bring him for walks … I was allowed to walk the dog around the grounds. I'd be there all all afternoon It is so relaxing, I come back on the ward after, and I was so relaxed and cheerful and happy, that the doctor asked [SW] to*

bring the dog in every week... Pet therapy. And it really does work. And that is what we did each week. (Steve)

Another story involved a ward manager who trained Bandit to undertake tasks in the ward and took the SUR on errands in his car driving at high speeds up the motorway. Reflection by SURs on the legitimate nature of such activities was limited.

3.2.1.3 *Allocation of blame*

Team meetings, written pieces and focus group discussion frequently revolved around establishing why incidents experienced by SURs had resulted in conflict, violence or other undesirable outcomes. Bandit's initial account of his private hospital experience was that: '*the staff, they're not trained enough to cope with the situation. They end up being aggressive'.* However, he acknowledged that there was: '*something wrong with the system*' and that individuals were not wholly to blame.

Denys pointed to the lack of foresight of his colleagues for contributing to the situations that led to their bad experiences. After prolonged discussion about Bandit's experience of trying, unsuccessfully to obtain help, when short of money (see appendix 6), Conrad analysed the incident as indicative of the following: the system makes you dependent on it, then it treats you badly when you try and depend on it, then you get frustrated and react, then the system punishes you for your reaction. However, overall it was argued that staff could be more understanding and tolerant of patients' challenging behaviours and that the behaviour of staff was often challenging for patients.

3.2.1.4 *Labelling and Stigma*

Early team discussions focused on the notion that falsehoods about service users were accumulated in their medical records, which lead them to receive negative labels that then prejudiced the care they received. As we have seen, SURs considered the idea of accessing and examining their records as a worthwhile research exercise, though they later abandoned the idea.

A number of SURs expressed the view that stigma was the greatest disability that they had to deal with. This stigma operated within and outside of psychiatric services. Some SURs objected to doctors' eagerness to apply diagnostic labels towards a categorical understanding of them, preferring the open minded enquiring questioning of psychologists. However, SURs generally accepted the diagnostic labels that had been assigned to them. Sometimes this was done grudgingly, as Sheriff said of his diagnosis: '*I accept it but I don't believe it* '. It was also recognised that diagnostic labels served to usefully explain and excuse their behaviours of the past that they now regretted. Yet SURs were also acutely aware of how diagnostic labels of mental illness served to discredit them, both inside and outside of institutional care.

Denys made the interesting observation, by way of a lengthy example, that the label of being a 'mentally disordered offender' evoked both expectations

amongst staff that patients would react in a deviant manner, and deviant behaviour amongst patients, conforming the label they had been ascribed.

Though SURs recognised the power of diagnostic terms as labels, they sought a degree of closeness to psychiatric discourse rather than distance. Some SURs openly proclaimed themselves to be 'manic depressive', 'schizophrenic' and 'psychopathic'. Furthermore, SURs would explain themselves and one another in terms of ideas and concepts that appeared to emanate from mental health care professional discourse. Conrad spoke of how a psychiatrist had convinced him that mental breakdowns caused damage to the hardwiring of the brain. Eric spoke of how medicine to the body was like fuel to a car. Taking a more psychologicistic approach, another SUR described one of their peers as: '*playing the victim role'* and '*denying responsibility'*.

Though SURs often revealed the diagnostic terms that they had been assigned, they were far less willing to disclose details about the offences they had committed, perhaps illustrating the greater stigma of criminal deviance.

3.2.1.5 *Religion*

For a number of the SURs religious beliefs were important to their self-understanding.

Conrad clearly demonstrates this in his written piece, 'A Very Psychiatric Christmas' (appendix 6). SURs acknowledged that in times of crisis and difficulty, such as when held in prison or secure provision, people turn to religion.

Denys suggested religion as a topic for our second focus group, volunteering to lead it. He began the session by reading an extract from a Watchtower[9] publication instructing young people that might feel ugly and unclean to know that God loved them. The reading emphasised that cleanliness could promote a sense of purity and holiness. The reading resonated with other SURs who readily identified with the experience of feeling unclean and a social pariah. Bandit expressed frustration about women that he attempted to chat up, shunning his advances. Further discussion revealed that lack of material success compounded SURs' feelings of being unclean and unattractive. Denys offered the consoling view that: '*God is saying that your heart is clean*'.

Conrad suggested that mental health professionals have lost sight of the healing potential of religious beliefs. Both Eric and Conrad complained that the secular mental health care system sometimes trivialised their beliefs as a potential symptom of mental illness. Eric recounted how his CPN had got him to look at a set of cards, each with a statement about experiences, in an attempt to enable him to identify warning signs of him becoming mentally ill. Eric remembered that one of the cards stated '*being over religious'*. Eric asked *'how do you even rate that? … what magnitude is being over religious?'*

[9] Watchtower is a text of the Jehovah's Witnesses

Other SURs cited examples of patients being prevented from engaging in religious practices. Though Conrad said that his Christian religious needs had often been accommodated within hospital, for example with visits from a priest, a Muslim interviewee said that he had been unable to see an Imam and that the unit he had been in failed to make adequate arrangements for Friday prayers. Conrad speculated that staff undertook a sort of cost benefit analysis regarding people seeking religious support, as he stated:

> *I think the way they deal with religion in hospital is that they ask themselves 'is religion part of the reason why you got ill, or is it part of the way you are going to get better?' And if it's the latter then they are quite happy for you do what ever you need to do religiously.* (Conrad)

As elsewhere, Conrad's comment illustrates a level of not really knowing that SURs had about the true intentions and purposes of the staff that cared for them.

3.2.1.6 *Cultural difference*

The focus group about religion was also intended to address culture and cultural differences. However, the session remained focused on religion. However, culture often featured in team and focus group discussions, though somewhat tangentially. SURs perceived racism as operating in several different directions. Ernest believed racist stereotypes of black people informed psychiatric thinking and practices. Sheriff thought that Asian doctors were particularly racist towards black patients, whilst Conrad thought black nurses were racist against him. Bandit thought African nurses exercised racism against African patients of a different nationality from their own (see his pen profile above).

It was acknowledged that hospitals try to accommodate culturally specific diets, but that the specially prepared food was sometimes inappropriate and often cold (Halal Brussels sprouts being the most memorable reference).

Eric related a story of a family visit having to be conducted in English so that the observing nurse could monitor the conversation. Some of the family had poor English and the conversation was, therefore, very limited.

3.2.1.7 *Medication*

The last focus group (over two meeting) was led by Conrad who began by reading one of his written pieces on this topic (see appendix 6). SURs described experiencing psychiatric drugs as a powerful force with significant side effects. Ernest described gaining weight

> *and you are sitting there and taking this medication and he* [doctor] *is saying what's gonna happen, he's gonna stabilise you're gaining this weight and I don't know for other people but when they put me on ---- for the first time I was gaining weight right – I was in –like – I dislike myself because it was like looking in the mirror and not seeing myself –* (Ernest)

SURs commonly experienced receiving large doses of drugs when first admitted to hospital that not only led to considerable weight gain but also induced sleep. As Steve put it: '*all I wanted to do was sleep all the time – I mean – it knocks you for six*.' In response, Conrad speculated:

> *I think they do that to you sometimes on purpose – 'cause they look at you, you know, and say this person hasn't really slept much over the past months so for the next two weeks they give something that will make them sleep. I am certain.* (Conrad)

Again Conrad's comment illustrates how SURs guessed what staff's intentions were rather than reporting what staff said. Though medication might induce a much needed rest it was also recognised to knock you out when you needed all the personal resources you could muster to deal with an unsafe in-patient environment.

SURs expressed the view that doctors were very economical with information about medication and allowed little opportunity to reach a concordant view with them about it. As previously stated, doctors were accused of brushing aside patients' concerns about undesirable side effects and the failure of drugs to produce any perceived therapeutic benefits. This is perhaps best illustrated in Steve's account of his eight years in a special hospital, where he remembered feeling desperately embarrassment when he grew breasts, as side effect of the medication he was taking. His pleas to have his medication changed were continually ignored, whilst staff taunted and teased him, until he was transferred to a medium secure unit where his psychiatrist changed his medication to eradicate the problem.

In the focus groups there was also a little discussion about the absence of alternative methods of treatment, such as counselling made available.

Bandit recounted stories of a fellow patient being overmedicated and subsequently dying, and a tale about a ward being used in a covert improper drug trial experiment. It appeared that SURs felt that drug treatment was a major way in which their sense of self and integrity of self were substantially challenged.

3.2.2 <u>How things could be better</u>

When SURs agreed to present their work to a City University open seminar they chose the topic of the 'therapeutic relationship'. Possibly this indicates that it is here that they thought change was most needed. As stated earlier, SURs thought that staff/nurses needed to improve the level of understanding, empathy, trust, honesty, loyalty, compassion and respect they showed to patients. Though SURs could readily cite examples of where these qualities were absent and, less frequently, present, deciding on a good solution for improvement was more difficult. SURs advocated better training of staff, informed by the service user perspective, which their prospective presentation is a step towards. The therapeutic relationship is a topic that cuts through all the aspects of care discussed above. For example, Conrad asserted that

medication (despite its impersonal nature) could be far more efficacious if drug treatment decisions were agreed in fuller partnership with patients.

In their carefully prepared questioning of Jim Symington from NIMHE, SURs indicated the areas and issues that desired improvement to be made in services. They asked Jim to explain how forensic mental health care policy might be improved to enable discharged patients to gain work (without loss of benefits), and to overcome stigma and prejudice. Eric asked questions about whether services were racist and, if they were, how might this problem be overcome. Steve asked about how might good practice be generalised. Conrad questioned how safety of service users and accountability might be better monitored through independent means.

Perhaps more than anything else, SURs wanted greater transparency, openness and honesty in relationships with those that cared for them. Without it they distrusted those that cared for them, whilst fearing for their safety and future.

To this end Conrad suggested a regime in which all ward matters are talked about in meetings of both staff and patients, perhaps reminiscent of therapeutic community regimes of the era of social psychiatry. Also suggestive of bygone psychiatric practices, Ernest and Conrad recommended that patients could be employed to do jobs whilst patients within hospital, to give them a sense of worth and esteem. With a prospective view, Ernest pointed towards the pioneering practices of a South London mental health care trust in giving employment opportunities for discharged patients.

3.2.3 Moving on

SURs repeatedly spoke of the experience of in-patient forensic mental health care as like being in a hole. In the pit of despair, without any clear sight of release and a multitude of influences (such as niggling interpersonal ward based conflicts and the tranquilising effect of medication) pushing down on you, progress appeared like a near impossible uphill struggle. The struggle required hope and determination, which are difficult to muster when you are ill and in hospital. Denys portrayed himself as having overcome such adversity and criticised others for not being able to rise to the challenge. SURs spoke of ambitions to get started in life, with a job and a partner and money in the bank.

Though Denys asserted that they needed to just forget the past Sheriff pointed out that their future life trajectories would inevitably involve mental professionals checking up on them and ordering their lives. Conrad spoke of how they needed to ensure that their: *'past did not become their future'* by recognising what might trigger deterioration in their mental health. Perhaps most strikingly, SURs yearned for employment. Participating in the research was part of building this future. Steve aspired to work for a supermarket collecting trolleys. He continued with the project partly because he had so far been unable to get such a job. At least two potential recruits had preferred the supermarket option to joining our team. Bandit asked us to help him find a cleaning job in the University. When the group reconvened to plan their

seminar presentation in November 2005, Bandit announced that he had secured a job as school crossing controller (lollypop man), subject to a CRB check. Denys talked about enrolling on an IT course at university and saw his participation in the project as working towards this goal. Eric and Conrad intended to continue with research activity.

4 Conclusion

This project enabled a group of forensic mental health care service users, with no previous experience of undertaking research, access to, and control of, the means of research production. However, this freedom was restricted in two key respects. First, the SURs were employees of the RPAG members, not the other way around. Secondly, they were engaged in casual, part-time employment, for a limited period.

It is always easy for research project leaders to excuse the limited success of their study by saying that they would have done better with more resources. We too would, of course, make this claim. However, it is perhaps worth briefly reflecting on what appeared to work more or less successfully in the project.

The planning stage towards making the research bid and ethical approve went quite well. Having found a partner organisation the RPAG soon agreed the aims and objects of the research (though officers of the partner organisation proved to be unreliable in subsequent contribution to the project). Despite fearing that the ethics committee would object to a project founded on tenets of participatory research, vehement despised by many, the MREC agreed approval, wanting only a few points of clarification.

The recruitment process proved every bit as difficult as we feared. Perhaps somebody could consider our detailed account of our endeavours and provide us with some realistic advice as to how we might have improved matters.

Within the limits of the research project the capacity building that we undertook was adequate. However, were we to have undertaken a bigger project involving SURs in more research activities then we would have had to think carefully about how capacity building was to be managed so that they would not fail in their research work. Associated with this issue is the difficulty of coping with people whose disability prevents them from consistent performance. How should lateness, absence and failure to undertake work be managed? We resolved to largely excuse it sympathetically and demonstrate that we still wanted and valued people whilst pointing out on only a couple of occasions that it would inevitably limit the success of the project.

In setting the research questions we might have insisted that their first research question was more neutral, so to avoid the disapproval of those unfamiliar with participatory research who branded us unscientific and without objectivity. Yet, as we argue in the revised report and our response to the fmh reviewers, it was probably better to go with the main research question the

SURs had chosen rather than to insist that they change it, thereby acting against the principles of participatory research.

The data collection went quite well and the focus groups in particular involved lively, if not always entirely focused, discussion. The group formed in a way that allowed for open discussion, though unfortunately one SUR felt too agree with the behaviour of another to be able to continue and then stopped coming. The lead researchers made it clear to the SUR who withdraw from the group that his contribution was valued, and when the group reconvened after the project was completed to plan their seminar presentation he rejoined.

Though the lead researchers undertook the final analysis of data, SURs did get involved in preliminary analysis of their data, some much more than others. At the end of the project the analysis in this report was approved by the SURs and adopted in their presentation.

Closing the group was difficult, as some SURs wanted the group to continue indefinitely. However, the ending of the group was punctuated on a high note with a meal at an Indian restaurant. On reflection a number of RPAG members said they felt rather peripheral to the project, feeling that they might have done more had they had time. Though very enjoyable for the lead researchers, the project was very hard work, consuming a substantial part of our working week. We devoted a considerable amount of time to recruitment, the organisation and running of meetings, sorting out pay, publicity and report writing. A more ambitious project of this sort would certainly require more human resources.

Though we were fairly pleased with the report it met with a mixed response. Had we more thoroughly explained our methodology we might have avoided the severe criticism of one of the reviewer who does not recommend wide dissemination of the report. However, a greater explanation of our methodology might just have riled the reviewer further.

Finally, we were a little disappointed that we were not more successful in persuading the SURs to take part in presentation of their work, though we are now optimistically working towards a presentation with them in November, which will be a major achievement for the SURs, if it is successful.

This innovative project took the risk of transgressing the normal procedures of traditional, scientific and respectable research to pioneer participatory research in forensic mental health.

A City University newsletter article conveys the sentiment of what this and other user involvement projects within City University School of Nursing attempt to do, namely to put service users in the driving seat (http://www.city.ac.uk/citynews/archive/2005/05042005_2.html). This is, perhaps, a useful metaphor for evaluating the degree of involvement and control SURs had in this project.

The lead researchers and other RPAG members took more than just a backseat driver role. We were like a very anxious driving instructor, frequently touching the steering wheel and dual controls, when SURs took their hands of the wheel and feet off of the pedals. In particular, when SURs showed an interest in undertaking an ill-conceived user focused monitoring study, we stopped them from driving up, what we thought to be, a dead end. Yet the car was not crashed, and (at the risk of sounding trite) it was driven along an interesting route. The fmh reviewers of the report accused us of both taking too much control and too little control (see appendix 7). Had we given more direction we would have reduced the amount of user control of the project. Had we sat back, only acting when instructed to do so by the SURs, then we could have been criticised for not adequately supporting the SURs. Like all dilemmas the problem is beyond any definitive resolution.

On the whole, both RPAG members and SURs enjoyed, learnt from and otherwise benefited from undertaking the project. Furthermore, the project produced useful findings; both about the process of involving forensic mental health care service users in research and about their reflexive evaluation of experiencing services. These benefits have not been gained without the risk of failure. Undoubtedly we shall have critics discrediting our findings, not least for its lack of 'science'. On this point we were quite correct (see reviewers comments, (appendix 7)), as two of the three fmh reviewers criticised our research for its lack of objectivity. However, as Telford and Faulkner caution, this is just one amongst many barriers to the development of user led research in mental health:

> *The debate about objectivity may present another barrier to the involvement of service users in research. The stereotype is that clinicial researchers believe themselves to be objective and "scientific", and service users to be subjective, and unscientific with unrepresentative views.* (2004: 554)

The success of the project was only possible as a result of an academic institution and our sponsor's willingness to be flexible enough to meaningfully involve forensic mental health care service users in research. It produced an open dialogue about what SURs found inadequate about the services they receive and how they wish them to be better. Though two of the reviewers have fixated on the SURs criticisms, much is said about what they liked about services. Many of these findings may not be a surprise to service providers and may affirm that what are widely regarded to be good policies and practices are appreciated by service users.

