Language and the Illness Model

Language and terminology in mental health - or rather, mental illness - is fraught with differences of opinion and ideology, and different preferences for expression.

Many people adhere to the medical model, the dominant view in psychiatry, that there are mental illnesses in much the same way as there are physical illnesses or disorders. However, many other people do not, wishing instead to challenge the way the medical model encourages professionals to label people within a restricted set of categories and treat them accordingly.

This particular report tends to use the language of the illness model reflecting the language used by the supported user researcher and the participants.

It is hoped that this report will be of use to all patients, service users/survivors, professionals and other people interested in forensic mental health, regardless of their individual ways of understanding and describing mental health problems.
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Acknowledgements

Geraint and I would like to thank a number of people for their help and support with the project:

- The participants who generously gave of their time and talked to us honestly and often in depth about their feelings, views and experiences.
- The staff at Llanarth Court hospital and in the community, especially John Boardman the patient advocate who provided a lot of practical support and encouragement to Geraint. Also, Margaret Lougher, Dr. Alan Lillywhite, Tony Barbe’, Pete Murray and all of the Treowen ward staff who made us feel very welcome.
- Yasmin for being our 'pilot interviewee'.
- Gwent Research Ethics Committee whose positive attitude towards user-led research and willingness to support an unfamiliar and innovative piece of research enabled us to undertake the project.
- Our fellow user-researchers who were always very supportive and encouraging.
- The Strategies for Living Team at The Mental Health Foundation for their support, particularly Vicky Nicholls for her help and direction at difficult stages in the process.
- The Strategies for Living Wales Advisory Group for their ongoing support and assistance.
Preface

I became involved in this project after my idea was chosen along with 5 other people from Wales. I had met Rachel Waters (Research Training and Support Worker for Wales) who after a meeting at the hospital, told me that the project will be approved or not by The Mental Health Foundation, Strategies For Living, Welsh Advisory Committee. I did get chosen and the project has been very interesting.

I decided to look at leave for patients under section 37/41 because I didn't think anyone else would have done research in that area and it would be an interesting topic. I had a lot of experience of parole having spent a long time in hospital and knew quite a lot about it. I thought knowing what is involved would be an advantage.

At first I was rather negative about going ahead with the research. I thought there would be loads of difficult reading and writing. I found the work quite hard - it took a lot of energy out of me, I had to concentrate so hard. Although there was a lot of work to do, I enjoyed the project very much. We regularly met up in different venues to discuss different issues about the project and often had a meal in the evening and tea and coffee supplied during the training sessions. Sometimes when we met up in a group I found it difficult to concentrate and I sometimes had to speak to Rachel again individually before I went ahead with the work.

As we got more into the projects we sometimes worked in groups of 2 or 3 on problems and questions on paper - about ethics and interviewing people - a tricky business! Getting information from people takes skill and there could be dire consequences if any information wasn't kept confidential. My memory and concentration have been greatly affected by the anti-psychotic drugs and the long time I have been in hospital. Even so it did not take away my enjoyment of the project, and I really enjoyed meeting up with the other researchers and listening to their points of view. It made me feel better because I got an insight into other people's mental illness and what their lives were like.

My project involved interviewing 5 patients on section 37/41. I felt special in a way, going into the hospital as a researcher rather than a patient. Sometimes I felt a bit embarrassed interviewing other patients as I felt I was 'just a patient' myself but it was still very fulfilling. It made me use my mind more than I usually do - it was very challenging.

I hope people read this report and I hope it helps people to understand a bit more about freedom and parole in a secure hospital. I've been in hospital myself and I know what it can be like not having any parole and feeling lost and locked in.

Geraint Rees (supported user-researcher)
Introduction

User involvement in forensic mental health research has so far been very limited, and has tended to consist of small-scale consultations and audits (Faulkner and Morris, 2003). However, there is a strong commitment from the National Programme on Forensic Mental Health Research to the involvement of service users in research. This agenda is supported by Department of Health Guidance (Research Governance Framework for Health and Social Care, 2001). The Adult Mental Health Services for Wales, Strategy Document has identified user-led research as a priority area for research in mental health.

Research involving users of forensic mental health services faces significant challenges. Measures taken to ensure security can make it difficult to gain access to service users who wish to become involved and there are often concerns from staff and management about confidentiality and access to information.

Attitudes of staff and society in general can limit successful patient involvement:

"Users of forensic mental health services are widely regarded as inferior, and as having less value compared to those who provide services - not ideal conditions for collaboration" (p.15) (comment from interviewee, cited in Faulkner and Morris, 2003).

However, the limited work which has been done suggests that many patients are keen to be involved in research initiatives, particularly if they consider it to be relevant to their daily lives and to their own understanding of their situation. Encouragingly, many staff working in forensic settings have an understanding of the potential benefits of involving service users in research (Faulkner and Morris, 2003).

Examples of previous user-led research carried out in secure settings have proved impossible to find, although it is possible that there are small scale unpublished and/or recent pieces of work.

Baker's (2003), study of inpatient satisfaction in a secure setting brings up many issues of relevance in working with this particular group of users. The study, which involved service users in the formulation of questionnaire items, revealed apparently high levels of satisfaction with the service, although many patients made negative comments about the security restrictions on the ward. Baker comments that the users of this service typically had long histories of institutionalisation, as such they may experience fear of criticising the system, have low expectations of services, and are unlikely to view themselves as consumers with valid viewpoints.

Lindow (2001) points out how for recipients of secure services the 'main point' is not the quality of care but 'how to get out' (p.138).

This research study focused on leave for patients in a secure setting detained under a section 37/41 of the Mental Health Act 1983- a Home Office order under which patients are severely restricted in the amount and type of leave from hospital they are entitled to. It aimed to find out how patients understand the system of gaining leave, how they feel about this system and what they see as the benefits and disadvantages of having leave.
Method Summary

We decided to use a qualitative method and undertake semi-structured interviews, as we wanted to obtain detailed information about feelings and experiences. The interview schedule is based on the issues that the supported researcher felt would be important to ask about, as well as basic factual information. We took a reflexive approach and spent time considering the supported researcher's experiences and both of our expectations in order to minimise their impact on our findings. We discussed the interview schedule with a former secure hospital patient and she suggested a few minor changes. We then interviewed five participants who were all male inpatients under section 37/41. The interviews lasted between half an hour to an hour and a half. The project involved a lot of ethical considerations, particularly around informed consent and confidentiality, and we had to gain permission from the local research ethics committee. A detailed qualitative analysis was carried out on the interview transcripts from which a number of themes emerged. (please see appendices 1 and 2 for the interview schedule and ethics committee paperwork).
**Method**

We decided to take a qualitative approach and to use semi-structured interviews. This was because firstly, we wanted to obtain detailed rich information about participants' feelings and experiences that would be best obtained through an interview. Secondly, there were problems with other methods, for example, we had to bear in mind that some of the potential participants might have difficulties with reading and writing and therefore would find a questionnaire difficult. We also considered using a focus group but felt that some people would be inhibited in front of other patients.

**The Question Schedule**

It took 8 months to put together the question schedule for the interviews. There were 8 main topics. These included the basic and factual information we thought it would be important to know, and also areas which the supported researcher felt from his experience were important and relevant to cover. The questions were almost all open ended and we encouraged interviewees to talk as openly as possible about what was important to them. (see appendix 1 for question schedule).

**Piloting the Interview Schedule**

We found it very difficult to find someone to pilot our interview schedule as the questions could only be tested properly on someone who had spent time in a secure environment. We didn't want to pilot the questions on a current patient as we knew it might be difficult to find enough participants and didn't want to 'waste' a potential participant, especially if it turned out that we needed to make major changes and the pilot interview could not be used in the analysis. Through various contacts we eventually identified a woman who had spent considerable time in a secure environment but was now living at home. She was not well enough to be interviewed but was keen to read and comment on the schedule. We discussed the schedule and I asked her opinion about various aspects such as was it understandable, were the questions meaningful, were there any questions that could cause offense or upset etc. She was happy with the questions and only suggested some minor changes in wording.

**Criteria for participants**

Participants had to be under section 37/41. They also had to be mentally well enough to be interviewed and to understand that it was their choice to take part. We were worried that staff would select who was 'suitable' to be interviewed and that this would turn out to be people with particular views or attitudes. However staff were happy to let us wander round and approach any patients in Treowen ward, although they made suggestions as to who might be interested. We initially wanted to interview patients on different wards as well as Treowen - the re-hab ward which the supported researcher was in, however, we couldn't find any patients who were both well enough to be interviewed and willing to be interviewed on other wards.
Accessing participants

The hospital advocate talked to some patients he thought might be interested on our behalf - some of these patients subsequently volunteered to be interviewed. We put posters up in ward areas and the hospital café but had no response from these. We then visited the ward taking flyers to give out. Here we were able to sit down with patients and tell them about our research. We found most of the participants this way. Interestingly patients tended to say yes or no straight away, and didn't seem to be influenced by finding out more about the research. We arranged a suitable date and time with the patient and they signed an informed consent form. (see section below on ethical issues). We completed interviews with 5 patients.

Location

The interviews took place in a small but comfortable room off the lounge area of the ward. There were staff very close by in case of any incident. Participants were able to smoke in the room if they wished although some people chose to go outside into the main lounge for a break/smoke. The staff were generally very welcoming - we were invited to stay for lunch on several occasions. The interviews lasted between half an hour to one and a half hours. Participants were paid £5 as a token of thanks for their contribution.

Reflexivity

We spent some time talking about the supported researcher's experience of being in hospital, and identifying what both of our expectations were. This helped us to ensure that although most of the questions were based on the supported researcher's experiences and views about what might be important, the wording of the questions was not biased. During the interviews we were also careful not to steer the participants in any particular direction.