However, perhaps the most important finding was how little service users felt they really knew about the intentions of the professionals that cared for them, often imaging them to be 'playing mind games', practising sleep therapy or illicit drug trials. SURs remarked how revealing the City University mental health seminars were as these events informed them of what mental health professionals researched and learnt about (something that had previously remained out of sight to them). What professionals discussed and wrote in their records was largely an unknown mystery to SURs.

Seemingly, just as forensic mental health care service users have been alienated from the means of forensic mental health care research production so too have they been alienated from the production of their care. Perhaps the question that needs to be asked is not: 'how can professionals provide a 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?' A solution might enable service users to feel less of a done to, vulnerable and poorly treated group of people that are second guessing what professionals are up to. In view of this, we might ask: why cannot Health Care Trusts employ service users in a variety of roles (not just in the evaluation of their satisfaction with services)? Why cannot academic seminars within mental health care institutions (as well as in a university) be open to both service users and staff? 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 mental health services, and particularly forensic mental health care, that militates against such change. This was most strikingly illustrated to me (Paul) through a focus group and subsequent analysis within this project, in which (in accordance with participatory research) I became their subject. Bandit described an incident in which a nurse had responded to Bandit's verbal threats by (rather roughly) physically restraining him. Bandit lodged a complaint. The nurse and his colleagues concocted a false account of what had happened. Steve angrily stated that '*the staff always stick together'*. I said that my experience as a nurse and researcher taught me that staff did not always stick together and that nurses sometimes felt unsupported by psychiatrists, which sometimes lead them to exercise illicit means to secure their personal safety and control over patients, such as that described by Bandit. In a subsequent meeting, in which these data were being analysed, Conrad identified this dialogue between Bandit, Steve and myself as a rich point, remarking that I was very honest in saying something that staff in hospital would be unlikely to admit, and said what a pity it was that staff and patients did not normally have an open discussion about such matters. Conrad's analysis had highlighted that though I could enjoy this discussion with Bandit, Steve and Conrad about forensic mental health services as a researcher, I do not think I could have so easily had as open a discussion had I been a health care practitioner involved in their care.

This disruption of traditional research by participatory research, in this discussion and elsewhere in the project, has produced useful findings about how service users experience the service. 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?

References

Carr W. and Kemmis, S. (1986) *Becoming Critical: Education, knowledge and action research.* London: Falmer Press

Crawford, M. and Rutter, D. (2004) 13(4) Representativeness of members of user groups, *Journal of Mental Health,* 13(4) pp 561-568.

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

Department of Health (2002) *NHS Research and Development Strategy Review of Mental Health,* www.doh.gov.uk/research/documents/mhfinalappendices.pdf (Appendix 5, pp 44-56).

Faulkner, A. and Morris, B. (2003) *Expert Paper: User Involvement in Forensic Mental Health Research and Development,* NHS National Programme on Forensic Mental Health Research and Development, Liverpool.

Finkelstein, V. (1985) Paper given at World Health Organisation Meeting, 24-28 June, Netherlands.

Floyd, M. (1984) The employment problems of people disabled by schizophrenia, *Journal of Social Occupational Medicine* 34(3): 93-95.

Heyman B Shaw M Davies J Godin P Reyholds L 2004 Forensic Mental health as a Risk Escalator: A case study of ideals and practice. *Health Risk and Society* 6 (4) 307-325

Krueger, R. A., & Casey, M. A. (2000). Focus Groups: A Practical Guide for Applied Research (3rd Ed.). Thousand Oaks, CA: Sage.

MIND (2004) Crisis What Crisis? The experience of being in crisis in Bristol. (Bristol Mind)

Oliver, M. (1992) Changing the Social Relationship of Research Production? *Disability, Handicap and Society,* 7(2) 101-114.

Patton, M (1990) *Qualitative evaluation and research methods, 2nd edition,* London, Sage.

Pollock, L. (2005) Inside out: research and forensic services, *Mental Health Nursing,* 25(3) p21.

Rose, D. (2001) User-focused monitoring, *Mental Health Care* 4(6) 207-210.

Rosenhan , D. (1973) On being sane in insane places, *Science,* 179, 250-258.

Schneider, B., Scissons, H., Arney, L., Benson, G., Derry, J., Lucas, K., Misurelli, M., Nickerson, D. and Sunderland, M. (2004) Communication Between People With Schizophrenia and Their Medical Professionals: A Participatory Research Project. *Qualitative Health Research,* 14(4) pp 562-577.

Scott, J. (2003) A Fair Day's Pay: A guide to benefits, Service user involvement and payments, The Mental Health Foundation, London.

Strauss, A., & Corbin, J. (1990). Basics of qualitative research: Grounded theory procedures and techniques. London: Sage Publications.

Telford, R. and Faulkner, A. (2004) Learning about service user involvelement in mental health research, *Journal of Mental Health* 13(6) pp 549-559.

Webb, C. and Kevern, J. (2001) Focus groups as a research method: a critique of some aspects of their use in nursing research. *Journal of Advanced Nursing*. 33, 6, 798-805.

Zarb, G. (1992) On the Road to Damascus: first steps towards changing the relations of disability research production, *Disability, Handicap and Society,* 7(2) 125-138.

(Appendix 1)

NHS NATIONAL R&D PROGRAMME ON FORENSIC MENTAL HEALTH
CALL FOR OUTLINE PROPOSALS
User Involvement in forensic mental health research
INFORMATION AND APPLICATION GUIDANCE

1. **Introduction**

The National Programme on Forensic Mental Health R&D was established in April 1999. It has built on the work of the R&D Programme set up as part of the High Security Psychiatric Services Commissioning Board, which was first established in September 1996. The Programme has the remit of supporting the evidence base for the provision of services for mentally disordered offenders by commissioning research and developing research capability. An Advisory Committee informs the Programme on the commissioning, dissemination and implementation of R&D. The Programme and its predecessor bodies have undertaken several exercises to determine research strategy and priorities with a range of stakeholders. Our strategy is also informed by national research priorities arising from the implementation of the National Service Framework for Mental Health and the NHS Plan. Information on research currently supported by the Programme and a series of expert papers on key areas of forensic mental health are available on our web site.
http://www.doh.gov.uk/research/rd3/nhsrandd/timeltdprogs/fmh/fmhrd.htm

In March 2003 the Programme Advisory Committee considered current national research and service priorities and identified the need to promote user involvement in forensic mental health research. The provision of mental health services for mentally disordered offenders involves health and criminal justice agencies and takes place in a range of settings including the community and prisons as well as specialist secure services. Work to involve service users in forensic mental health R&D must take account of specific issues relating to forensic services as well as building on the valuable work to involve consumers in R&D in the wider NHS. Details of this work are available on www.conres.co.uk
The Programme invites outline applications from groups or individuals to undertake a research project which addresses the concerns of users of forensic mental health services and clearly demonstrates appropriate involvement of users at all stages.

The outline proposal should
- Demonstrate how users are involved in developing the proposal and undertaking the research
- Address a question relevant to the quality of forensic mental health services
- Show that appropriate research skills and experience are available to ensure that the proposed research design will answer the question posed. We understand that this may be a developmental project. However all research involving NHS patients must be undertaken in line with the Research Governance Framework for Health and Social Care. This means that the research project must have independent peer review and the approval of the appropriate research ethics committee. The project will need management approval from the relevant NHS Trust or institution. It may be that groups or individuals with experience of forensic mental health services who wish to be involved in this work do not feel that they have the relevant research experience or skills available to them to pursue an application. The Programme will attempt to match people who express such an interest with appropriate groups or academic institutions, however we cannot promise that we will find a
match. The maximum project grant is £50,000.

2. **Assessment of Applications**
The National Programme will consider your outline application using the following criteria:
- The relevance, impact and importance of the research proposal for forensic mentalhealth
- The feasibility and scientific quality of the proposal
- The relevant experience and expertise of the research team
- Value for money

If your proposal is short listed we will ask you to develop a full proposal.

3. **General Application Guidance**
- All applications must be made on the standard application form. The application should be self-contained so that reference to any literature quoted is not essential tounderstanding the proposal.
- Incomplete or incorrectly completed application forms will not be accepted
- Forms are available on disk from Beverley Hilton (0151 794 4887). Do not use additional sheets for your responses;
- All information must be confined to the spaces provided. Additional information willnot be circulated.

• Forms must be typed using a font no less than **10 point**
• Faxed applications will not be accepted
• The attention of applicants is drawn to the Research Governance Framework for Health and Social Care
http://www.doh.gov.uk/research/rd3/nhsrandd/researchgovernance.htm
Standards in
this framework apply to all research which relates to the responsibilities of the Secretary of State for Health. This document sets out the responsibilities and standards that must be applied to work managed within the formal research context.
• Applicants are reminded of their responsibility to discuss patient care costs associated with this research with relevant NHS providers and to secure their agreement in line with the provisions of the operational guidelines of EL(97)77 http://www.doh.gov.uk/research/documents/noncomrd.htm . You will not need to provide a breakdown of these costs at the outline proposal stage – but these will berequired at the full proposal stage.
• For information and guidance on how to involve users in research please access
http://www.conres.co.uk

4. **Notes on completing the Application Form**

Section: 1 COVER SHEET

• **Project Title**

This is the project title by which the project will be known and which will be used in all correspondence.

• **Lead Applicant Details**

If there are more than four additional applicants, please give details on further pages.

Section 2: RESEARCH PROPOSAL

A: Summary of project

Please provide a summary of the research topic in lay language - the main aims, design and anticipated findings (do not exceed 250 words)

B: Relevance to NHS R&D Priorities

Please identify which NHS R&D Priorities the Project will support

C: Aims and objectives

Please specify the main aims of the research proposal and the expected achievements

D: Outline of project

Please include brief information on the following sub headings:
• the study design (how you will design the research to ensure that it will answer the question posed?)
• the subjects to be studied (who will be researched?)
• the data to be collected (what information will you collect from those involved?)
• the study procedures -including recruitment and access to information. (how will you go about obtaining the information?)
• data analysis and statistical support (how will you analyse the data you obtain?)
• sample size calculations (how many subjects will you need and how did you arrive at this figure?)
• research supervision arrangements (who will be leading the project?)
• expertise in the team (relevant experience and qualifications)

• Project timetable (how long will the project take?)
• For information and guidance on how to involve users in research please access http://www.conres.co.uk

SECTION 3 SUMMARY OF COSTS

• Please summarise the costs of the project. This should include salary costs (including NI, superannuation and pay awards, but not inflation uplifts), an estimate of travel costs for research purposes on public transport or at NHS private transport rate @ 30p per mile.

• **Please include costs which will payable directly to support user involvement under the appropriate headings**

• Please identify organisational overheads separately. These are payable at a maximum of 40 per cent of University salary costs.

SECTION 4: CURRICULUM VITAE OF APPLICANTS

Please complete a one page curriculum vitae for each applicant. Not all the sections may be relevant for consumer applicants- fill in as appropriate with experience and job history. Do not attach separate CVs as these will not be considered. Publications should be cited in the following format: Author(s), year, title of article, journal and first and lastpage.

SECTION 5 DECLARATIONS

Please ensure that this section is completed with the signatures of all applicants We welcome confirmation of the support of potential host organisations in the NHS and criminal justice facilities.

5. **Assistance Available**

If you have any queries or if there is anything you are unclear about please contact us before submitting your application

Kathryn Harney
Programme Manager
Tel No: 0151 794 5251
Fax No: 0151 794 5258 Email: k.harney@liv.ac.uk
Sue Spiers
Programme Officer
Tel No: 0151 794 5590
Fax No: 0151 794 5258 Email: sspiers@liv.ac.uk
Beverley Hilton
Programme PA
Tel No: 0151 794 4887
Fax No: 0151 794 5258 Email: bhilton@liverpool.ac.uk

PLEASE RETURN YOUR APPLICATION FORM TOGETHER WITH 25 PAPER COPIES and a copy on a floppy disc to:-

Beverley Hilton
National R&D Programme on Forensic Mental Health,
c/o HaCCRU,
University of Liverpool,
Quadrangle,
Brownlow Hill,
Liverpool,
L69 3GB.

Please mark the envelope "USER OUTLINE"
By 1.00pm June 16 2003

(appendix 2)

Have you used mental health care services in a prison, special hospital or secure unit? Would you like to evaluate these services?

forensic mental health

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

We would like to encourage you to join a research project to evaluate the services you have received.

We are health care researchers at City University and Revolving Doors Agency, sponsored by the DoH national forensic mental health R&D programme.

City University
Paul Godin
Jacqueline Davies
Bob Heyman

Revolving Doors Agency
Chandra Fowler

What will be our role?

- **We will support you in developing ideas and undertaking research**
- **We will support you in getting your voice heard**
- **We will provide the protection of anonymity and confidentiality**
- **We will provide an opportunity to work creatively with other service users in a convivial environment**
- **We will provide employment on a casual basis at City University, which might lead to further employment opportunities.**

If you participate, what are the benefits for you?

- **You will be employees of the University**
- **You will be paid an hourly rate of £6.38 for approximately three hours a week (payment should not affect DSS benefit)**
- **You will meet with other service users to develop ideas in a supportive setting. Refreshments will be available and the meetings should be enjoyable**
- **You will direct the research project from the outset**
- **Your voice will be heard**
- **You will be supported in developing your ideas and skills**
- **Your input should help improve services**
- **You may also find this project will provide you with further opportunities**
- **You may withdraw at any stage from the project. However, we hope you will find it worthwhile and wish to continue**

If you think you would like to be involved, please contact us:

Paul Godin 020 7040 5933 p.m.godin@city.ac.uk
Jacqueline Davies 020 7040 5886 j.p.davies@city.ac.uk

(appendix 3)

City University London

St Bartholomew School of Nursing & Midwifery

Ref 28 (ii) B 23 November 2004

Involving service users as researchers in the evaluation of forensic mental health care

Service user researchers are currently working together with City University academics and mental health care workers to explore how research can be undertaken to evaluate the hard end of mental health care (forensic services) with a view to informing improvements. The project team has already drawn up a programme of work with a view to starting research in early 2005.

So far eight service users have been recruited – but more are needed. They are employed by City University and have experience of receiving or trying to obtain mental health care in prison, young offenders units, secure units and special hospitals. With the support of academics and mental health workers they will carry out research drawing upon their experiences. Above all, the project aims to hear the voice of those who have been discredited and invalidated through the double stigma of mental illness and criminal behaviour.

The service user team has already identified the following research areas:

- How clinical records may be used unfairly against patients
- How bad psychiatric staff can provoke patients into violence
- Investigating how conditions in secure units lead to reoffending
- Evaluating the success of secure provision in terms of rehabilitation
- Showing how a lack of respect by service providers damages the holistic healing of service users
- Examining why there are no psychologists or counsellors on wards in secure units

The project is sponsored by the Department of Health's Forensic Mental Health R&D Programme. The programme has commissioned City University, in collaboration with the Revolving Doors Agency, a charity concerned with mental health and the criminal justice system, to develop this research initiative. It is hoped that the project will have research results by Summer 2005.

City University welcomes enquires from both forensic mental heath service users who would like to become involved in the project, and enquiries from professionals who would like to know more about it. Contact Dr Paul Godin on 020 7040 5933 or p.m.godin@city.ac.uk or Jacqueline Davies on 020 7040 5886 or j.p.davies@city.ac.uk

For media enquiries please contact:
Claudia Draper in the City University press office on 020 7040 5982 or 07815 304107, **c.draper@city.ac.uk**.

Notes to editors
City University, London is the university for businesses and professions with a strong focus on health sciences. It is a centre committed to scientific rigour and particularly the promotion of patient-centred services and multi-professional approaches to teaching and research.

(Appendix 4)

Health Care Research Unit

Have you ever used mental health care services in prison, special hospital or secure unit?

Would you like to take part in a research project of these services and get your voice heard?

We can pay up to £20 per week (which will not normally affect any benefits you may be receiving) until June 2005 to employ you as a service user researcher.

If you'd like to get involved, please get in touch with:

Paul Godin PhD ☎ **020 7040 5933**
p.m.godin@city.ac.uk

Jacqueline Davies MSc ☎ **020 7040 5886**
j.p.davies@city.ac.uk

We look forward to hearing from you.

(appendix 5)

Audit trail of minutes

Engaging Service users in the evaluation and development of forensic mental health care services.