Ethical Issues

Gaining Ethical Approval

As our study involved interviewing in-patients, and one of the researchers was also a former patient, we were required to gain permission from the local research ethics committee. This involved a number of challenges. Finding the relevant local committee proved to be quite difficult and I eventually found the contact details through e-mailing a question to the Welsh Assembly website.

After contacting the committee secretary we were sent a large amount of paperwork. A number of factors made completing this difficult. The forms were based on the assumption that the research was medical, (drug testing) and that the lead researcher was a doctor. There were a lot of questions which were irrelevant to us and not enough space for us to describe our project and the possible risks. We had to attach several extra pages to explain our study. It was worrying as we knew they wouldn't be expecting or familiar with the type of work we were doing - (or possibly even qualitative research in general), also we didn't know whether we were allowed to change/add to the form - but it was impossible not to. A copy of our paper work can be seen in Appendix 2.
After having sent in our paperwork we were required to attend a meeting to answer questions and discuss our research with the committee. The meeting was very formal - boardroom style, and very intimidating. When we were called into the room we were automatically referred to as Mr. Rees and Dr. Waters which served to illustrate how they are used to meeting doctors and not service users! There weren't any service user representatives. Most of the members were doctors and there were also a few other professionals.

Some of the committee members used very formal, slightly jargonistic language. The first question was really long and was about analysis using grounded theory as opposed to hypothesis testing. Even with a background in research I found the question very difficult to follow in that rather intimidating situation and I feel it could have been asked in a much simpler way.

There followed several more questions covering the nature of our sample, and the safe storage of data. We agreed to make a small change to our plans for keeping the transcripts safe, which seemed like a good idea.

Overall, I felt the set up and arrangements of the committee made it very inaccessible and off putting to people who are not academics or experienced researchers. We felt that the process could have been carried out in a much less intimidating way, while remaining just as thorough.

However, we were pleased that the committee took us seriously, had considered the relevant ethical issues, and did not patronise us at all. They were also very positive about user-led research calling it 'innovative' and wishing us luck with the project.

**Ethical considerations**

*Informed Consent*

We wanted to ensure that participants understood that partaking in the research was entirely voluntary and, importantly, that the research was completely independent of the hospital. We had planned a process which involved giving out written information for patients to take away and then an initial meeting - separate from the interview - during which we would explain the nature of the research, stress our independence from services etc. However, in reality this did not work out as we had planned. Many patients found it difficult to take in written information, and did not want to attend an additional meeting as they were concerned about missing out on trips out. They generally did not want to discuss the research for very long before agreeing to it and arranging a time for the interview.

I was concerned that we were not able to access patients in private so staff could see who was and who wasn't agreeing to take part. However, patients did not show any outward signs of feeling under pressure to partake in the research. Patients tended to either say no straight away without hearing any details about who was managing the research, or they said yes immediately and were very enthusiastic about taking part, also before they knew details about the nature of the research. It seemed that they had pre-formed opinions about whether or not it was a good thing to be involved in research, and this affected their responses more than the information we were giving them.
Confidentiality

This was a particularly important consideration in light of the small sample size involved in the study and the type of sensitive information which participants could possibly talk about during the interviews. We had initially planned to keep the tapes and transcripts in a locked drawer in the supported researcher's room. However, the ethics committee expressed concern about this and suggested that they were kept in the ward staff office in a locked drawer. We were concerned that this would mean that staff would have access to people's interview tapes - which could discourage participants from talking openly. In the end, the tapes and transcripts were kept in a lockable drawer in the Mind Cymru office to which only I had access.

I also had to be very careful in writing up the report not to identify any participant. With only 5 interviewees this was quite difficult and some quotes had to be missed out. Others have been slightly changed to reflect the same meaning but without specific details which could identify a participant. There is also the possibility that readers within the hospital will be able to work out which members of staff certain comments have been made about. As I am not familiar with the hospital and staff team, it was difficult for me to know how likely this was. Fortunately, the majority of comments to which this concern applied were very positive.

Analysis

The interviews were recorded and transcribed by an experienced member of staff at a local university. A detailed qualitative analysis was carried out from which a number of important themes emerged.

The amount of time required to introduce the supported user researcher to the basics of conducting research and to produce the interview schedule meant there was not sufficient time to carry out a thorough literature search before starting the fieldwork stage. This meant that the interview schedule was entirely based on the supported researcher's ideas about what was important to ask around the issue of leave. In user-led research the researcher's perspective as a service user is one of the most valuable aspects of the research, and this research is unique in that all of the questions asked have been developed through the researcher's personal experience of being a patient in a secure hospital.

An attempt has been made at the analysis and writing up stages to explore relevant literature and where appropriate make links between the findings of our study and previous research. This report is not intended to be ‘academic’, although it is hoped that the references to academic literature will be of interest to practitioners and academics in the field.

It is important to bear in mind that this report is based on the perspectives of the participants and may or may not reflect staff or other perspectives on various topics. Patients' views about hospital life, including issues such as risk assessment, relationships with staff, leave, etc may differ greatly from staff views reflecting the substantial differences in positions, power, knowledge and experiences between the two groups. This research aims to represent patients' views and feelings and thus only reflects this perspective.
Findings

Participants' experience of being in hospital

The experience of being in hospital under a section 37/41 was generally seen as hard and frustrating. People found it difficult to cope with the lack of freedom.

'It's a hard process - hanging about, and waiting and plodding on'

'Sometimes I get fobbed off because I can't do things other people do, can't just walk out of the door and get on the bus and go to town, that sort of thing, you just can't do that.'

Boredom was a problem for patients especially when they were not able to go out of the hospital. One patient explained how hard it was to stay in the ward for long periods of time:

'some people would say sitting in their house for 2 hours waiting for the gas man to come would be like torture, …but here they expect you to get up at nine o clock in the morning, be down for nine o clock here, and expect you to sit here til 11.00 at night ..just reading the paper or having a game of hangman - that's just stupid'

Going out on trips could be unpredictable and depended on the staff available and transport.

'They haven't got a vehicle to take us out in because the windscreens smashed - we're going to be stuck here all weekend'

'Haven't been out all this week - staff problems - they're on a course'

However, one participant pointed out that:

'Most of the time there is staff to take us out'

Participants talked about many benefits of having leave from the hospital.

'a bit of freedom and being away from everybody else'

'seeing new places, different things, seeing new people, seeing different scenery - you're not seeing the same things all the time'

'doing things I want to do, no-one telling you what to do'

Being able to go out on a trip made a big difference to patients' everyday life.

'it makes it a lot better knowing you can spend four hours in the community as opposed to four hours on the ward which drags.'

It also had benefits beyond the immediate benefit of having something to do..

'knowing you're going out gives you some hope in your life - I mean it's a hard slog - just drinking tea and smoking'
Patients often didn't know whether they would be going out until the day of a trip. This meant sometimes they would be hoping to go out but then wouldn't be able to.

'Sometimes you wake up in the morning and think oh please can I go out today, please, and you don't, and it's disappointing'

For some patients, the only way to cope with the severe restrictions placed on them was to accept their lack of control over the system.

'You just accept it and in time it gets less and less upsetting but that's not in your control'

'You have to accept that you can't control them'

'I've been locked up for that many years - I just get used to the system, doesn't bother me…'

Awareness of Rights and Legal Status

None of the participants was able to give a comprehensive answer to questions about rights. Responses varied and included

'you can have a tribunal once a year'

'a right to participate in research training, know all about medication and I believe I'm here for treatment'

'I get unescorted. I go to college on my own and into town on my own'

Some reasons for the apparent limited knowledge about rights are considered in the discussion section.

Relationships with Staff

Participants generally felt positively about the staff and felt they got on well with them.

'I've always got on with the staff, they look after me well'

Staff were compared favourably to other hospitals

'here they treat you like an individual not like a collective group, they respect you as an individual'

Overall participants felt they could talk honestly to staff, although several people mentioned feeling more comfortable talking to some staff than others.

'I can share my problems with the staff'

'I pick the staff I want to talk to - those who understand me'

'I've got a female keyworker, there's certain things I just wouldn't be happy talking about in front of a female'
One participant didn't feel so positively and expressed many negative views about staff.

_They don't care what we think, they are more interested in their wages_

This participant felt that the nature of his offences affected how staff felt about him in a negative way.

Another participant mentioned an individual member of staff (who had since left) who he felt had not treated him fairly by refusing to take him out when he could have. He commented:

_They should bend over backwards to help you, …not be spiteful…not take a cynical approach even if they don't like you as a person because it's their job and they should (take you out)_

One participant who felt generally positive about staff, said that he would like to be able to spend more time talking to them.

_Every time you're depressed they put you on tablets and injections and things…I'd like them to talk to me and see what the problem is_

Trust and confidentiality were very important to the participants. Most of the participants felt that they were able to trust staff although several mentioned needing time to get to know staff before being able to trust them.

_I couldn't share my problems with the staff at first - I didn't trust them enough but now I can_

_It takes time to get to know someone before you can trust them_

Confidentiality was seen as important. All patients were concerned that information should not be passed on to other patients. Some participants were happy about information being passed between staff:

_I got to know them more, was able to talk to them…you know they're not going to go and talk about what you said to all the patients_

_(Interviewer) what about other staff?_

_I don't mind that because it's all like, it's all confidential isn't it_

Another participant however, was not happy about this:

_It gets all round the hospital,… they go and tell other staff like and the doctor and things like that,…they don't tell me they're going to tell other staff_

Staff had a big influence on patients' day to day lives, from deciding whether or not patients were able to go out on a particular day, to requiring them to attend various sessions, and to obey various ward rules, such as being downstairs by certain times.