Date	Attended		Topic
	RPAG	SURS	
1 Oct 2004	3	3	Welcome, posters, recruitment, HR
14 October	6	0/2	Seminar on action research: The City Nurse Project
2 Nov	2		FMH conference, poster presentation
11 Nov	4/5	4	Seminar on Therapeutic Relationships (Rose McCabe)
18 Nov	5	4	Overview of Research – Bob presentation
25 Nov	4	3	Rehabilitation and disability – Mike presentation
1 Dec	4		Presentation of poster to Health Care Research Centre, City Univ
2 Dec	5	3	FMH service user research – Keith Halsall
9 Dec	4/5	2/5	Stock take and Seminar: Young people and substance misuse
6 Jan 2005	5	5	Prepare for MSU conference at Institute of Psychiatry
13 January	4	4/6	User involvement in research (Ian & Alan) / Bowers lecture
18th Jan	2	1	MSU conference, IoP Oral presentation
20 January	5	5	A Bristol Study – Chandra and UFM.
27 January	6	6	Journalist (Laurence Pollock) visiting for interview
3 February	7	4	HR debrief on LP, rules of meeting, planning for project
10 February	3	3/6	Focus Group presentation. Seminar: therapeutic relations. Al. McE
17 February	6	5	HR, FG1: A Very Psychiatric Christmas
24 February	6	7	FG2: Culture and religion
28th Feb	1		Participation in PIN project through INVOLVE
3rd March	4	6	FG3 Bandit. Prepare for Three Bridges presentation
4th March	2		Talk at Three Bridges, Ealing. Lunchtime seminar
10th March	4/5	5/7	FG4 medicine.Seminar medicine in schizophrenia and asthma
17 March	6	6	FG4 (cont) prepare for Jim Symington visit
24 March	6	6	Prepare for JS visit. Circulate first transcripts
14th April	3/ 4	3/6	Discussion of methods to analyse focus groups: JS prep
21 April	6	5	Meeting with Jim Symington – recorded interview.
28 April	5	5	Analysis of FG 1 – CR led.
May			*Mental Health Nursing* :Inside Out: research and forensic services
5 May	4	4	Visit from Diane Hackney, an experience SUR
12 May	4/6	3 /4	Circulate LP article, Seminar:advanced directives. Chris Flood
19 May	5	5	10/11 presentation. Sue Spiers visit. Discuss the report
26 May	5	6	Analyse focus group 2 and 3.
2nd June	2	5	Analysis
9 June	4	6	Analysis
16 June	3 /4	3/5	Seminar: Diana Rose: ECT from user perspective
23rd June	5	5	Report writing
30 June	6	5	End of project – meal out.

1st October 2004, 12.30-2pm in the Committee Room, 24 Chiswell Street.

Present (in order of arrival):
Jacqueline (Research Fellow, minutes)
Steven (Service User Researcher)
Mike (Director of the Rehab. Resource Centre)
Paul (Convener and Principal Investigator)
Conrad (Service User Researcher)
Ernest (Service User Researcher)
Apologies received from
Alan (Research Fellow in of Mental Health)
Lisa (Lecturer in Forensic Mental Health)
Patrick Callaghan (Head of Mental Health Nursing Dept at City U.)
Bob (Associate Dean for Research)
BE (Women's Service User)
Ian Moran (Revolving Doors Agency)

1. Welcome and introductions (see above).

2. Minutes of previous meeting: 16th January 2004

(2a) Recruitment

Service users suggested a list of places/organisations where it would be appropriate to distribute the leaflet or put up a poster for recruitment.

- Residential care places, e.g. Churchill House
- Housing Associations, e.g. St Mongo's
- Support organisations, e.g. Circle 33
- Home Office lists
- Mad Pride
- Sure Trust – organises employment of those who have received prison and psychiatric intervention. Steven will speak to Sandra.

Changes to the leaflet were discussed. For example should it be catchier to include 'Get your voice heard!' Should it include details of support for basic skills such as literacy? It was thought these suggestions might be included on a poster for display but that it would be more important to get the leaflets out.

A supply of leaflets was available at the meeting for recruitment purposes.

No one has been recruited from WISH or Revolving Doors. SURs thought that these organisations might not be the best source of participants.

SURs will approach friends and associates. One friend approached so far has already found a full-time job with the security office and will not be available. It may be that there is a small window of opportunity when service users are well enough to participate but do not yet have a full timetable.

(2b,c, d) screening, job description, turnover, and references These have all been dealt with through City University Human Resources. I think next of kin information is not being collected.
(2e) 'Forensic' was a new term to at least one of the SURs.
(2f) Pay This may become a research item in itself. How much someone on benefits can claim may vary depending on their disability. One SUR said that those on 'incapacity' could earn up to £72 a week. This was news to another SUR. SureTrust would be able to provide information on this. If a sum higher that £20 a week is possible, the SURs may take on some hours at another job, for example working at a supermarkets.
(2g) Honorary contracts Hopefully these won't be necessary. An email has been sent to Helen Reid on 4/10/04 to find out more.

(3) Resourcing the RPAG list b-g. There is no (a) because of a technical error. The SURs thought it a fair list. Some discussion was had about possible risks in the research.

- The choice of location for interviews would need to consider the risks to all parties. Going into an unknown person's home might be unwise.
- Those who have been through the forensic system all suffer being 'tarred with the same brush'. SURs thought that the reference system would help filter out those at risk of being dangerous.
- Risk of new researchers not complying with ethical guidelines will be monitored by the RPAG.
- Guidelines and procedures for how the SURs will undertake research will not be prescribed at this stage as this could limit SUR leadership.

(4) Dissemination SURs were keen that their work is disseminated to those who are in a position to improve services.

3. Progress since January (see above) SURs would visit HR at the end of the meeting.

4. FMH conference 2nd November, poster presentation.

The poster was presented and discussed. It was agreed in its present form there was too much text and it was not eye catching. Conrad would work on it over the weekend and bring it to Chiswell Street on Monday afternoon. Steven and Ernest would ring if they had comments on the poster. Steven was keen to use the poster as a base for a recruitment poster but this second poster would need to be less busy. Suggestions for making the poster more visually interesting were discussed. Perhaps putting on a picture of a passport (probably not).

5. Any other business (none)

6. Future meetings

It was agreed to meet at 3pm on 14th October at Whitechapel, Philpot Street, E1 2EA. This would coincide with 4pm seminar on *Reducing conflict on acute inpatient* wards, the first in a series of seminars open to all. Flyers for the series were distributed at the meeting.

Visit to Human Resources on 1st October.

Paul and Jacqueline showed Ernest, Conrad and Steven up to the HR department at Northampton Square. Matt Beattie talked to each SUR in turn.

Bank details

SURs discussed their difficulties about a bank account. Matt said that it might be possible to raise a cheque rather than pay directly into an account. He was not sure this was still an option.

P45/P46/P38 Matt is able to produce an emergency P46 for those without this paperwork. A P45 would allow for the right tax to be deducted from the beginning. Without the P45 SURs will have to claim tax back.

Passport/birth certificate This is up to the SURs to organise.

NI number Matt was able to provide information on how to find out what your number is, or get one set up.

Thursday 14th October 2004 3-4pm Whitechapel

(Followed by a mental health seminar 4-5pm)

Present at the 3-4pm meeting

Paul Convener
Jacqueline Minutes
Chandra Revolving Doors Agency (RDA) Service User Coordinator
Mike Director of the Rehab Resource Centre, City University
Lisa Lecturer in Forensic mental Health, City University
Alan (3.10 – 3.30) Research Fellow in Mental Health Department, City

Attended the seminar 4-5pm

Convener: Alan
Team members: Paul, Jacqueline, Lisa, Ernest, Steven
Others present: Mental Health lecturers, students, service user(s) and professionals

Apologies

Ian Moran (RDA) suggests Chandra replaces him as the RDA representative in the team.

1. **Welcome and introductions (see above)** tea, coffee and biscuits were shared.
   - **i)** Chandra is Pete Fleishmann's replacement at RDA. He has recently moved to London from Bristol where he has been involved in a number of service user projects including research.
   - **ii)** Alan talked about the challenges of getting ethical approval and the role of full-time paid researchers in having the time to spend in getting ethics.
2. **Minutes from 1st October** – these had been circulated in advance to those present on 1st October and were tabled for those who attended 3-4 pm
   - **a)** <u>The poster(s)</u>
     - i) Conrad worked on the conference poster after the 1 October meeting. The latest version was shown. This will be ready for 2nd November FMH conference and Alan will take it to the Service User Involvement Conference in Nottingham later in November.
     - ii) A recruitment poster has been produced which was given to Chandra and Alan to recruit more SURs.
   - **b)** <u>Recruitment</u>
     - **i)** Chandra has asked the RDA service user group for volunteers. Six have shown an interest. Paul and Jacqueline will visit the group on 19th October to discuss the project Noon – 1.30? There was discussion about whether the RDA service users were 'forensic enough'. Their diagnosis, if any might be PD. Their contact might be seeing a CPN for diversion and may or may not have been diverted.. Lisa's view was that anyone who had contact with mental health services and the judiciary were

forensic. Five of the six are regular attenders at the RDA midday fortnightly meeting.

ii) Alan talked a little about the '128' research project. Chloe and Sophie who are visiting 128 acute wards to collect data might be able to deliver leaflets and posters but it may be inappropriate for a first visit. Alan can supply the mailing lists of the 128 wards. Alan also suggested the local trust (ELCMHT) news letter, press and communications person: Janet Flaherty. Janet.Flaherty@ELCMHT.NHS.UK (email supplied by Alan next day)

Alan has good contacts with SURGE and will email Paul their contact details. Chandra was concerned that SURGE has a preference for DoH initiatives and may have a narrow focus. FMH is an arm of the DoH so their preference for DoH may be to our advantage. (details supplied by Alan the next day)

Sarah Gibson
SURGE Co-ordinator
Mental Health Foundation /
Foundation for People with Learning Disabilities
7th Floor
83 Victoria Street
London
SW1H 0HW
E-mail:sgibson@mhf.org.uk
Direct Line: + 44 (0) 20 7802 0338
Switchboard: + 44 (0) 20 7802 0300
Fax: + 44 (0) 20 7802 0301

iii) Lisa suggested approaching her contacts at Springfield

iv) Jacqueline and Paul had visited the Mental Health Department team meeting to ask their help in recruiting SURs. They took leaflets and made suggestions. J&P have also been in contact with the publicity manager in City University to arrange a press release for the project.

v) The editor of *Mental Health Nursing* … Pollock. Would like to visit us and interview the SURs for an article in this national journal. Copies of Mental Health Nursing were distributed.

vi) Another journal we may target is *The Advocate* Articles by Keith Halsall, a service user researcher with his own funded projects, were circulated.

c) Human resources/payment/time sheets.
Three SURs visited Matt Beattie at HR after the last meeting and organising their contracts began well.

3. **Agreeing the programme** As no SURs were present at the main meeting little progress could be made on planning the programme. Some possible presentations were suggested. Mike suggested David O'Flynn and Brenda Smith who have been doing Service User involvement research in Lewisham.
4. **Future meetings**

It was agreed to meet as a group next in the committee room on 11th November at 3pm. This will be followed by a seminar by Dr. Rose McCabe from Queen Mary *Does the therapeutic relationship in psychiatry matter?* After the seminar, Alan encouraged Steven and Ernest to attend saying that McCabe is very focused on service user involvement.
It is planned to meet more than once a month in the long term. As well as the MH seminars it might be possible to have presentations from others once a fortnight.

5. **Any Other Business.** Mike and Chandra were concerned that they had come to meet with SURs but none were present. They asked what Paul had done to ensure that SURs had attended and asked that he made an effort to remind SURs about the date, send a personal letter to each one and encourage them generally. Paul replied that he had phoned the SURs and sent out agendas with covering letters.

Seminar – Reducing conflict on acute inpatient wards – The City Nurse Project

Ernest and Steven both signed the register and will be sent certificates for their attendance at the seminar.

The seminar was presented by two City University Researchers who are undertaking an action research project in four wards in East London. They are spending time on the wards supporting managers and staff in being therapeutic rather than confrontational. This was based on Len bowers theory that they were diametrically opposite. They measured the increase in therapeutic interaction by recording the decrease in negative incidents.

The seminar was an example of how research is disseminated in academic settings.
I tried to have a quick discussion of action research with Ernest. – This could be discussed more fully at a meeting?

Questions were asked about the response of service users to the action research. The researchers had asked patients to compete a 200 item questionnaire. They had very little response.

At the end of the seminar both Jacqueline and Paul had to leave immediately for other engagements. Although refreshments are usually available after the seminar, there were none on this occasion.

Thursday 11th November 2004 at Whitechapel

Attended:
Paul (Convener) Principal investigator, City University
Jacqueline (Minutes) Research fellow, City University
Lisa, Lecturer in Forensic Mental Health, City University
Mike, Director of rehabilitation resource Centre, City University.
Conrad, Service user researcher
Steven, Service user researcher
Ernest, Service user researcher
Denys, Service User researcher

Apologies
Chandra, Revolving Doors Agency
Bob, Director of the health care research unit
Alan, Research Fellow in mental health department and convener of the mental health seminars.

1) Welcome and Introductions (see above)
2) Minutes of previous meeting: 14th October 2004
   a) **Poster** for the FMH national conference on 2nd November was displayed. Conrad said he was happy with the final outcome of the poster which he worked on.
   b) **Recruitment**. Flyers and leaflets have been distributed to a number of suitable sites, for example Churchill House.
   c) **Human resources/payment/timesheets** Steve, Ernest and Conrad have already visited the HR department. Denys brought documentation with him to the meeting but there was no one from HR present to read them. An opportunity for others to organise salaries needs to be made. Matt Beattie of HR is to be invited to the next meeting.

3. Agreeing the programme and future meetings

When	Where	Presentation
18th November 4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Bob Overview of research methods
25th November 3/4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Mike Rehabilitation/disability research
2nd December 3/4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Keith Halsall (4pm) FMH service user research.
9th December 3pm & 4pm seminar	Philpot Street, Whitechapel	Paul & Jacqueline MSU risk management and rehabilitation
6th January 3/4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Lisa Forensic mental health care in South Africa
13th January 3pm & 4pm seminar	City University Philpot Street, Whitechapel	Alan Overview of service user involvement in research/ training & policy making

4.1.1 Paul proposed an interview with MH journalist in the future. This idea was well received.

4. Topics of interest were explored.
   a) Discussion of NHS plans to ban smoking in NHS settings, except psychiatric where it calms …
   b) Experiences in settings were discussed. For example, in high secure hospitals, moving to a villa may be seen as a privilege, but life could be worse in these more autonomous settings where an individual could be vulnerable to campaigns of aggression and drugs.
   c) Differences between locations and settings.
      i) There may be a pecking order in high security hospitals.
      ii) Staff working at one may be recruited from those 'kicked out of' RSUs.
      iii) Opportunities for patients may be better at Broadmoor than Rampson. Conditions in main hospital settings, even if related to the MSU (eg satellite wards) may be better than in the MSU.
      iv) Service users may be treated well at time 1 and time 2 but have a bad experience at time 3.
   d) it was proposed that research involved hypothesis testing.

It was **agreed** that such discussions may be usefully tape recorded at future meetings.

5. Any other business
   a. London Development Centre. Lisa gave a presentation on a recently published document which presented goals for the next three years. Forensic services will be expanded to bring patients back from the private sector. There was socme discussion of why there is an ongoing problem with beds within services. The documentation emphasised the involvement of service users in developing services.

6. 4pm, presentation by Dr. Rose McCabe from Queen Mary
   Does the therapeutic relationship in psychiatry matter?

At the end of the presentation, there was a discussion about McCabe's study of service user perceptions of the causes of problems. McCabe found that those who expressed a biological foundation for their problems responded better to the care provided than those who said their problems were caused by the supernatural. Questions were asked about these findings, including the stigmatisation of adopting the latter view.

18th November 2004 at 24 Chiswell Street

Attended:

Paul (Convener) Principal investigator, City University
Jacqueline (Minutes) Research fellow, City University
Chandra, Revolving Doors Agency
Bob, Director of the health care research unit
Lisa, Lecturer in Forensic Mental Health, City University
Conrad, Service user researcher
Steven, Service user researcher
Ernest, Service user researcher
Denys, Service user researcher
Matt Beattie, Human Resource Department (items 3 and 4)

Apologies

Alan, Research Fellow
Mike, Director of the Rehabilitation Resource Centre, City University

1. Welcome and Introductions (see above)
2. Minutes of previous meeting were circulated.
3. Recruitment. The need to get up posters and recruit more SURs was discussed. Conrad will take flyers to a meeting on the last Wednesday of the month.
4. Matt Beattie discussed HR issues took details from SURs.
   SURs can visit him at the Human Resources department on the 2nd floor of the Innovations Centre, Whiskin Street, near the main university buildings at Northampton Square (Nearest tube: Angel). An appointment is not necessary, but to be sure he is in, it may be best to phone Matt on 020 7040 8013
5. Chandra spoke about the Bristol study and the need to be open about expectations and experiences of attending meetings. It was agreed that Chandra would present the Bristol study on 20th January.
6. The programme for meetings - updated

When	Where	Presentation
18th November 4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Bob Overview of research methods
25th November 3.30pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Mike Rehabilitation/disability research
2nd December 3/4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Keith Halsall (4pm) FMH service user research.
9th December 3pm & 4pm seminar	Philpot Street, Whitechapel	Paul & Jacqueline MSU risk management and rehabilitation
6th January 3/4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Lisa Forensic mental health care in South Africa
13th January 3pm & 4pm seminar	City University Philpot Street, Whitechapel	Alan Overview of service user involvement in research/ training & policy making
20th January	24 Chiswell Street	Chandra – the Bristol survey.
27th January	24 Chiswell Street	Laurence - journalist
3rd February	24 Chiswell Street	
10th February	24 Chiswell Street	Diane --- Alan's contact
17th February		

7. Overview of research methods **by Bob** Bob gave a presentation based on the attached handout sheet. Paul circulated a brief version of Rosenhan's study *On being sane in insane places*

8. Topics of interest were explored.

4.2 Why do providers talk to service users and professionals differently?

Other studies on this subject were discussed.

a) Chandra talked about Diane Rose's study of ECT. Diane Rose will be presenting this study at 4pm on 16th June at Whitechapel as part of the mental health seminar series.

b) Paul talked about Nikki Britten's research on case notes and the pejorative way in which service users were talked about.

9. Any other Business

Certificates for MH seminars. Alan to bring next week.

	City Nurse Project		Rose McCabe	
Steve	Attended		Attended	
Ernest	Attended / Received		Attended	
Denys	-		Attended	
Conrad	-		Attended	

25th November 2004 at 24 Chiswell Street

Attended:
Paul (Convener) Principal investigator, City University
Jacqueline (Minutes) Research fellow, City University
Chandra, Revolving Doors Agency
Bob, Director of the health care research unit
Lisa, Lecturer in Forensic Mental Health, City University
Conrad, Service user researcher
Steven, Service user researcher
Ernest, Service user researcher
Denys, Service user researcher
Matt Beattie, Human Resource Department (items 3 and 4)
Apologies
Alan, Research Fellow
Mike, Director of the Rehabilitation Resource Centre, City University

1) Welcome and Introductions (see above)
2) Minutes of previous meeting were circulated
3) Recruitment. The need to get up posters and recruit more SURs was discussed. Conrad will take flyers to a meeting on the last Wednesday of the month .
4) Matt Beattie discussed HR issues took details from SURs.
5) SURs can visit him at the Human Resources department on the 2nd floor of the Innovations Centre, Whiskin Street, near the main university buildings at Northampton Square (Nearest tube: Angel). An appointment is not necessary, but to be sure he is in, it may be best to phone Matt on 020 7040 8013.
6) Chandra spoke about the Bristol study and the need to be open about expectations and experiences of attending meetings. It was agreed that Chandra would present the Bristol study on 20th January.

7) The programme for meetings - updated

When	Where	Presentation
18th November 4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Bob Overview of research methods
25th November 3.30pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Mike Rehabilitation/disability research
2nd December 3/4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Keith Halsall (4pm) FMH service user research.
9th December 3pm & 4pm seminar	Philpot Street, Whitechapel	Paul & Jacqueline MSU risk management and rehabilitation
6th January 3/4pm	Committee Room, 1st Floor 24 Chiswell Street, EC1	Lisa Forensic mental health care in South Africa
13th January 3pm & 4pm seminar	City University Philpot Street, Whitechapel	Alan Overview of service user involvement in research/ training & policy making
20th January	24 Chiswell Street	Chandra – the Bristol survey.
27th January	24 Chiswell Street	Laurence - journalist
3rd February	24 Chiswell Street	
10th February	24 Chiswell Street	Diane --- Alan's contact
17th February		

8) Overview of research methods **by Bob** Bob gave a presentation based on the attached handout sheet. Paul circulated a brief version of Rosenhan's study *On being sane in insane places*

9) Topics of interest were explored.

4.3 Why do providers talk to service users and professionals differently?

Other studies on this subject were discussed.

a) Chandra talked about Diane Rose's study of ECT. Diane Rose will be presenting this study at 4pm on 16th June at Whitechapel as part of the mental health seminar series.

b) Paul talked about Nikki Britten's research on case notes and the pejorative way in which service users were talked about.

10) Any other Business

a) Certificates for MH seminars. Alan to bring next week.

	City Nurse Project		Rose McCabe	
Steve	Attended		Attended	
Ernest	Attended / Received		Attended	
Denys	-		Attended	
Conrad	-		Attended	

2nd December 2004 at 24 Chiswell Street

Attended:

Paul (Convener) Principal investigator, City University
Jacqueline (Minutes) Research fellow, City University
Conrad, Service user researcher
Ernest, Service user researcher
Denys, Service user researcher
Mike, Director of the Rehabilitation Resource Centre, City University
Lisa, Lecturer in Forensic Mental Health, City University
Bob, Director of the health care research unit

1. Minutes of previous meeting were circulated.
2. HR: November pay will be made on 20th December. Ernest is still waiting for NI number. Conrad is still waiting for bank details.
3. Two main research themes:
   a) A wish to demonstrate services are unsatisfactory
   b) A wish to suggest how they could be better

   Topics within this might be
   - Communication between patients and professionals
   - Playing the game
   - Who's whose friend? – Relationships.
   - Britain is a multi-cultural society
   - Practical help
   - How to move on and leave the past behind

   Methods

   Get research records
   Reflexive diaries
   Interview other service users
   Interview service providers

   Outcome

   Design a questionnaire.
   Reports under different themes.
   (Could be in a magazine form)
4. Keith Halsall talked about his work in Bexley MSU. He is working with Steve and Tina; all 3 are service users. Steve aims to work with 5 black men, Tina with 5 white women, Keith with 5 white men.

   Keith wants research to be enjoyable with
   ◊ Social events
   ◊ Payment
   ◊ Produce a magazine for everyone at the end.
5. What research experience have SURs had to date?
   a) Junior doctors asking for help but no feedback
   b) Trainee psychologists' questionnaires
   c) Nursing MSc dissertations.
6. Next meeting

   9th December at 3pm at City University School of Nursing, Alexandra Building, Philpot Street, **Whitechapel** (room to be agreed). This will be followed at 4pm by a seminar in the lecture theatre in the same building.

9th December 2004 at Whitechapel

Attended:
Lisa, Jacqueline, Eric, Denys, Alan,
Bob, Conrad, Steven

Apologies
Paul, Mike, Chandra

A brief meeting was held before the mental health seminar

i. Minutes of previous meeting (2nd December) were circulated.

HR: Denys wanted to know what could be done if the payment on 20th December didn't arrive. **Jacqueline to check with HR**

ii. MSU conference on 17/18 January at Institute of Psychiatry. Service user researchers are welcome to come to the conference. Paul and Jacqueline are committed to making a presentation on this current project and welcome the participation of service user researchers in giving this presentation. In the last minutes Jacqueline noted our research desires to include

A wish to demonstrate services are unsatisfactory

We might be heard better at the conference if we said we wanted to demonstrate what was good and what was bad. This was challenged as a reality by some present at the meeting.

- ◊ Conrad has made initial inquiries about getting individual clinical records by.
- ◊ Mental Health Seminar

Young people and substance misuse: is strengthening the family the solution.

There are three methods of drugs education

(i)	information giving	The first two have been linked with increased drinking and smoking.
(ii)	decision making/values model	
(iii)	social skills/social competency model	Social skills… may work.

Problems with delivering drugs education aggrevated by switching methods – different in religious education, PHSE and biology classes where the education is given.
(A. Simpson handouts/information to follow).

6th January 2005 at 24 Chiswell Street

1. Welcome and Introductions

Mike City University
Jacqueline City University (Minutes)
Eric, Local low secure ward, MSU
Bandit Cascade House
Chandra Revolving Doors Agency (mental health and criminal justice)
Conrad Living independently in North London
Paul City University (Convener)
Sheriff Local low secure ward, MSU
Bob, City University
Denys, Living independently in East London

4.3.1 Apologies

- Cliff of Cascade is now working for Tescos and not available for research
- Lisa is teaching this afternoon.

2. Minutes of previous meeting (9th December 2004) Circulated. Names corrected.

3. Presentation: 18th January. (see powerpoint presentation attached) At the meeting the presentation was amended and **agreed**. **Jacqueline** to ask if some SURs can attend the conference
Conrad and Denys 17th and 18th
Bandit 18th Morning only **done**

4. Future meetings

13th January at Whitechapel. Map was distributed to new people
3pm meeting: Ian & Alan presenting on other service user involvement at City
4pm seminar by Prof Len Bowers on acute psychiatry research.

20th January at Chiswell Street
3.30 Matt from HR to be invited to look at documents
4pm Chandra will present on Bristol study.
Apologies in advance from Conrad and from Lisa

5. Any other business - Payment for attending.

- ◊ Attending the conference will probably not be paid.
- ◊ Timesheets are filled in by Paul, Jacqueline and Bob and forwarded to payroll.
- ◊ Payment is made a month in arrears. So December work will be paid at the end of January.
- ◊ Paperwork needed to be shown to HR:
  - passport or birth certificate
  - NI (National Insurance) number
  - Bank details
  - P45 or P38 (P46 can be generated if you don't have this)

13th January 2005 at Whitechapel

1. Welcome and Introductions

Service User Researchers	Research Project Advisory Group
Martin Bandit Eric Denys Ernest (seminar only) Sheriff (seminar only)	Paul (Convener) Jacqueline (Minutes) Mike (Disability and Rehabilitation) Alan (Mental Health Research)
Invited speaker: Ian Light, Service User Research Consultant.	

2. Minutes of previous meeting (6th January 2005) Circulated.

3. Matters arising

Matt Beattie from Human Resources (HR) City University will attend the meeting 3.30-4.00pm on 20th January 2005 at Chiswell Street.
Matt needs to see

- ◊ Proof of identification, for example passport or birth certificate
- ◊ National Insurance (NI) number
- ◊ Bank details (account name, sort code, account number)
- ◊ P45 or P38

4. Presentation by Alan and Ian Light. (attached) The work of Diane Rose was discussed. The questions she used for the base of her study were circulated (attached) and an article based on the work was made available (attached).

5. Discussion There was considerable interest in Diane Rose's questions. Rose's work was one of the first service user led studies and she views the questions as good for when they were used in the late 1990s but there is a need to move on from them. She is exasperated how often people still want to use them.

6. Seminar with Len Bowers. Len looked at a range of work on conflict and containment. He concluded that there is an over perception in conflict on wards and that containment is often used inappropriately, even generating conflict. Len's team are selling an anti-absconding package and aiming to produce materials to reduce conflict and containment.

7. Future meetings

20 January 3.30pm 4.00pm	Chiswell Street Matt Beattie HR issues Chandra: Bristol Study (questionnaire)
27 January 4pm	Chiswell Street Laurence Pollock: journalist from *Mental Health Nursing*
3rd February 4pm	Chiswell Street Planning our research activity
10 February 3pm meeting 4pm seminar	Whitechapel Diane Hackney Experience of Service User Research Alastair McElroy *Friend or Foe? Self Harming patient's perceptions of care.*

20th January 2005 at Chiswell Street

Attended	
Service User Researchers	Research Project Advisory Group
Bandit Eric Denys Ernest Sheriff	Chandra Alan Jacqueline Lisa Bob

Minutes of last meeting (13th January 2005) distributed in advance and tabled.

1. **Human Resources** Matt Beattie visited to take people's details for payment purposes. He brought forms for completion, made notes of bank account details and photocopied documentation (Thank you Matt).
2. **Presentation** by Chandra
   a. Outline of **Revolving Doors Agency:** advocacy for users of mental health and justice system. Chandra's job is to get users involved. Researchers present were invited to join his group.
   b. **User Focused Monitoring** research discussed using flipcharts (see attached). 90 page document brought to the meeting will be copied and made available. Monitoring first done in adult psychiatric services in Kensington & Chelsea in 1997. There was resistance to it in early years but now well established and has been successfully replicated in a number of Trusts. However, it hasn't been done in forensic settings.
3. **Discussion** (Led by Alan)
   a. Why not in forensic? Possibly because of dual problem. User involvement exists in main prison population. Issue of confidentiality greatest in forensic mental health. Possible punishment of not being listened to. Staff know they shouldn't have a moral judgement. They try not to have an emotional response – but they do. Staff may be source of gossip.
   b. What questions might the team ask if they did undertook a UFM project (see attached). Complaints can be categorised. For example, staff encourage complaints about food –because they eat from the same kitchens! Complaints about staff treatment are discouraged. A story was related about how a petition against a staff member was stopped by individuals being persuaded to remove their name. Arguments for not making complaints might include: you will be here for a long time; you don't want to create conflict now …' It makes sense on one level. You'd lose 'settledness'.
   c. Monitoring might include asking questions which allowed categorising. There was a discussion of 'minority ethnic'. The word minority not liked. Alan talked about his work with Bhui on cultural diversity.
4. **Future meetings**

   Next week, Laurence Pollock, editor of *Mental Health Nursing* will visit the team at 4pm at Chiswell Street. Laurence is a journalist known to Paul and Alan.

27th January 2005 at Chiswell Street.

1. Introduction and Welcome

Researchers	Research Project Advisory Group
Martin Bandit Eric Sheriff Steven Denys	Paul, Convener, Senior Lecturer, City University Jacqueline (Minutes, Research Fellow, City University) Lisa (Lecturer in forensic mental health, City Univ) Alan (Research fellow, mental health dept., City Univ) Mike (Director of disability and rehabilitation studies, City) Chandra (Service User Liaison, Revolving Doors Agency)
Guests Laurence Pollock Editor of *Mental Health Nursing* Claudia Draper Press Officer, City University.	

2. Minutes of the last meeting (20th January) were circulated.

3. Matters arising.

a. **Jacqueline** to contact Matt Beattie (HR) for future meetings.
b. Future plans for research to be discussed next week.
c. Continue with attending Whitechapel seminars, but review.

4. Interview by Laurence Pollock

Laurence began by setting ground rules. Anything said in the meeting could be used in the article unless the individual (or team) expressed a wish for it not to be used. Comments would be used verbatim but the identity of the person would not be revealed.

a) Why are you getting involved in this project?
b) What were your expectations and how far have they been met?
c) How can you affect research?

Comments I found interesting.

◊ It's worse in acute care – they treat you like you are insane/ they laugh at you and talk down to you there.

◊ Some people have experienced worse than me. For example women.

◊ The good work of staff is spoilt by a few bad individuals. Examples of good staff involve those who engaged patients in meaningful conversation, activity – eg helping with the paperwork – developing clerical skills.

◊ The pressure from senior management magnifies as it moves down the hierarchy – and patients are at the bottom.

◊ I hope this research is beneficial – but I don't have confidence that it will be. The research would have more future if we got the service providers round the table.

5. Future meetings

3rd February 4pm	Chiswell Street Planning our research activity
10 February 3pm meeting 4pm seminar	Whitechapel Diane Hackney Experience of Service User Research Alastair McElroy *Friend or Foe? Self Harming patient's perceptions of care.*
17 February	Chiswell Street

Jacqueline to invite Jim Symington from NIMHE to attend.

3rd February 2005 at Chiswell Street.

Attended

Denys	Bandit	Alan
Sheriff	Bob	Paul (Chair)
Chandra	Conrad	Jacqueline (minutes)
Eric	Lisa	

1. Pay/Human resources **Jacqueline to ask Matt about pay slips**
2. Discussion of how the session with Laurence Pollock
   - ◊ It is difficult for us (service users) to know what to give a journalist. We gave him some areas that we thought might be useful but didn't touch on others. Afterwards I thought of things I could have said (Eric)
   - ◊ Although we know Laurence is trustworthy, how the article will come out is still unknown (Alan)
   - ◊ Earlier conversations weren't reflected in the meeting last week (Paul)
   - ◊ Being late made it difficult to contribute (Denys)

Discussion of previous article by Laurence Pollock on sexual dysfunction and medication. Led to discussion of why people comply with medication and the consequences of refusing to take a 'depot'. The cost of medication (and other services). The risk of costs shifting from the state to the individual.

3. Rules of conduct for the meetings
   a. Confidentiality. Paul acknowledged in meetings we talk about personal issues for service user researchers. The advisory group do not discussed named individuals with anyone outside the meetings. However, if there were serious concerns about an individual a member of the advisory group would first discuss this with the individual and may then have further discussions, with a key worker.
   b. What is available as data (see item 4)
   c. Keeping time.
4. Planning the research
   a. What we have ethical approval for
   b. Biographies through interviewing each other
   c. Interviewing service providers/policy makers (eg Jim Symington – see attached)
   d. Other suggestiosn:
      i. getting records
      ii. written stories – two people who given stories to the Paul and Jacqueline **agreed** that their stories could be circulated for discussion at the meeting on **17th February**. (attached)
   e. What data we have
      i. Notes of the meetings
      ii. Written stories (attached).
   f. Where are we now? We could interview each other
      i. RPAG members
      ii. Service providers

iii. Policy makers

g. What questions could we set based on the themes that have emerged?

i. Compliance and playing the game
ii. Culture and religion
iii. Drugs and medication
iv. Complaints procedure
v. Other topics.

5. Future meetings – next week in Whitechapel (see attached)

Apologies: Mike is in Africa for most of February
Chandra is unable to make Whitechapel meetings (eg next week)
Sheriff is unable to come on 17th February (tribunal)
Bandit is unable to come on 28th April (court appearance)
Jim Symington has offered to come in March.

17 February 3.30 4.00	Matt Beattie, Human Resources Discussion of our written materials	Chiswell Street
24 February	Lisa to summarise London Policy in preparation for Jim Symington's visit	Chiswell Street
3 March	Possible visit from Jim Symington or Prepare for Three Bridges Presentation	Chiswell Street
10 March 3pm meeting 4pm seminar	Disempowerment and empowerment in mental health (MB)	Whitechapel
17 March		Chiswell Street
24 March		Chiswell Street
Spring Break (Easter)		
14th April		Whitechapel
21 April		Chiswell
28 April		Chiswell
5 May		Chiswell
12 May		Whitechapel
19 May		Chiswell
26 May		Chiswell
2 June		Chiswell
9 June		Chiswell
16 June		Whitechapel
23 June		Chiswell
30 June		Chiswell

Matt Beattie HR

Researchers can visit him at the Human Resources department on the 2nd floor of the Innovations Centre, Whiskin Street, near the main university buildings at Northampton Square (Nearest tube: Angel). An appointment is not necessary, but to be sure he is in, it may be best to phone Matt on 020 7040 8013

10th February 2005 at Whitechapel

1. **Introduction and Welcome**

Conrad	Lisa	Eric
Ernest	Paul	Denys
Martin	Jacqueline	Sheriff

Apologies from Diane Hackney who has a bad back.
Concern expressed about those not present – regards were sent to Steve.