_I thought that was really spiteful, but in the end it was his decision, and it affected me you know, because I was stuck on the ward_
Relationships with staff were also seen as affecting the leave a patient had.

'if they think you're ready (to have more leave) they put it through to the doctor.....they give you day to day care so they know more about you than the doctor does'

'if you show your feelings and you're honest with them like, it makes a big difference.....if you keep things bottled up like here, they think you've got something to hide.'

**Relationship with Consultant**

As with the staff, overall patients felt positively about the consultant. All but one participant made only positive comments about their relationship with the consultant, and most stated that they felt he was a good doctor.

‘actually, I can’t praise him enough as a consultant, you know’

The consultant was seen as being trustworthy, as listening to patients, and as being helpful.

'I can talk honestly to the consultant - he listens’

‘I can trust this consultant - he’s always tried his best for me’

Patients felt that the consultant was very careful and less lenient in giving out leave than other consultants they had had.

‘...he’s careful in his ways...it’s not as liberal as (name of other secure hospital)’

However, they felt that this was a positive thing as ‘he has earned respect from the home office through being careful’

Although participants felt that the doctor was ‘careful’, they also pointed out that they were able to have more leave on their current ward than in previous wards as the ward they are currently in is a ‘re hab’ ward.

‘this being a re-hab ward...they are more lenient’

One patient, when asked why his current consultant was his favourite said ‘well, he’s the one that gave me unescorted ground parole’

Participants acknowledged that although the consultant seemed to have considerable respect at the home office and hence influence over the leave they were allowed, that he was also part of a complex system.

‘...at the end of the day...even as your responsible medical officer, he’s still a small cog in a big wheel, you know, with the 41..’
Factors Affecting Leave

A variety of factors were believed to affect the leave a patient was allowed.

Behaviour

A main factor thought to affect leave was behaviour. In general, aggressive or violent behaviour was seen to be related to reduced leave. Avoiding aggression and talking honestly to staff was seen to be related to increased leave.

‘you get parole quicker if you behave yourself and don’t attack them and if you’re polite then they treat you alright’

‘…if I behave, don’t shout at the staff, if I didn’t shout, swear, pick on the junior staff, I would get more leave’

…it’s if you’re telling them how you feel and you’re telling them the truth. If you keep things bottled up here they think you’ve got something to hide’

Several participants mentioned that ‘behaving oneself’ led to more leave.

‘if you behave yourself and do as you’re told’

‘patients who don't go with the flow are affected'

Occupational Therapy (OT)

Attending OT sessions was also seen to affect the leave a patient had. Going to sessions was thought to be related to increased leave and vice versa.

‘If I don’t attend sessions here maybe that’s why I don’t get trips’

‘Not going to OT would affect your leave because the doctor would look at your report…’

Some participants felt that there should be more choice about attending sessions, particularly as they felt there wasn’t much choice available about the topics of sessions.

‘They try to implement their job into your life…it shouldn’t affect leave but it does’

‘you should definitely have the opportunity to choose, I mean ‘fred’ might not like digging the garden but someone else might’

‘I mean one of the sessions here is ..hangman on the bloody board – I mean if after 5 years in rehab they want to motivate me into doing something..that’s stupid coz I’m as motivated as anyone – my personal view is that you have to do what you want to do and not what they want to do’
Rules

Participants all agreed that keeping to or breaking the rules would have an effect on leave.

‘If you don’t keep to the rules you would lose parole’

‘if you break the rules?…. - they have a chat to me and then go in front of the doctor and he says we're suspending your parole until we think its best for you to go out again'

One participant felt that breaking the rules was being disrespectful to the consultant.

'If you break the rules you are dishonouring the consultant's trust'

The affect that breaking a rule would have on leave was unpredictable and depended on what rule had been broken and the individual circumstances.

Absconding

Although none of the participants admitted to having tried to abscond, most said they had thought about it, and they could understand why other people did.

'I've thought about absconding - just the hospital getting to me'

'I've been tempted to do a runner - I never have'

'I can understand why...people who've been in here a long time - the whole world passing them by. '

Most participants felt that absconding would have a serious negative effect on the leave a patient was entitled to and this was generally what stopped them from doing it.

'Everything would be revoked if I absconded'

'I've got too much to lose if I absconded'

Mental Ill Health

2 patients mentioned illness as a factor affecting leave.

'They keep an eye on you - any sign of relapse - that would affect your parole'

This patient who was due to leave the hospital very shortly, felt that a patient who was ill would be at risk in the community.

'I mean, I hope he's not going to say to someone who's been sat there talking to themselves all day - "yeah - you can go out unescorted"......you may not be safe in the community'

Another patient who was being refused unescorted leave commented

'.I still haven't got unescorted...because I keep telling lies and saying silly things....they say "we can't let him out, he's not right in the head"
Views About The Process of Gaining Leave

3 of the 5 participants said that they felt the system of gaining leave was generally fair.

'The leave has been fair - you have to be tried and tested'

'I think parole is fair - the consultant's done his best to get it quickly for me'

'If the doctors are refusing someone parole there has to be a good reason'

2 participants however, were more critical of the system.

'Trouble with this place there's too many rules. They're making rules all the time here about something.'

'No, I don't think it's fair - he gives other people more leave than what I get'

All the participants felt that the system was very slow and frustrating.

'Sometimes you get fed up with things being so slow but you have to work at it'

A particularly difficult time for patients was when they first came in and saw other patients having more leave.

'I didn't think it was fair when I first came in - other people going out and I'm stuck on the ward all the time'

The Home Office

The Home Office was seen as causing delays and also criticised for only knowing patients as cases rather than individuals.

'You have to wait too long for the home office'

'to the home office you're a file not a person.......I mean whatever you've done in your life you're still a person....you're a human being and they don't treat you like that - they treat you like a number'

The 3 participants who were generally more positive about the system talked about illness, risk and trust.

'He can only make his decisions on how you are - you might not be safe in the community'

'The process is relatively easy - I'm getting more and more trusted'

'yeah - risk assessment affects your parole because if you're no risk then it's alright to go out in the community - go off on your own'

Several patients mentioned that having a choice about where to go would improve their leave.
'he turned to me and said "it's your day, wherever you want to go, I just follow you" - what a difference - that's good staff…'

'I was really shocked when she said "is there anywhere you want to go?"

Most patients also said that they wished they had more time when out on trips and that they disliked being rushed.

'when you go into a shop with staff they keep going "hurry up" like, and you haven't got much time'

Preparation For Life Outside

Having leave was seen as a way of preparing for life outside and starting to develop social networks.

‘I need to have more leave in the community to adjust – so the more’s given to you the better’

‘I'm moving on…did a lot of rehab work…getting myself used to going out, going off on my own in the community and doing different things, getting myself ready to go out’

All of the participants wanted to leave hospital. Most of the benefits of being out of hospital mentioned by participants were related to freedom and doing ‘everyday things’.

‘freedom – no staff watching you – you can go where you want to go not where staff want to go’

‘looking forward to being back with my family, being able to go to work and stuff like that’

Participants were also looking forward to leisure activities and most mentioned the importance of being able to spend time alone.

‘I will enjoy just being able to go around on my own, do my own thing’

‘getting out and doing things other people do – going to the cinema, no more boredom – just enjoy my freedom’

However, most participants also had some worries about leaving hospital. One big worry concerned not knowing many people outside of the hospital.

‘I don’t know anyone apart from my brother’

‘I don’t have many friends’

Participants talked about the difficulties of meeting people, particularly meeting ‘suitable’ people.

‘before I came here I did a lot of drugs and I’m trying to keep away from it really’

‘I used to go to singles clubs to find someone but I couldn’t find no-one’
‘I’m worried about meeting the right people who I can trust – I don’t like talking to somebody I know nothing about’

Two participants talked about the need to form social networks in the community to prepare for leaving hospital.

‘they should be encouraged….it would be pressure if you didn’t know anyone – were starting from scratch - rather than knowing a few people’

Other worries about leaving the hospital included becoming ill again and adjusting to changes in the outside world.

‘that I’ll get ill again – I don’t want to come back in’

‘the amount of time most people have been in, things change – it’s not the same as when you came in….my brothers – they’ve got their own lifes to lead, and places change don’t they’

One participant was worried that people would find out about his past offences.

‘I’m worried that when I go in the community, they’ll find out what I done, and they may take it out on me’

This person wanted to live in a place with staff.

‘I need 24 hour staff, as long as there’s staff I’ll be fine’

Institutionalisation

Although all of the patients we interviewed wanted to leave hospital, some of them mentioned that there were some patients who didn’t want to.

‘some people don’t want to get out, they don’t care – well it’s not that they don’t care, but it’s been bored out of them’

Institutionalisation was seen as a possible cause for people not wanting to leave.

‘they don’t mind sitting here, lighting a fag, picking up their cup, and spending their day doing that – that’s sad if you ask me….they’ve become vegetables’

‘people need to live, try to be normalised again as soon as possible’

One person felt that some patients may not want to leave as they would feel worried about having to make their own decisions.

‘some people might not want unescorted – we’re in a sort of cocoon here….any decisions made have to go through a care team before it gets to you. Outside there’s no one holding you back’
Discussion

The Importance of Leave

Being able to have leave is very important to patients. It helps in coping with their current situation by relieving boredom, providing enjoyment and something to look forward to in the short term. Patients also felt it was helpful in preparing to move on. However, perhaps most importantly, having leave gave patients some hope for the future. This can be vitally important when the patient may have to remain in a secure environment for a number of years.