2. **Minutes and paperwork** sent by post and distributed in the meeting

    a. Discussion of the abstract and the methodology of repertory grids
    b. Pay issues, Matt will attend at 3.30 next week (17th February)
    c. Extra pay may be available for work done outside the meetings, eg writing.
    d. Restating of rules of confidentiality. If we have concerns, Paul or other RPAG member will discuss them with the service user researchers first. SURs will be treated the same as other employees.

3. **Focus groups presentation** **Paul & Jacqueline**
    - We wish to capture what is said in the meetings in a structured way. From the progress we are making, focus groups have emerged as a practical methodology.
    - There may be some initial effect on the group of recording. Some members have participated in recorded activities. For example, Newham Centre for Mental Health video recorded some sessions.
    - Focus groups require a chair/discussant to keep the discussion on track, and a moderator to note down what is not captured by audio recording.

4. **Discussion**
    - There is a view that there should be larger numbers. The SURs could run focus groups with other service users (EN)
    - Will focus group activity stop other planned activity? (ER) Jim Symington is still invited/coming and we hope to invite others. Focus group discussions could lead on to other things after June.
    - There are so many views out there. I'm not representative (ER) People are very different. A ward changes every 6 months (EN). When I arrive in a manic phase, I rush round and get patients to fuse together. This will help later in my [depressive] phase. You have to be careful with staff –you can't trust them. (CL). Eric– each case is different, for example I have language issues, he [SR] doesn't. There is a want to know what others say

5. Future meetings

17th February at Chiswell Street.
3.30 Matt,
4pm focus group on 2 written pieces
24th February
3rd March
10th March Whitechapel booked (Alan's speaker has cancelled)
17th March
24th March Jim Symington?
SPRING BREAK
14th April
…
30th June

6. The seminar **Alastair McElroy**

a. Sign up sheets – do people have certificate from last month?
b. Next months speaker has pulled out. Alan will plan something else.

Therapeutic relations are something you can discuss directly with staff, but you'd talk about it differently with patients. AM applied personal construct theory through the use of repertory grid technique – we have notion of attributes/constructs and attach to an individual. A nurse can't have a TR unless s/he knows where the patient is coming from. Therefore, theoretically, if you know the patient thinks you are selfish, and you can see why they thinks this, then you can have 'sociality', which is a necessary condition for a TR – you don't have to be the good nurse, you don't have to be loved by the patient, though 'commonality' (seeing the world in the same way) does help.

Questions included one from CL – there are bad nurses – harm is sometimes done. AM agreed, but said that it was not the overt but the subtle incidents which he had focused on.

Minutes from meeting on Thursday 17th February 2005

Present		Apologies
Steven	Paul	Lisa
Bandit	Jacqueline	Sheriff
Eric	Bob	Mike
Denys	Alan	

Bandit gave his apologies for next week.

1. **Human resources** Matt Beattie kindly visited the meeting before 4pm to take bank details etc of service user researchers. Matt advised us to contact Gavin Hawkins from payroll about claiming back tax.
2. **Minutes**
    c. Jim Symington can attend lunchtime, 24th March or after Easter. It was **agreed** to invite him after Easter but if no suitable date could be found, lunchtime on 24th would be acceptable to most present.
    d. The methodology of focus groups was briefly restated. The need for a chair and monitor was discussed.
3. **Focus group**
    - Conrad's *A Very Psychiatric Christmas* was read to the team. The discussion was recorded on tape and mini-disk and notes were made by a number of group members. All team members present contributed.
        i. The piece was praised by Bob and Denys.
        ii. SURs present mostly agreed with Conrad's piece. The view was given that overall nurses do not talk to disturbed patients, but too readily restrain aggressively.
        iii. Challenges were made: Patients know what will happen to them if they barricade themselves in – so why do it?
        iv. The training of nurses was questioned. Exceptions of flexibility and humanity were presented (allowing pet animals)
        v. Those outside may have a misunderstanding of what is happening. A family asked which members of the MDT are friends.
        vi. Comparisons between services were made. Higher the security was matched with harsher treatment. Prison was compared favourably with high security and the advantage of knowing a discharge date was agreed.
        vii. Diagnoses were discussed. Current policy changes around personality disorder and indefinite detention were discussed.
4. **Future meetings**
    - **Next meeting** (24th February). It was **agreed** to discuss cultural and religious beliefs and mental health care. Denys, who made the suggestion, agreed to chair the session.
    - Jim Symington is to be included in the programme.
    - An acknowledgement from the interim report to the sponsors was included. It was **agreed** to invite the sponsors to attend a meeting (possibly towards the end of the project) to discuss their expectations and the outcomes.

24th February 2005 at Chiswell Street

Present

Service user researchers	Research project advisory group	
Denys	Paul	City University
Sheriff	Jacqueline	City University
Eric	Lisa	City University
Steven	Alan	City University
Bandit	Bob	City University
Conrad	Chandra	Revolving Doors Agency
Michael		

1) **Minutes** of last meeting

Jim Symington will visit the group on 21st April 4-5.30pm. Jim is Programme Director at London Development Centre for Mental Health

2) **Focus group on culture and religion.**

a. Paul listed previous statements by service users that have led us to this topic of religion and culture:

i. Conrad's writing
ii. Denys's question to Rose McCabe
iii. Service user descriptions of poor provision for religious and cultural diversity.
iv. Concern that a cultural rift sometimes occurs between staff and patient that leads to poor care.

b. Denys read a piece from *The Watch Tower* that he wished to share with the group. The piece covered issues of appearing ugly to others and being loved by God, and being clean *Does Denys relate this to the efforts of mental health staff to get patients to conform in their behaviour and to focus on their personal hygiene?*

c. The discussion was recorded and will be selectively transcribed. Interesting points that were raised were:

i. Over religious behaviour is seen as a sign of relapse.
ii. Some service users associate their problems with evil spirits. Attempts to manage these evil spirits through burning incense are not allowed.
iii. There was an example of a good priest who offered friendship and support to a service user when he was a patient. Priests hear confessions which are confidential.
iv. There was plenty of laughter round the table. It was acceptable to laugh at what was said about supernatural beliefs. Was it nervous laughter? Not everyone chose to participate in all the debate.
v. Religions, for example Christianity, can be difficult for someone who is different (deviant). Some churches are negative about homosexuality.

3) Future meetings

- **Next meeting** (3rd March). It was **agreed** to discuss Bandit's piece.
- Diane Hackney is still willing to come. Try to timetable her in for May/June
- Alan sends his apologies for next week, and the week after. He has a speaker for the Whitechapel seminar on 10th March (information attached)

3rd March 2005 at Chiswell Street

Present
Steven ; Conrad ; Sheriff ; Eric ; Denys;
Bandit; Paul; Jacqueline; Bob; Chandra

1) **Pay issues**

Name	Pay received	Payslip received
Steven	None	One month only
Conrad	Yes, tax deducted	Yes
Sheriff	Not sure	Not sure
Eric	No	No
Denys	Yes	Yes
Bandit	Jan Yes, Dec No	No

Jacqueline is to send note to Matt Beattie and Gavin Hawkins about the above. Denys would like his payslip to be made out to ….

2) **Future opportunities**: Paul and Alan to look at Advocacy bid through King's fund.

3) **Three Bridges**: Jacqueline and Paul to visit tomorrow.

4) **Focus group on Bandit's written piece.**

   a. Financial concerns of team members and accessing crisis loans; budgeting; obligations of Social Service to provide help.

   b. Difficulties of living in supported housing. Constraints on visitors and smoking cannabis. Not every one knows the different levels of support/independence.

   c. The difficulties of making complaints in the [unfair] system.

   d. How to move on from history as service user. How to explain missing years?

   e. Labelling of mental illness and offending history.

5) **Next meeting**: Thursday, 10th March at Whitechapel
   3-4pm Focus group on medicine taking
   4-5.30 seminar : *Medicine-taking decision-making for people with schizophrenia*
   (Dr Glenn Marland)

10th March 2005 at Whitechapel

Before the meeting began there was a discussion of Africa and about recording equipment.

1. **Payroll issues**

   Steve has collected a cheque from Gavin Hawkins.
   Eric has still not received any payment.
   Conrad would like to complete another P46 to correct his tax code.
   A cheque will be sent to Sheriff.
   Jacqueline to ask Matt to organise P46s.

2. **Focus group on Medicine**

Present
Bandit, Conrad, Eric , Ernest, Steven
Paul, Jacqueline, Mike, Bob

The focus group was recorded.

Conrad read his two pieces on medication.
One written in January, the other written after 3rd March 2005.

The team discussed the lack of privacy when receiving medication on the ward. You have to queue for medication, even if there are several others waiting. You can't come back later. Everyone sees what you are given. There is a stigma in having a depot, stigma of having a larger dose. Suggested hierarchy in the ward related to medication. Greater privacy in medication giving was thought to be desirable.

3. **Seminar**

Present
Bandit, Conrad, Eric, Ernest, Steven**,**
Paul, Jacqueline, Mike, Bob**,**
Alan, Sheriff, Denys,

Comparison of medicine taking for schizophrenia, asthma and epilepsy. All conditions where life long medication is prescribed. There are similar approaches to taking medication in all three groups. Slides will be available from Alan.
At the end, Paul asked about assertion of wellness = denial.

4. **Future meetings**

There are two meetings before Easter. Both are at Chiswell Street at 4pm.

Thursday 17th March 4-5.30	continue focus group on medication.	Chiswell Street
Thursday 24th March 4-5.30	Discuss Jim Symington's visit	Chiswell Street
	SPRING BREAK	
Thursday 14th April 3-5.30	1 hr meeting followed by seminar.	Whitechapel
Thursday 21st April 4-5.30	Jim Symington visit	Chiswell Street
Thursday 28th April 4-5.30		Chiswell Street
Thursday 5th May 4-5.30	Diane Hackney (service user researcher)	Chiswell Street

17th March 2005 at Chiswell Street

Present
Bandit, Conrad, Eric , Ernest, Steven , Sheriff , Chandra, Paul, Jacqueline, Bob, Alan, Lisa

1. Minutes from last week:

a) One said they were too long. Another said they were too brief.

b) Payroll issues

Jacqueline has not heard from Matt about P46s.
Eric said thank you, he has received a payment
Conrad has a letter from tax office for reclaiming tax.
Bandit has still not received payment
Sheriff has received his cheque
Ernest asked for Matt Beattie's phone number to give NI details.
Jacqueline to contact Matt again.
Matt Beattie's phone number is 020 7040 8013
He is based in
Human Resources Department
City University
2nd Floor, Innovations Centre
Whiskin Street

c) focus group on medicine. To be continued today.

d) Presentation by Dr Glenn Marland *Medicine… schizophrenia* (see below)

e) Advocacy bid: this will be in June.

f) Sponsors visit. Sue Spiers will visit some time in May. Chandra has already met Sue.

2. Focus group on Medicine

Starting with the seminar last week, Ernest asked what differences there were between mental health patients and asthma/epilepsy? The seminar focused on the similarities, not differences. Mental illness drugs have strong side effects that you don't know about until after you have begun the treatment. For example weight gain. Once you have started medication, you can't come off straight away. You must wait 3-6 weeks. Sudden cessation is worse than side effects. There is no test to see what suits YOU, medication is given on a trial and error basis. Eric pointed out that not everyone gets all the side effects so to be told the whole list to begin with would be excessive. Bandit talked about errors made in giving medication. Are unethical experiments conducted? Are overdoses given on purpose? Do staff close ranks to protect each other?

Conrad compared mental illness to cancer and chemotherapy – MI has no urgency therefore side effects seem not worth the treatment. But, MI relapses may cause long term damage leading to untreatable mental disorder.

Ernest talked about not being allowed to be angry. Pathology of being too angry and also being passive. Steve talked about opportunities for role

play in hospital where he could safely get angry with nurses. Do patients know their rights? (Paul said that under 1983 law they should).

Alan asked if tapes could be edited and used for teaching purposes. Could they be part of the report. Ernest wanted SURs to be involved in the editing.

3. Preparation for Jim Symington visit

Lisa presented 8 slides on the Forensic Mental Health in London … Strategy…

The key aims include a reduction in private and high security use.

Which is to be reduced first?

4. AOB

a) Future bids

i. Advocacy bid – look at in June

ii. Ethnic bid. Consider in near future.

b) Future discussions

- Illegal medication and alcohol in hospital

c) Chandra invited service user researchers to participate in two meetings through revolving doors agency.

- A research meeting ethnic minority people who have experienced homelessness and mental illness (1st April)
- A research meeting on black and ethnic use of the criminal justice system. (10th April at Clerkenwell Road.

5. Future meetings

Thursday	Location
24th March 4.00-5.30pm	Cont prep for Jim Symington visit on 21st April **Chiswell Street**
	SPRING BREAK
14th April 3-4pm 4.00-5.30pm	1 hr meeting followed by seminar. **Whitechapel** **Roger Evans** *Supporting acute in-patient mental health nurses to work therapeutically*
21st April 4.00-5.30pm	Jim Symington visit **Chiswell Street**
28th April 4.00-5.30pm	Focus Group **Chiswell Street**
5th May 4.00-5.30pm	Diane Hackney (service user researcher) **Chiswell Street**
12th May 3-4pm 4.00-5.30pm	1 hr meeting followed by seminar. **Whitechapel** **Chris Flood** *Advance Directives in community mental health*
19th May 4.00-5.30pm	Sponsors: Sue Spiers and Kathryn Harney **Chiswell Street**
26th May 4.00-5.30pm	
2nd June 4.00-5.30pm	
9th June 4.00-5.30pm	
16th June 3-4pm 4.00-5.30pm	1 hr meeting followed by seminar. **Whitechapel** **Diana Rose** *Consumers' perspectives on ECT*
23rd June 4.00-5.30pm	
30th June 4.00-5.30pm	

24th March 2005 at Chiswell Street

Present		
	Denys	Paul
	Conrad	Jacqueline
	Steven	Mike
	Eric	Alan
	Bandit	Chandra
	Sheriff	Lisa

1. Practice questions for Jim Symington

Role Play exercise: preparing questions for Jim Symington.
Alan took the role of Jim (Thanks Alan)
Notes made by Jacqueline and Conrad to be brought to the meeting this Thursday.

Suggested start to the question below

a) Introduction and invite Jim to say what his role is **Conrad**
b) Complaints procedure and advocacy
c) Benchmarking and targets
d) Ethnic Minority over representation **Eric**
e) What is the way forward?

2. Transcripts of 2 focus groups were made available for those who wanted to read them over the Easter break.

3. Future meetings

Thursday	**Location**
21st April 4.00-5.30pm	Jim Symington visit **Chiswell Street**
28th April 4.00-5.30pm	Focus Group **Chiswell Street**
5th May 4.00-5.30pm	Diane Hackney (service user researcher) **Chis St**
12th May 3-4pm 4.00-5.30pm	1 hr meeting followed by seminar. **Whitechapel** **Chris Flood** *Advance Directives in community mental health*
19th May 4.00-5.30pm	Sponsors visiting; **Chiswell Street** Sue Spiers and Kathryn Harney
26th May 4.00-5.30pm	
2nd June 4.00-5.30pm	
9th June 4.00-5.30pm	
16th June 3-4pm 4.00-5.30pm	1 hr meeting followed by seminar. **Whitechapel** **Diana Rose** *Consumers' perspectives on ECT*
23rd June 4.00-5.30pm	
30th June 4.00-5.30pm	

14th April 2005 at Whitechapel

Payroll issues

Noted and sent to Matt Beattie and Gavin Hawkins

Present

Meeting and Seminar		**Seminar**
Conrad	Paul	Alan (speaker)
Eric	Jacqueline	Martin
Ernest	Mike	Steve
		Sheriff

1. Future meetings

21st April Jim Symington - starting at 4pm.
28th April Focus group
5th May Diane Hackney visiting to talk to us
12th May **Whitechapel** Chris Flood
19th May sponsors visiting – Sue Spiers and Kathryn Harney
26th May Analysis
2nd June Analysis
9th June Analysis
19th June **Whitechapel** Diane Rose
23rd June Report writing
30th June Final report changes.

2. Analysis processes were discussed with Eric and Conrad and they were given typed transcripts of the first 2 focus groups to read, make notes on and highlight passages they thought important. We discussed making tapes available to listen to the focus groups, and coloured highlighters to mark text.

3. Feedback on previous visitor

Paul spoke to the Journalist, Laurence Pollock who interviewed the group in January. He will publish a piece, based on the interview, in May edition of his journal.

4. Future of the team

We are looking at funding opportunities to continue research.

a) Advocacy project with King's fund. Call not out until June.
b) Pump priming money for 3-6 months to work on further analysis and publications.
c) Ethnicity bid with FMH. Too specific for us. Not likely to get more FMH money until we deliver.

5. Jim Symington visit Preparation

Jim Symington will be with us next week from 4-5.30. Please will all team members arrive promptly at 4pm for the meeting?
Lisa suggested we invite press officer and get photographs taken.
The questions to be asked were discussed.

(i) Conrad to do welcome and initial question

(ii) Eric agreed to ask about race. Issues around discrimination were discussed in term of attitude. Questions could be phrased in terms of:

a. How can the [bad] attitude of staff be addressed?
b. Problems of attitude need acknowledging/recognising
c. How can these attitudes be changed? Through education?
d. One attitude problem is 'favouritism'. How can bureaucracy change that?

(iii) Eric had written down a question on reoffending being due to lack of funds and how is reoffending to be avoided?

(iv) Ernest wanted to know about how discharged service users could get back into the workforce. Mike talked about initiatives by Rachel Perkins in South West London. Lisa has worked there. She said that personal experience of mental health problems was seen as an asset within the trust. Ernest was concerned about how offending got round. We talked about CRB checks.

(v) Lisa talked about the double stigma of mental illness and offending. She thought that Jim would want to hear about that. Conrad reckoned that he managed mental illness as the main stigma – disability, chemical imbalance. But as his offending was due to his illness he couldn't be stigmatised as a criminal. One of the main problems is the embarrassment of what is done when ill. How to cope with the embarrassment later is ongoing problem.

6. Seminar

Alan presented on multi-disciplinary team working in a London acute ward. He discussed the analysis process used for looking at the qualitative data. Team members read the transcripts, coded them and then as a group they compared the coding done. A 4 way model of different styles of MDT working were presented. Conrad asked about the frequency of each model in practice.

Ian asked about the lack of service user perspective in the findings. Alan responded that teams were advised to keep the service user at the centre of their thinking.

21st April 2005 at Chiswell Street

Present		Apologies
Steve	Alan	Bob (Damaged foot)
Conrad	Paul	Sheriff (leave suspended)
Eric	Jacqueline	Mike (other work)
Ernest	Mike	Bandit (with solicitor)
Denys	Lisa	

(Chandra arrived late)

Guest

Jim Symington

1. **Business**
   a. Minutes of meeting of 14th April
   b. Next meeting we will work on analysing the focus group of 17th February. Transcripts were distributed. Eric asked for a highlighter to help work (provided).
   c. Denys would like his writing distributing to the group
   d. Conrad provided another written piece for the group
   e. Eric provided an example of a letter from the tax office. To be looked at next week.

2. **Interview with Jim Symington** (recorded)

Introductions (Conrad)	**m's responses**
What are Jim S's goals? (Eric)	To improve MH services in the eyes of service users and their families.
Accountability and value for money (Conrad)	NIMHE can't make anybody do what they don't want to do.
Discrepancies between services and the need for benchmarking (Steve)	Different trusts make different decisions. An issue that needs addressing.
Alternative models of care from Europe and America (Steve)	These are being looked at.
Employment for service users – example of Rachel Perkins at St. Georges (Ernest) Alan suggested the resettlement officers in job centres have a responsibility to find work for all and have contacts. Chandra suggested Metamorphoses in Islington for finding jobs for those with criminal record and substance abuse history.	St George's example of experience as essential/required for jobs has been followed in non-forensic mental heath, particularly in the voluntary sector, for example Tulip, Mind in Hammersmith' and in offending sphere by NACRO. However, no examples of specifically forensic mental health. Jim gave example of Peter Bedford projects: cleaning buildings; National social Inclusion Team (Miles Renaldi and Davis Morris who have looked at who MH people next with, stigma and the support they get from beyond the services.)
Why are black and ethnic minorities	Hard to unpick. Need to take a step

over-represented (Eric)	backwards. Some ethnic groups spend longer in hospital. More of them are on sections, they are perceived as dangerous, they have less support outside (especially refugees). Jim said he would like to hear Erics view, perhaps later.
Isn't the system racist (Conrad)	Not fair to say institutionally racist. But the system does fail whole groups.
SDPD bill and locking people up	There is a tiny minority that need locking up
Recovery from mental illness (Ernest)	This can be done. For example depression. Lots of people experience some level of depression and recover. Mental distress is part of life which could be less stigmatised if society moves away from using medical labels. The individual needs to focus on what is possible. Having fun is an essential part of recovery. Different things help for different people. Example of Geoffrey Archer's account of mental distress while in custody. To get better you need confidence, luck and support.
What can be done about stigma Lisa called for pressure on regulators to take firmer action	MH language on TV newspapers needs challenging. (gave example e of Bruno bonkers)
Recent changes in financial support while in hospital and opportunities to try to work without losing benefits are welcome (Conrad)	Good
The complaints procedure (Steve) Needs to be confidential (Conrad)	Needs to be fair for both sides
Thanks to Jim for coming.	Jim suggested the service user researchers might like to present to his team towards the end of the research project.

28th April 2005 at Chiswell Street

Present		Apologies
Denys	Paul	Mike
Sheriff	Jacqueline	Bandit (in court)
Steven	Lisa	Eric (nurse rang on the day)
Conrad	Alan	
Ernest	Bob	

1. **Minutes of last meeting (21st April 2005)**
   Debrief on Jim Symington visit. He was 'a politician'. He had been positive. He'd come to listen and invited us to come to talk to his people. The prepared questions had gone well.
2. **Future of the group**
   a) Paul has bid for money to continue the group in September. The current funding will keep the group going until 30th June. No meetings are planned for July and August. We will know in just over a month if we have funding for a few meetings in the Autumn.
   b) Conrad asked that references be prepared for the SURs.
   c) It was agreed that we would present to the Whitechapel seminar series in November (probably 10th November). Conrad offered to read 'Psychiatric Xmas'There will be limited funding for the presentation. Any presentation will need preparing, designing and rehearsing. Presenting would help prove stigma wrong (Ernest)
   d) We need outcomes to be able to continue the group.
   e) So far we have 'mined the past'. To move forward we will need new objectives.
   f) One suggestion well received by the group has been UFM (user focus monitoring). This would require a lot of hard work, not just a meeting once a week.
3. **Analysing the focus group**
   The transcript from 17th February had been circulated in advance. It was made available again on the day.
   Conrad read the analysis with written prepared comments.
   Emergent themes were
   Violence towards patients – a method of treatment
   Polarisation of good and bad nurses/staff/places.
   Debate about whether consequences of actions (kicking off) are inevitable/ foreseeable.
   Talk about talk – talk is important to de-escalate situations. What would the staff say about these same situations. Staff, like patients, see contradiction in the nurses' role (counsel and discipline) [Mason has written about opposing roles, the patient is forgotten in the nursing textbook]. A patient's talk is used as evidence against him/her.
   Powerpoint selection of quotes attached.
4. **Next week**

5th May Diane Hackney visiting to talk to us at Chiswell Street

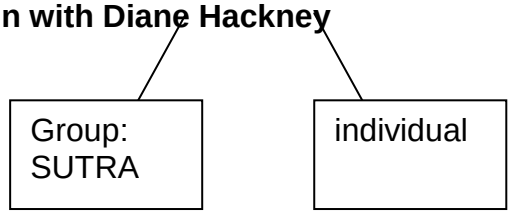
5th May 2005 at Chiswell Street

Present		Apologies
Steven	Paul	Mike
Conrad	Jacqueline	Lisa
Sheriff	Alan	Bandit
Denys	Bob	Eric (no nurse for escort)
Visitor: Diane Hackney Mental Health Training and Consultancy		

1. **Minutes of last meeting (28th April 2005)**
   a) These were not sent in the post, but tabled on the day.
   b) The team will present the project on 10th November at 4pm to the Whitechapel audience
   c) Analysis so far is included as an attachment to the minutes.
2. **Presentation on 10th November 2005**
   a) Proposed title

      Forensic Service Users Perspectives [on the development] of Therapeutic Relationships [with service professionals]

      [Possibly edit out words in square brackets?]
   b) To prepare we need
      i. Framework of how to use the time (4-5.30pm)
      ii. Abstract of 200 words
      iii. Who will present? Steve was concerned about stress of presenting. Diane advised peer support and having at least 3 people for a task to allow for problems of drop out on the day
   c) **It was agreed** that everyone would prepare a contribution for the 200- word draft abstract for the 3pm meeting next week, based on the above title.
3. **Discussion with Diane Hackney**



As an experienced researcher she talked about
◊ Remembering your role as a researcher, not a patient advocate
◊ Patient confidentiality and over familiarity needs to be managed – staff may not manage it well for you.
◊ More open interviews when two service users talk together.
◊ Most staff are good, but a minority are bad.

4. **Next week**

Whitechapel. Meet at 3pm for an hour to discuss abstract for the November presentation. At 4pm we will go to the seminar presentation by Chris Flood.

12th May 2005 at Whitechapel

Present				Apologies
Meeting (3-4pm) & Seminar			**Seminar (4-5pm)**	
Conrad	Lisa	Alan	Bob	
Eric	Paul	Sheriff	Mike	
Denys	Jacqueline			

1) Laurence Pollock's article in Mental Health Nursing was distributed.
2) Presentation on 10th November.
    a. The shortened title was approved
    b. Paul's abstract was discussed and agreed with minor alterations (see attached)
    c. Alan's proposed abstract would be useful for the report introduction.
    d. Conrad suggested plan for the day. Following Diane Hackney's suggestion – Conrad would like a team approach, with each person speaking for a few minutes.
        i. Conrad could read A Very Psychiatric Christmas
        ii. Give a service users view of therapeutic relations
            A. Would Steve like to talk about differences in therapeutic relationships in Rampton/Kneesworth)?
            B. Denys might talk about how he avoided conflict while in a medium secure unit.
        iii. What hinders therapeutic relationships?
        iv. How can you ensure a therapeutic relationship never happens? (A bit tongue in cheek, turn normal question on its head). This would make a good conclusion.

    Discussion: Needs to be interactive. Needs to have methodology/background explained early on (and briefly). The presentation will need illustrations of trust and failure of trust, not just assertions.
    Eric and Denys both agreed to participate in the presentation in November. Eric was wanted to know why we had to wait until November. Paul explained seminar programming.

3) Next week Dr. Sue Spiers and Kathryn Harney, the programme managers from our Sponsors FMH will be attending our meeting.
    a) Conrad may read 'A Very Psychiatric Christmas', followed by discussion.
    b) We could ask similar questions to those posed to Jim Symington. What is their overview of service user involvement in forensic services?
    c) We could ask what they want to see in the report, what they expect, what they think we may overlook.

4) AOB
    a. Conrad would like a reference for his interview with to Camden and Islington Trust next Friday.
    b. Eric is not sure he has the transcript from 24th February. Please send it out again. Eric brought an initial analysis of 17th Feb transcript.

Seminar: Chris Flood *Advance Directives in Community Mental Health Care*

Slides will be made available.
Certificates are available for those who attended the seminar.
The illustration of the woman and her dog brought the presentation to life.

Questions asked

What was the service users role in writing the leaflet?	Paul
I found them very professionally led.	Conrad
Controversy about insight – it's like sunshine	Other Service User
Plans may help more voluntary admissions and less sectioning	Other SU
Criteria for inclusion in the study	Len
Characteristics of those who declined to be included	Len
How was success of plans measured	Len
How did staff respond to the plans	Alan
Different levels of 'centres of excellence – eg Lewisham	Other SU
Who does the extra work of these plans	Alan
Who are the independent workers? Need to be another Trust	Conrad
Offering £10 vouchers for time – creating bias	Male Nurse
What about legal responsibility for the plans?	Female Nurse
- illustration of the dead dog.	
Measures of quality of life	Other Service User

19th May 2005 at Chiswell Street

Present		Apologies
Steven	Paul	Mike
Eric	Jacqueline	Lisa
Denys	Alan	
Sheriff	Bob	
Conrad	Chandra	
Visitor: Sue Spiers, assistant programme manager from FMH		

1. **Minutes of last meeting** (12th May 2005 at Whitechapel)
   a) Laurence Pollock's article **Send a response**
   b) Presentation for 10th November 2005. To be presented as:

Forensic Service Users' Perspectives of Therapeutic Relationships Presented by members of the Forensic mental health Project Team Organisations: City University with Revolving Doors Agency

   Roles in the presentation might include
   (i) Conrad's Xmas piece **Robert Typing**
   (ii) Denys's story of not being hurt **Circulate**
   (iii) Steve's story of moving from high security to private sector
   Digital recordings may be used for the presentation (and the report).
2. **Introductions**
   Sponsoring this project was a bold step for the FMH. They want to know/show if they were right to sponsor us. Should the project be done again, should there be more projects like this?
3. **Discussion of the report**
   a) Membership of the group
      i. How have late joiners fitted into the group? Those who arrived after December didn't stay.
      ii. Why have some left? (sceptical about implementation?)

	October	November	December	January	February
Joined	Conrad Ernest Steve	Denys	Eric Sheriff Bandit	Martin	Michael
Left				Martin	Michael

Jacqueline rang Bandit on Friday

   b) Report to include a clear idea of how the research has gone and the benefits accrued for you personally and how can this be passed out to others. What have people taken from this, what will they have three months after this?
      i. Conrad spoke of his CV/reference for work within the Trust.
      ii. Eric spoke of his application to SANE and developing a CV based on this project.
      iii. Paul is making efforts to reassemble the group in the autumn for a few meetings, to apply for King's fund advocacy project and Sainsbury Employment research.
      iv. Sue may want peer reviewers (there is strength as a group)
      There is a wish to continue the group.

c) The report must also include something tangible. Don't just include the best bits; include the bad bits.

d) The report will be reviewed.

e) How can the report bring about change? The report will feed into policy and prioritisation schemes. The report will be sent to appropriate departments within the Department of Health. The report will show service user involvement in the programme and what service user contribution can be. It can raise awareness as a policy issue. The team's recommendations may not automatically become policy. The report will have a better impact if it is not all critical. Eg. Good experience at Kneesworth and why it was good need to be included.

f) As well as the report to fmh, produce something accessible to service users and providers with any funds left over from the main project. Conrad suggested a leaflet for patients. The presentation on 10th November is a first step.

g) Journal articles from the project should acknowledge funding

h) The report should contain an executive summary and clear recommendations for: research, practice, service provision, etc.

4. **Examples of data**
   a) Conrad read A very Psychiatric Xmas (5 minutes).
      The piece is valued by the group because of its humour.
      Humour needs injecting into the wards.
   b) Denys read 'This is my piece …' (5 minutes)

A description of a day including thoughts
How grateful should you be in this situation?
When coping, how good should you be?
The story implies that it's going to be rough
Denys is acting himself, not putting on a show.
Someone regressing and no one is helping.
Discussion of earlier story of provoking psychiatrists
Eric was unable to attend two meetings this month. The staff said his response was good, he had not been 'fragile' . Eric felt tested(?) . Eric felt it was easier to manage because he was given information and an explanation about why he couldn't come.
Sheriff said that sometimes being quiet is seen as a negative symptom. He gave as example a student nurse who asked 'what's wrong?' and if things were OK. I just didn't want to talk.

5. **Future meetings.**

26th May Analysis: 24th Feb & 3rd March focus groups
2nd June Analysis apologies from Jacqueline/ Alan & Bob
9th June Analysis apologies from Alan
19th June **Whitechapel** Diana Rose Seminar on ECT Chandra will attend
23rd June Report writing in the small meeting room
30th June Final report changes venue?

6. **AOB**

Denys is concerned about P60 and claiming back tax. To be discussed next week.

26th May 2005 at Chiswell Street

Present		Apologies
Eric	Paul	Alan
Steven	Lisa	*away until 13th June*
Conrad	Jacqueline	
Denys	Mike	
Sheriff	Bob	
Ernest		
Eric & Sheriff's address is now 12 Kenworthy Road E9 5TD		

1. **Minutes of last meeting (19th May 2005)**
   a) The meeting with Sue Spiers went well. Thanks to those who attended and participated. Minutes were sent to Sue.
   b) Bandit was rung about his departure from the group. He said that he found the dynamics of the group difficult and feeling angry about some of the things said to him and had therefore chosen to withdraw rather than face conflict.
2. **Future meetings**
   a) Proposed meal on last meeting: 30th June. Curry in Whitechapel was suggested. (Brick Lane, eg Lahor) Suggestions next week. Should it be 4pm? Eric needs to organise his time in advance. Sheriff and Eric have to be back at 8pm. Sheriff and Eric to explore in the ward arrangements for them to attend.
   b) Next week (see agenda)
3. **Payroll**
   P60s should be sent to people this week. If you have already claimed tax back, keep the P60 for future employment records to avoid tax problems. If you have not claimed the tax back, send the P60 to the tax office with your name and address (see letter drafted by Jacqueline).

Analysis

Eric passed analysis of 17th Feb focus group to Jacqueline.
Conrad had prepared analysis on 24th Feb FG. We worked from that.
Conrad handed his analysis to Jacqueline at the end of the meeting.
Conrad also brought 2nd section of 'On why mental health patients piss me off' (distributed).

Conrad, Paul, Jacqueline and Eric reported on what they had read and analysed with others making impromptu comments.

Paul and Jacqueline will collate the comments and report back in a similar form to the report on the first focus group (see attached).

Please bring your analysed transcripts of 'Bandit' focus group (3rd March) next week.