"For those of us who have been diagnosed with a mental illness, hope is not just a nice sounding euphemism. It is a matter of life and death"
Deegan, 1996

As in Baker's (2003) study of service user views on a secure ward, most participants in this study were dependent on staff and transport availability in order to have leave. This was sometimes frustrating and disappointing, and highlighted the powerful effect that staff decisions can have on a patient's everyday life. For people who are under such a severe restriction of their freedom, a short trip out can be vitally important, and a trip being unexpectedly cancelled can result in huge disappointment and feelings of hopelessness and despair.

Awareness of rights

Participants' responses to questions about their rights suggested that they had a very limited understanding of their rights under section 37/41. This could be due to a combination of several reasons. Findings of previous research asking patients about the law and their rights has found similarly low levels of awareness, including in general (non-psychiatric) hospitals (Goldbeck & Mackenzie, 1997; Bradley et al, 1995; Sugarman & Moss, 1994). Patients may have been given information at a time when they were not able to understand or remember it.

Atkinson et al (2002) recognise that ‘While some patients have a keen interest in their rights others do not appear to organise their experience of treatment within these terms.’ It may be that the user researcher in this study was one of the former ‘types’ of patient and that the participants we spoke to did not consider knowledge of their rights to be especially relevant to their personal situation.

Another possibility is that participants were not familiar with the type of language we used to ask about rights. More imaginative ways of obtaining information which made the issue relevant and meaningful to the patients own situation may have resulted in more informed responses.

The issue of language and personal relevance may also have affected participants' responses to questions about risk assessment. Although several participants talked about having ongoing risk assessment and what this involved, others said that they did not have any risk assessment, or that they’d only had one when they came into the hospital. Again specific non-jargonistic questions relevant to the patients' everyday lives may have revealed more about patients' experience of risk assessment.
Relationships with Staff

Participants were generally very positive about the nursing and other ward staff. Most staff were seen by most of the participants as trustworthy, helpful and as treating patients as individuals.

Recent research has found that nurses continue to report the nurse-patient relationship as their most important role (e.g. Jackson and Stevenson, 2000; Laskowski, 2001), and that this applies as much to forensic nursing as to any other area of nursing (e.g. Hammer, 2000; Rask and Aberg, 2002). Patients may value the relationship with the nurse more than the nurse's professional competence (Svedberg et al, 2003).

Building and maintaining positive relationships on a secure forensic ward is complex due to the need to balance differing values and requirements. Mercer and Mercer (1998) state that 'forensic hospitals are places of confinement where the values of custody, detention and imprisonment are interposed with those of care, consideration and compassion' (cited in Martin & Street, 2003).

The participants in this study felt that it was important to be able to trust the staff. This has been reflected in other studies.

Svedberg et al (2003) found that patients in their study felt trust was essential. Trust to these patients meant being able to rely on the nurses' competence, to be treated in a friendly manner, and to feel that the nurse was compassionate. They also felt that the patient needed to have confidence in the nurse in order to be able to express private thoughts and feelings.

Several of the participants in the current study pointed out that it takes time to develop trust in a person, and that good honest relationships have to be built up over time. They also felt that being honest with staff and talking to them about their problems resulted in them being seen as improving and hence having more leave.

This could be one reason why it is that participants felt that the hardest time was when they first came into the hospital. They had no or very restricted leave, were still trying to come to terms with their situation and yet it was at this time when they felt most unable to talk to staff about their feelings and thoughts.

Some participants talked about being able to talk to some staff but not others, and about choosing particular staff members to confide in. Recent research has found that 'personal chemistry' between patient and staff member was a precondition for the patient to be able to share their thoughts (Svedberg et al, 2003).

It therefore seems important that patients have access to a number of different staff to talk to as well as their assigned keyworker. At Llanarth Court patients can request to change their key worker. One of the participants had chosen to do this. He felt the change had gone smoothly and that he had not experienced any negative attitudes from staff as a result of his decision.

A patient's decision to change key worker or to consistently confide in another member of staff may simply reflect this personal chemistry rather than being due to any particular difficulties with other staff.
Confidentiality

A prerequisite for developing trust in staff was being able to rely in confidentiality. However, participants' views about what confidentiality meant were very varied. All participants agreed that it was unacceptable for staff to tell other patients about things they had said, and no one had experienced this. There was disagreement about whether it was acceptable for staff to pass on information to other staff.

Confidentiality in mental health care is a complex issue. Relevant legislation and guidance tend to rely very much on professional discretion around issues such as capacity to consent to information being shared, and risk, as well as the relevance of the information being shared to ensuring that the user receives the appropriate level of care, treatment and support.

In the forensic secure ward environment where our participants were living, a multi-disciplinary team of staff provided a high level of care, treatment and support to patients, many of whom would be categorised as high risk. Therefore it is likely that a lot of information would be judged appropriate to be passed on to other staff in the team.

McHale (2000) points out that 'it is particularly important in such a situation that the boundaries of disclosure are clearly delineated' (p.258)

Patients may benefit from learning about the nature of confidentiality in the secure hospital environment. Being aware in advance that information is likely to be shared with other staff may help to prevent the patient's feelings of betrayal when they discover that information has been passed on. Having a clear understanding of who information will or will not be passed on to may also enable patients to have more trust in the staff.