2nd June 2005 at Chiswell Street

Present		Apologies
Eric	Paul	Jacqueline
Conrad	Lisa	Mike
Denys		Bob
Sheriff		Alan
Ernest		*(away until 13th June)*

1. **Minutes of last meeting (26th May 2005)**
   a) Discussion about restaurant outing - Sheriff and Eric reported that they had made requests for leave that day. Paul explained that he had received an email from the Local low secure ward charge nurse requesting details of outing, which had been answered. It was agreed to meet at around 5pm or 6pm and the go for a curry in a local restaurant.

2. **Pay queries**
   a) Eric and Sheriff questioned details about their pay, which were answered by Paul.
   b) P60 were received by everybody

3. **Analsyis**
   Comments were made about the 'bandit' transcript, page by page, with Eric, Conrad and Ernest making specific references to the text and the themes and meanings they gathered from it.

   In summary, a major point of discussion was about Bandit's behaviour and mode of behaviour. As an example of how users experience using services it was thought to illustrate how the system encourages dependence. Once having made someone dependent on it the system then treats users badly, which engenders frustration and rage. This then may lead to outbursts that are then not dealt with kindly or sympathetically.

   The session finished at 5.35, having reached page 20. It was agreed to continue analysis next week, **9th June at 4pm,** at **Chiswell Street**

   Please bring your analysed transcripts of 'Bandit' focus group (3rd March) again to this meeting.

9th June 2005 at Chiswell Street

Present		Apologies
Conrad	Paul	Alan
Denys	Lisa	Mike
Eric	Jacqueline	Bob
Sheriff	Chandra	
Steven		
Ernest		
Visitor: Matt who has experience as a criminal justice service user from Revolving Doors Agency		

1. **Minutes of last meeting (2nd June 2005)**
   Tabled

2. **Bandit focus group discussion – starting page 17**
   a) Violence on wards and difficulties in making complaints
   b) Leaving the past behind you: Difficult to decide what to leave behind and how to leave it behind. How do you tell people about your history. Does stigma vary with clinical diagnosis. How useful is the diagnosis to the individual.
   c) Clinical teams and how they work. Psychiatrists as over critical, psychologists as helpful. The impact of the professionals' gender. Strategies for getting discharged.

3. **Future meetings (all Thursdays)**

16th June	1 hour then Diana Rose seminar **Whitechapel**
23rd June	Report writing Chiswell Street, Meeting room
30th June	End of project meal (to be arranged) Sheriff may start college and not come.

16th June 2005 at Whitechapel

Present			Apologies
Meeting (3-4pm) & Seminar		**Seminar (4-5pm)**	
Conrad	Mike	Alan	Bob
Eric	Paul	Sheriff	Lisa
Steve	Jacqueline	Denys	Chandra

1. **Minutes of last meeting (9th June)**
   - **a.** Conrad gave his analysis of 'bandit' to Jacqueline. Steve was still working on his analysis. Please will people bring their comments to the next meeting for Jacqueline and Paul to put them together for the report?
   - **b.** Future meetings (see below)
   - **c. AOB**
     Steve asked about work projects for people with mental illness
     Mike offered information on Portugal Street, off Kingsway (Between Aldwych and Holborn)
2. **Writing the report.** We discussed what to write in the report. Paul has prepared a sheet (attached) will team members please complete this sheet and bring it with them next week.
   - **a. Executive summary**
     - **i.** Headlines needed (Paul)
     - **ii.** Insights into what it's like living with mental illness (Steve)
   - **b. What has the project achieved**
     - **i.** FMH Service Users have come together weekly to work with university researchers to develop research (Conrad).
     - **ii.** Written material has been produced, collected together, discussed/analysed. Focus groups have been undertaken. A volume of good information has been collected.
   - **c. What has been the SUR experience?**
     - **i.** The project has been experienced as empowering, a confidence booster/felt valued
     - **ii.** The seminars attended have been interesting and provided new information for service users.
     - **iii.** Time to go into experiences in depth. An opportunity to express ideas. A sense of release [cathartic?]
     - **iv.** Got some started in writing.
   - **d. What have the SURs learnt?**
     - **i.** That others remember similar experiences after discharge. That what happened to me happened to others. We all found staff abusive. NHS offers a place of safety – but in reality it is a scary place. They keep you in to show they are doing a good job. There are exceptions. Steve talked again about Kneesworth. Conrad said 1 of his 7 admissions was good.
   - **e. What have the SUR gained from doing the project?**
     - i. A references
     - ii. A work history
     - **iii.** Bank and tax details set up for other jobs**.**

f. What should anybody else wanting to undertake a similar project in the future learn from our project?

- **i.** Payment is important, including how it is done
- **ii.** Meeting in a neutral environment, away from the clinic, with neutral staff in necessary.
- **iii.** Having a reference from key workers was good.
- **iv.** The group was made up of service users who were discharged, and in rehabilitation wards. They worked well together. You need to be in rehab to undertake research. You need to be able to take care of yourself.

g. What recommendations should be made?

- **i.** Patients have different conversations together than if led by professionals. They get better information (Steve).

3. Diana Rose Seminar (see handouts were available)

Conrad asked about consent.
Young woman asked if there was a match between those who reported giving consent and those who reported improvement (analysis not done).
Denys asked whether ECT was good for keeping people out of hospital. Diana explained that it usually ECT requires a day in a hospital setting.
List of next year's seminars was also distributed – See 10th November.

4. Future meetings

23rd June Report writing Chiswell Street, Committee Room

30th June End of project meal at Tayyabs, 83-89 Fieldgate Street, London E1 1JU. The restaurant is walking distance from our Whitechapel building. We will meet at Whitechapel City University building at 5.30 and walk to the restaurant. Paul to book a table for 6pm. Regular members of the team are all welcome. The project will pay for everyone's meal and the usual payment for three hours time will be made.

……..

10th November Presentation at the mental Health Seminars, Whitechapel.

24th June 2005 at Chiswell Street

Present		Apologies
Sheriff	Lisa	Alan
Eric	Paul	
Ernest	Jacqueline	
Steve	Bob	
Denys	Mike	

1) Minutes of last meeting (17th June at Whitechapel)

2) One page sheet to prepare for the report was circulated again. Alan Bob and Jacqueline have completed their forms. Will others please complete and give to Paul/Jacqueline. People repeated what was said last week:-

    c. Better understanding of the MH service, insight, reduce stigma
    d. Meet others and know not on our own with our experiences. Nice to be here, new people, new ideas.
    e. A chance to talk without interruption, an open forum, not diverted, not under the microscope.
    f. Empowering / feeling of accomplishment
    g. Research project a chance to have our say and query what should be tter and say what went on.
    h. Exposure to research and his preference for something more structured. Any SURs who wish to be more involved in writing the report over the summer should get in touch with Paul.

3) The ReFer Report was discussed. SURs were asked to provide pen portraits of themselves. Will people please provide a description of themselves that they would be happy to have printed. Paul and Jacqueline will visit Bandit on Friday to discuss his contribution to the report and a pen portrait.

4) Pay and P60s. At the end of the project it is up to the SURs to inform the DWP (their social security payment office) that they have been earning and that this earning has now ended. Denys has spoken to the tax office about his P60 and asks that we send a letter to the tax office.

5) Next week we will meet outside the Whitechapel school of Nursing at 5.30 and go to the restaurant: Tayyabs, 83-89 Fieldgate Street, London E1 1JU.

6) Next term we will have a series of meetings in October

    13th October 2005 Chiswell Street, 3pm committee room
    20th October 2005 Chiswell Street, 3pm meeting room
    27th October 2005 Chiswell Street, 3pm committee room
    3rd November 2005 Chiswell Street, 3pm committee room
    10th November 2005 Whitechapel – presentation

30th June 2005 at Whitechapel – meal out

Present	
Sheriff	Lisa
Eric	Paul
Steve	Jacqueline
Denys	Bob
Conrad	Mike
	Alan

Paul McL. (Nurse escort for Eric).

No minutes were taken.
It was agreed that Conrad with co-ordinate pen portraits and that output from the project would be written collaboratively. Drafts would be sent to SURs.

(appendix 6)

CREATIVE WRITINGS BY SERVICE USER RESEARCHERS

A VERY PSYCHIATRIC CHRISTMAS

by Conrad

I was twenty when God spoke to me. He'd hinted at his existence before, of course, but this was direct. He told me that my mother was not going to die. He was absolutely right; she is going strong now, and looks set for two more decades. When he spoke to me I was absolutely terrified.
I has been praying – crying really – for about two hours, pleading, begging, asking, snivelling, etc. You get the picture. Suddenly a mighty wind shook the room and a voice spoke – from everywhere it seemed – and said.
"As you have asked so shall it be done for you."
Then it all stopped. Every thing was the same – except me: I was now a Christian. And terrified. Very little Christian, very big terrified. I couldn't handle it. Within three days I would be back in mental hospital for the third time. I'm a Christian though. This time would be unlike the other times, firstly it was at Christmas when the other two times were in spring and summer. Finally I felt it was completely unjustified. I did not need to be sanctioned. Not then, the first time maybe yes I can see that. The second yup. This time, no way man. I was receptive and ripe for some active intervention. A good therapeutic relationship, right drugs, good communication, a voluntary admission. What I got was like a tungsten fly trap – totally unbelievably unnecessary.
I came into casualty totally willing to use the system to help me. I was in crisis and I knew it. I couldn't handle what was going on in my head and my behaviour was becoming increasingly eccentric. Now I knew about this – it had happened twice before after all. And I felt that with some help I would be ok. I hadn't been taking drugs – you hear that – I hadn't smoked a joint, let alone anything else, for three months. Got that? No drugs? OK? Oh sorry I was harping on about something? Can't think why.
They believed me. "ok" they said, "were admitting you. Voluntary, no worries". Off I went trustingly, holding the hand of the mental health professional. Took a few pills, Bed, zonk out. Sleep, something I hadn't been getting lots of. ZZZ.

The Ward.

This place was a cross-section. Of everything. So much went on there; its undercurrents ran deep. Much of what happened was fuelled by boredom, and among the staff an uncaringness to entertain? Certainly the ethos was not conducive to healing or, it turned out, speedy or accurate transmission of information.
I wanted to go and buy some cigarettes, I was in a good mood. I felt I had survived the storm and with some support I would be ok. I didn't realize that the support would be a worse storm. I trusted mental health services at the time. Ha ha, hee hee, silly me. I couldn't go and buy the cigarettes. I was

sanctioned – for six months. What? Quietly I began to go insane. The process lasted about four days.
The atmosphere on the ward was very conducive to my growing insanity. None of the staff told me the same thing, I couldn't speak to a psychiatrist or a lawyer. So what if this medication I had been prescribed gave me really bad side effects. I would take it and be quiet or be injected with it anyway.

That was it really, Christmas morning 1996 – take the droperedol. It doesn't matter what you think it will give you after effects. Take it or be injected by force. Slowly a switch flipped, a fuse burnt out and a poor man denied the chance to become rich, flipped out. Pardon? Yes, denied the chance to become rich. I was going to earn a fortune that Christmas.
Oh Peter. The Big Issue. Friends, work, money, Opportunity. Gone for good. You see up until that Christmas for 3-4 months I had been working two days a week, thirteen hours a day – by the end.
And for about ten days over Christmas and New Year I could have earn't £1000to £1500 profit on top of £500 already saved.
Being sanctioned denied me this. I've only just recovered workwise really, eight years later.
My studies so far – my access course that would four years down the line make me a mental heath nurse – have only just recovered. I don't want to be a mental heath nurse either: the people you have to work with …
So I rang my sensai and begged for help on that Christmas morning. Then barricaded myself in my room. I wanted my sensai or lawyer, nothing else would do. Instead I got six riot police.
I lost of course. I didn't fight when it came down to it. I would have lost anyway. My major bone of contention is: they didn't need to break my wrist. I wasn't resisting. They came through my barricade, I curled up. They hit me three times then stopped. Handcuffed me curled up on the floor: as tight as possible on the left wrist snapped like a twig. It was agony.
"Does you head hurt?", the pig who'd hit kept asking me. "Get off my wrist" I replied as unconsciousness hit.
I was two days without medical attention, seriously. I was zonked at about 11.30 Christmas morning and it wasn't until 10.00pm. on the 27th. of the 12th. that I was diagnosed with "a very bad fracture that I must say you've looked after well".
That was my Christmas. Very damaging and totally avoidable. Today I am doing well, thanks, and trust no psychiatric professionals whatsoever.

Medication

by Conrad

Medication is a funny word. It means different things to different people and has many lexicons. Only in psychiatry is the term called fear injected. The fact of the matter is, to the majority of the population the word medication is entirely positive. It means, they know what is wrong with you, they can do something about it, and you are getting better. Most people would be

bewildered at the thought of medication as a weapon. You see, acceptance of the illness usually means acceptance of the cure, whatever that might be. Now an incurable illness, that sounds depressing – no? All long term mental illness is incurable Yup, all – the fact of the matter is the mad, as we are termed, are all incurably mad. We can be "maintained" or "stabilised," be in remission or "currently well". For us too there is no hope without medication and the fact is that medication has side effects. All of it. Psychiatrists know this as well as patients and we hate each other. Oh yes we do. They hate me and I hate them.

The suicide rate amongst psychiatrists is double that of the normal population. Bad vibes or bad Karma explains that. Mind you, suicide rates among mental health patients are far higher. Is that also bad vibes or bad Karma? Is there a negative spiral happening? Why does no-one care? Poor psychiatrists, they aren't helping us and we are infecting them. Why doesn't every ward in the country have a full time counsellor? Where is group therapy? Why has the nurse ignored me for the third time. Why - oh it is medication time.

Side effects, we know they happen and so do they. They can legally force any medication on you that they want, irrespective of side effects. The potential for abuse is huge. Why do they keep getting it wrong. So the next time you hear about a dangerous mental patient who has stopped their medication – think. Think chemical kneecap torture ongoing. Think powerlessness. Think no input into care. Think afraid. Remember, on medication and related topics, please to listen to the medicatee. Not to do so is bad Karma man, and you heard it here first.

Part 2

Now that some of my hysteria is vented there are a number of topics around the subject to explore. What happens with no medication? What if it doesn't happen for years? Suppose someone becomes ill, is diagnosed with a mental illness, is released and then stays well for ten years. Did they then have the "illness" as compared to a breakdown. If they do go back after ten years, would it have been better for them to have been on medication all that time? Think of the side effects. This is, I agree an extreme example, and most people need their medication – so what does it do, this medication, and what happens when it isn't taken?

The first thing that medication can do when it is correct, and it can sometimes take a decade to get right, is that it can make you really, really well. It can do this in such a way that people will argue - with you - that you don't have a mental health problem. You can lead a normal life, hold down a job, study, travel, make a good relationship, pursue interests and hobbies and manage your finance as well. You can do all of this as if you have never been unwell or didn't have an illness.

The second thing that medication can do is the opposite. It can restrict you deeply and keep you in 'mental health circumstances' e.g., on benefits, withdrawn, low confidence, bad hygiene, bad diet and always somewhat unbalanced. It does this usually when someone is on a high dose of anti-

psychotics, which also have a depressing effect, usually by depot. The individual is given no counselling to build up strong mental and ethical values which render such high doses unnecessary. They, therefore, cannot find their way out of the hole that they are in. This situation is very unpleasant.

Now the first thing that goes with lack of medication is sleep. It slowly grows less and becomes more unnecessary. This encourages delusional thinking. The person loses their reasonableness, they may go out and walk, but really they don't leave their own head. Drinking may increase and a once sweet tempered person may become regularly aggressive or even violent. The person is now on almost no sleep and may stop eating, or at least regular eating. Any savings will be swiftly spent on sprees. Bills, letters and appointments are ignored. Any illegal drug can send them over the edge. Finally comes intervention, section, and then you start again.

ON WHY MENTAL HEALTH PATIENTS PISS ME OFF . . .
OR,
A DAY IN THE LIFE OF THE MAN WHO SELLS BOOZE OPOSITE THE MENTAL HOSPITAL.

By Conrad

Always moaning aren't they? The only thing half of them can talk about is their illness. They never do anything new, and most of them take drugs. God, loads of them can't even manage to keep clean. They're just lazy, I mean they're all on benefits aren't they: I mean, they don't even bother to try and stay together. I'm sure half of them aren't really ill.
It's no excuse anyway, my friend is dying – I mean, he's H.I.V. positive and if he doesn't take his drugs, he dies. He stays together – none of this I don't want my medication bollocks. He wants to stay out of hospital, not just go in for free food and to save money. God they're so negative all of the time. They should not be allowed out – did I mention that they don't wash and they're all on drugs – some of them can't speak straight, just drool, it's disgusting. They're not like you or me. I don't understand why they're allowed out when there like that, you'd think they'd stop them drinking as well.
Pardon sir what's that, three cans of super strongbow, that'll be £2.97 Sir. So how's the hospital treating you then, really?, very interesting. Ten Mayfair as well sir and a packet of king sized rizla – looks like your going to have a, ha ha, good morning sir. Thank-you, bye. See what I mean – all on drugs, I mean its only 10.20 a.m.
Oh here comes a nurse – hey look sharp if you want it in your pocket now and pay. O.K. Hallo sir usual list is it?
"Yes, and you don't sell wagon wheels do you?" 40 b+h, ½ ounce amber leaf, 10 super kings, "Pardon sir sorry no – no call for them usually" 10 packs golden Virginia, 5 packets small green rizla, 1 lg blue, 1 clipper lighter, café-crème cigars, £Well you would have sold 12 today," That seems to be it, "Plenty of change for you sir I know." Thanks. Nice bloke that nurse always smiling – heard he wasn't smiling last week, got a black eye and a chipped

tooth. Someone punched him wearing a sovereign ring while he was trying to take it off them. So they wouldn't hit anyone
with it. She reckoned she would never have clumped him if he hadn't asked for the ring. Her boyfriend thought it was hilarious, he couldn't stop laughing while he was buying his vodka.
I suppose it's an ill wind. He reckoned that laughter is healing, that cancer can be cured through laughter. I must say that he is trying hard with his schizophrenia; I personally don't think that laughing your head off a psychiatrist helps your case – he'll think your on drugs, I said to him. I usually am he replied, laughing.

Mentally ill people piss me off. They're always moaning. Moan, moan, moan. They complain about they're illness: they're too depressed; they're not depressed enough. They complain about the medication, its side-effects, the body language of the nurse who gave it to them. They moan about the food, about the facilities, and about the staff especially. Mental health patients moan a lot.
Most of them are on the cadge as well. For a fag. All the bloody time. They get paid and waste the money in 3 days (1 if they're chronic). And you, who husbands and shepherds your tobacco, who budgets and excercises restraint. Is hassled, threatened, guilt-tripped, emotionally blackmailed and ganged up on. Because these arseholes need a fag. Sorry about that it needed to be said. Happily, personally, I no longer smoke. I f the worse comes to the worst – but I digress.

Mental health patients drain people's energy massively. They are very demanding. It costs £1000 a week to keep someone in hospital. And they keep coming back.

I don't know, snickers or mars, what about galaxy. Er that one – no, erm. Why doesn't she just buy all three. He thinks. She wants them all really. She looks fatter than last week, loads get like that it's all the meds. That and the chocolate, "No bag for them, o.k." heres 7p change miss. Hmmm boy she was here last year too. What no porn magazines sir only good old cigarettes, booze and junk food. Much better for the mind. A large bottle of Vodka, well you can't wank after that. The doctors Mercedes is going to get a ticket again – he does alright. Or is he a manager.
"Oh, hallo sister come for the afternoon round have you."

Scene: It is later though it is still very light. Achmed has handed over to his brother Mohammed who will sell into the dead zone. It is summer: alcopops and ice cream are in. sales of Tennants super and King-size blue (slims of course) Rizla are through the roof. Mohammed has a problem: it is small, female, upset and desperate for credit. Mohammed is very ethical about these matters. He hates requests for credit.

I am very sorry miss, no credit. But you do it for others I, just want 10 fags and two tenants, I'll pay on Monday, its not much, I mean come on . . . I. Mohammed holds up his hand (he hates this) look he says I know you, O.K, your over there. I'll give you one tenants and five fags from my box – now you'll come and see me on Monday won't you? Oh yes that's absolutely that's really good, I mean it's great (takes fags) really nice, friendly, I'll definitely (gets tenants) O.K. thanks see you Monday.
Mohammed's problem leaves, deep in conversation with her tenants. Mohammed sighs again and marks a paper with her name and a / for the beer. He knows his fags are gone. But he shrugs and, humming softly, kills a fly on the edge of conscious irritation. The next customer was sure to come soon. All the nurses had bought their fags – both the shift going in and the one coming out. And now, well it would be the slaughterers – those souls whose only desire at the end of each day was to be completely slaughtered. He knew his shop was only part of the process. Yet profitable luring not withstanding Mohammed was very law-abiding if a little creative on his tax return. No he would happily sell heroin (say) but if, and only if, it was legal to do so. Mohammed looked upon law-breakers – shoplifters say – as merely foolish. They obviously hadn't thought things through properly. A patient it takes sixteen nurses to restrain, who puts three off sick for a week, is a patient who has just volunteered for an extra six months. But they're mad; Mohammed's thoughts lazily idled along the sulphurous, decrepid groove; they can't help it.
Hallo sir, you're looking well, usual? Good, £2.19 tobacco, 50p blue rizlas, polos, tic-tacs, three flakes and a packet of salt and vinegar crisps. £4.98 altogether sir thank you. Pardon sir? Oh you were talking . . . again a patient leaves the shop talking to the voices in their head. Where are all the cool and hip, happy go lucky, intelligent and athletic, sane insane people? Oh funny comes the answer back; they don't exist. But they do. The problem is that they go to the other off-licence. Very simple you see. Dusk is starting to fall, and Mohammed has just sold his last three male customers condoms, and is wondering what's going on. He, however, never did find out. This did however bolster his vague suspicions that somehow the mental health thing was a big con trick. They were all having a great time at his expense – and on the taxes! (Creative accounting aside.) However, as he sold two pasty men a bottle of whisky and a four-pack of Fosters, he reflected that at least they spent most of his taxes back with him. A financial eco-web as it were.

It was 10.39 now and sales were dropping off. Stuart (big) turned up and they reloaded the shop for the next day. Mohammed gave Stuart his quarter whisky and ten fags for his work. Stuart drank the whisky as he walked back across the road to the hospital. By the time he reached the door it was done. Lovely, Lovely that, wasn't it? He said to his friends. The voices in his head

paid him no heed – they were too busy giving the security man the eyeball. “Hit him” one voice said to Stuart. Don’t be silly Stuart replied. And the voice lapsed into silence; rebuked. “Here have a fag,” another voice said, “touchy today wasn’t he.” “I dunno” said the first voice, “I mean what’s my motivation as the violent one?” “Well someone’s got to do it”.

Mohammed

Mohammed got home – went in, kissed his wife and lit up a large spliff. “God! I hate alcohol.” He said.

TWENTY WAYS TO ENSURE YOU DO NOT HAVE A THERAPEUTIC RELATIONSHIP WITH YOUR CLIENTS

By Conrad

1). Lying is always good, especially if it’s done consistently. Blatantly lying, to keep someone quiet, or cover up abuse is the best.

2). Set your client up. Deliberately and subtly wind them up, then when they explode have them injected. This method of approach is particularly effective.

3). Verbal abuse – the old favourite. Remember a miserable patient with no self- confidence is a quiet patient who makes no trouble.

4). Over application of the rules. Extreme unbalancing and destabalising, innumerable opportunities to humiliate and harass. Your life is hell, ha, ha, sums up this approach.

5). Treat all your clients appropriately – like lying, brain-dead five-year-olds. Every one knows that being patronised helps someone get well quicker. Really, really talk down to them and don’t forget to dismiss anything they say.

6). Always assure your clients that they’re side-effects are just in their heads. Maintain this attitude up to the point where they collapse in spasmodic agony, then ask why you weren’t informed of their side-effects.

7). Always remember that mental patients know nothing, remember nothing and are nothing. This means they can have no viable input into what medication they should be prescribed. The dirty word here is “insight”.

8). Malicious flirting is excellent fun. Flirt some locked up patients into hoping for a relationship, then mess with their heads. Disappoint them publicly, then laugh at the idea. Remember misery doesn’t cause problems and patients aren’t people.

9). Let the patients abuse each other. Keep score, hell, keep a book. Patient Gladiators is always good sport and the sound of faint tortured screams always brings a smile at note time. The buzz word here is “Place of safety”.

10). Over-familiarity shows contempt. The best time to implement this guide-line is on close-obs. Isn't it fun watching them pee, bath-time and the old favourite game – can I make you so uncomfortable you can't sleep. Make sure you have a lighter, if you piss them off enough they get locked in seclusion and you can go to sleep.

11). Bedtime is at 10.30 sharp. Oh the joy, then refuse a light after eleven and leave the patients to roast. Guaranteed to increase uptake of sleepers and allow you to be paid for doing nothing – everyone's a winner.

12). Play favourites part one. Allow one patient to get away with murder. Abuse, violence, continuous loud music playing etc. – all impacting on other patients, of-course. Seclude anyone who protests. This tactic owes much to Machiavelli and by setting patient against patient guarantees an entertaining shift.

13). Play favourites part two. You're the most hated nurse on the ward, patients would spit on your shadow, but they're too afraid. So make a patient your pet, show favouritism, give special treatment and wink at minor crimes. When everyone hates your pet almost as much as you – go on leave: your pet will soon need a vet.

14). Blatantly beat the crap out of a patient for no reason, have them injected and everyone write that they attacked you. They'll show you proper respect now.

15). Keep them banged up 24/7 for a month, two months, as long as you like. Taunt them with this when stir-crazy and then use they're reaction to justify keeping them in even longer. Remember, whoever writes the report writes the truth, always.

16). Remember you're always professional and never make mistakes. Therefore anyone who is suggesting you made one is mad and in need of medication – especially if they think they're a lawyer.

17). Always Cover for a Fellow Mental Health Professional. The golden rule. Observe always for self-insurance and a greasy career.

18). No drugs – they have terrible aside-effects. No not the droperadol, the joint. You evil, evil, mad person. Now we have to prosecute. You may be mad enough to section, but you're sane enough to go before a judge. Pardon?

19). Always lie to the relatives, if you can convince them the patient is deluded and lying themselves, so much the better.

20). Remember you are helping. You provide a safe, caring, nurturing – stop laughing.

Bandit

by Bandit

– Hi MIND, I'm bandit, known as I'm suffering from a paranoid schizophrenia and psychopathic disorder. I'm under [A hospital in south London] On 7th January I went down to see me CPN to see about the money that the Trust owes me due to I had no money not only because I had to go to this for a crisis loan. I was turned down due to - due to me paying back loans that I taken out – out –out – out way back in the 90s, so I was stressed. So anyway I met up with my CPN, went to my, I went into why I was in need of his help – with help, and about off the money that they owed me for my missing items, in which I set down with a former social worker, and wrote to the ward manager about the missing items way back in September 2004. Yes, until now have not got a reply of 'we are looking into your complaint', so I was telling my CPN all this and he wasn't offering me any help at all. So I then said if you're not going to help me I will do something silly on – on someone, i.e. Robbery. Still no joy I went to the staff canteen I took twenty five pounds from the till, which was enough money to live with my ward manager, now he's saying I punch him in the face twice in which I did not - I did not do so. But I spat in his face twice, and according to the policewomen I got in it for theft and assault, whilst being held down the ward manager gave me a rough treatment, i.e. being put down by putting his knee in my face and using force on me. Anyway, the story is that…I went for help – I to them for help – and I got nothing, in doing me – in doing what I did – what I done now pressing charges on me…now that – now that my missing items, I was in the a secure unit in sometime in 2004 and this nurse went to went – Currys and Dixons to buy me a mega hi-fi, which he did. It got broken so I put it in a staff office under the pigeon hole, no patients got the key to the office but when the time come for me to pick it up my hi-fi's gone missing, now staff are not – now staff are not are not remembering that I had this, that it was an office, so – so that is worrying me –so that is –that is worrying me that they could turn around and say that I did not have it at all, so I lose that and claim for my money. Anyway the next thing I'd like to bring up is that the fact – the fact that is that of me getting in attacked me. They turned me down a loan and I'm feeling low it came across my mind if that is the way life is going to be then I might as well join a few of my a few of my mates at the bottom of the Thames. Since this happened in social services in [a North London Borough] .. I told the .. in the office and I had a feeling of taking me own life and they couldn't even offer me help in the way I was feeling and their response was 'we can't help you' so I left feeling bad about the whole system and I started.. and I went into job hunting and I got a part time job and I'm so proud I'm fine now but its about time social services that they did nothing to help me and in my need I don't do not know if its because of my skin colour but something needs to be done about it, cause its not alright its they are there to help you no matter what creed and now I got a court case due me get caught at the hospital and that's not looking after me.

This is my piece as a story that will be told

by Denys

One day, while in hospital, after I'd just returned from one of my daily activities, while on parole, I was allowed unlimited time, due to the progress I made whilst in seclusion. I returned as I usually would, always at the right time. As I entered the ward I was approached by a nurse. As usual me being polite, nice and basically my normal self [It] began to talk as was obvious he believed there would be no reply. What I'm actually writing this very moment, so that you can understand me, is the truth. I've been asked to give a definition of what it is like while in hospital. Although I'm now an ex-patient that doesn't want anything to do with them any more. We began to talk, as I was saying, after we had finished I walked to my room. Really in the back of my mind, I had the same deceitful ideas I usually had about the place [], although they did not know why they was always so polite to me. I was in my room for just a moment as usual. First I had a shower to freshen up, it took about 15 to 20 minutes before I'd finished. It was now roughly tea time and I wasn't hungry. I very rarely was late. I was there, basically being detained and having tea, to me, just didn't make sense. Although by now to most patients it must seem to them very nice, considering the difference between now and what institutions used to be like, years ago – a big difference. Anyway, I'm not the sort of person that goes around justifying right from wrong. Although, this is always there in the front of me. What I really want to say about what goes on in places like that you would not believe, unless you were there to experience it for yourself. I don't mention it now for the moment because although it did hurt my feelings. Now they are most probably thinking to themselves, and I know they are including my psychiatrist. This I doubt, where that guy gone because, to tell you the truth, I really do feel like I'm demoralised, like a confused idiot, most probably, like the rest of the staff here, although be sure none of us here are going to mention it. I think I'll leave now is what most of them are thinking by now, I'm quite sure of it, although that's another story, that most probably will come out eventually, as things like that do. And how silly they will feel, believe you me.

Considering just this one more thing I'd like to write about while I was there is this never believe in professionalism is some thing you take for granted and, believe you me, they all did is why I was the only one that had permission to leave in the end I'm sure that is not all bad, including myself ready to admit it. Considering the basis of why I was there instead of the issue I was led to believe which as a definition to totally different circumstances so now, because of what I know and how they behave, to cut a long story short, don't believe everything you here, unless you know it's a true don't get the wrong idea things do happen to patients while they are in hospital, take it from me, the only way to survive is just don't get into if because, believe you me, they most probably live in fear now as they really have to remember what they did and just get on with their lives with …. Shame and humiliation in a world that does know how they made me feel for no reason at all but my prize is my freedom.

Friday, 13 May 2005

This is my other side of the story concerning what happened while I was in hospital concerning the ending, as such, for a crime committed well over the punishment received for what I did years before. Anyway, I've been thinking how to bring understanding to what I believe should have happened while patients alike with myself who's an ex-patient now and close to 17 months I spent in a medium secure unit working with patients on the other hand that need not only for themselves but for the trust of their psychiatrist mainly and most definitely not only the other patients but the team provided which we all receive while there in providing the services and problems that may have put them there as such bringing understanding to service users like myself who is now an ex-patient who did survive a difficult period while in hospital, which as far as I'm concerned a place that I honestly believe to be my understanding while I was there that there are ways of talking to doctors and nurses that believe possibly if you show them not only there but yourself really like every patient being held under the mental health act is that there is more to life than just being held usually against our will is what's going on and the way really to have some idea of what it mean in hospital where you don't want be there and are constantly being told how you should be …ing while on treatment so basically proving that you are capable of … joking the …ly after usually as I've had it three to four years of treatment probably that as the individual I know for a fact as a patient do not the being told when you don't take your medicine you become unwell is I think hard to explain especially me being one of the those people that really if that's the truth your telling me I and as someone that was around with an attitude that does not become the office it can be very hard to sit there which is usual and have a person tell you and possibly other members if their …able at the time to talk with the doctor or nurse social worker as lack a lot probably a few other people yourself and family if you locked any and try together as a team to decide as a team whether your health is 100%. When the time to leave if you as a patient can get that far when the rest of your friends or family or who ever may be apart of the problem which in my circumstances basically … my fault and some I should never done it anyway I dad survive from the … to me that now does … like had I which I'd been in before I was just about to be released when I did get hospitalised days before I was supposed to return home I did try and I did succeed although it …. Can be the idea of choice whether is all I can say and much further believe as the individual being a … that I am not anymore to have understanding basically the rights we all … whether being in hospital or having a choice … through behaviour if being a patient when its time to leave so really it doesn't have to be one sided its getting the problems usually what .. great ourselves in changing its circumstances to try and make the difference when its time to change and stop these problems from happening again although there are persons or people that don't believe to themselves that their not capable of surviving in the community and don't much rather prefer to stay in hospital because of the way they might be treated in the …., and …ed … .. are safer in hospital being looked after who might not have a mental illness of any thing else wrong with them possibly homeless or poor standard of living but usually conducts that in today's world is of unexpectable not just by the system but even the friends and family possibly colleagues you may keep.

Appendix 7

Capacity building session on focus groups

Focus Group Methodology
Presented 10th February 2005 Jacqueline Davies Paul Godin

What are focus groups?

A carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive non-threatening environments … Group members influence each other by responding to ideas and comments of others.

(Krueger and Casey 2000 p 5)

Thus group interaction is of central importance and gives a high level of face validity because what participants say can be confirmed, reinforced or contradicted within the group discussion

(Webb and Kavern 2001)

Process

- Fieldnotes should be taken during the discussion in order to capture the group interaction which might not be evident from recording.
- Check recording machine is working and take notes of the group interaction and any peripheral conversation that takes place.
- Listen to each tape and produce an abridged transcript with the relevant and useful parts of the conversation transcribed verbatim.

(Krueger and Casey 2000)

How might we do it?

- We would be the focus group
- Elect a chair/discussant and moderator each time
- Choose a theme, start with existing discussions
- Prompt with previous statements and thoughts
- Materials could include researchers' writings
- Discussion might be recorded with consent of everyone present
- Selective transcriptions to be analysed in subsequent meetings