Moving on and Social Networks

Forming social networks outside of the hospital was seen as vital preparation for moving out into the community. Many participants had lost contact with friends and family members, and were not confident about either their opportunities to meet people or their ability to form positive healthy relationships.

Particular worries concerned not being able to trust people, trusting in the wrong people who would let you down or harm you, getting involved with drug users and not knowing where to go to meet people. There is much evidence linking social support to well-being and improved mental health, and a lack of social support to poorer mental health outcome, and earlier relapse (Henderson, 1998; Strauss & Carpenter, 1972; Becker et al, 1998; Alloway & Bebbington, 1987). A limited social support network can be both a cause and an effect of poor mental health.

Patients in secure hospitals face numerous barriers to creating and maintaining social networks. Perhaps most importantly the amount of time they have spent in a secure environment, often more than 5 years, means that it is difficult to maintain contact with friends and family and there are very limited opportunities to form new friendships.

Stigma can be an additional barrier for discharged patients who are trying to build new relationships. One of the participants in this study felt that he would be in danger if people found out about the nature of his offence. This participant felt his only option was to live in 24 hour staffed accommodation.
Other patients have committed more minor offences at a time when they were seriously ill, but public ignorance and fear, often fuelled by the media mean that they also face discrimination and stigma which can make it hard to rebuild their lives:

‘……people like John, released from a secure unit 12 months ago, are immediately labelled as likely re-offenders with the assumption that all schizophrenics are killers. "Once people know where you have been you are labelled. They think that everyone who has been sectioned is dangerous, but that is not true" ' (Dobson, 2000).

Institutionalisation

All of the participants in this study felt that there were patients who did not want to leave and that the main reason for this was institutionalisation. Some participants used the term institutionalisation, others described these patients and their attitudes and behaviour in a way which fitted with the idea of institutionalisation.

Institutionalisation is used to describe a syndrome first observed in the late 1950's whereby people who spent long periods of time in hospital with little responsibility and little to do often became socially withdrawn, lacking in motivation, and eventually stopped wanting to leave the hospital environment.

Wing and Brown's studies of institutionalisation (1961, 1970) found strong associations between the length of time per day a patient spent doing nothing and the severity of negative symptoms. (Typical negative symptoms include loss of motivation, lack of ability to experience pleasure, social isolation and withdrawal, and decreasing ability to express emotions).

All of the participants in this study complained of boredom and of not having enough to do. However, the participants also talked about being strongly encouraged to attend various occupational therapy sessions, which they often refused to do as they felt they were being coerced into a limited range of activities which they did not enjoy. A wider choice of activities based on individual patient's preferences may help to engage more patients in activities and would help to alleviate many patients' reluctance to partake in any activities offered to them.

Institutionalisation can be difficult to avoid particularly with patients who may be required to stay in hospital for significant lengths of time. Work by Curson et al (1992) and Wing (1992) has suggested that there is still a risk of institutionalisation even in a small well-run inpatient unit with good social conditions.

Final Comments

Overall, those patients who were due to leave the hospital very soon, or who believed that they were progressing and would be leaving within a year, were more positive about many aspects of their experience than those patients who had no clear idea of when they might be discharged.

There are many possible reasons for this. Firstly, it could be argued that it is easier to see the positive aspects of a difficult experience when it is nearing the end. The patients who were due to be leaving soon also differed from the other participants in diagnosis, length of time already spent in hospital, and offence(s) committed. (Confidentiality concerns prevent further discussion of these issues).
It might be that talking to previous patients who have since left the hospital about their experiences and how they coped, might be very helpful to new patients or those who still have some time to go before they can think about discharge. They may be more inclined to talk to a former patient about their worries than a professional.

Reflections on Method

Baker (2003) has talked about the difficulties associated with obtaining honest and possibly critical responses from patients in secure units who may be institutionalised, have little belief in the importance of their views, and be reluctant to criticise the service. This did not appear to be a problem with our participants. Although 4 out of 5 of the interviewees were generally very positive about the hospital and staff they did not seem to hold back in being critical when they were not happy with a particular aspect of their care or environment. This could be due to the fact that one of the interviewers was a former patient and that the other openly identified herself as someone who experiences mental distress. Previous research has found that service users feel able to be more honest when talking to a user-researcher as opposed to a professional or academic (Faulkner and Layzell, 2000).

Despite our initial worries that it would be difficult to engage the participants and to get them to talk in any detail the participants seemed to value the opportunity to talk about their experiences and some talked for well over an hour. It was however, difficult to get some of the participants to expand on certain answers or to explain what they meant in more detail.

Sample

The sample was a very small self-selected group of patients. However, the small sample did reflect a variety of ages, diagnoses and time spent in hospital. Although the findings from such a small sample cannot be generalised to a larger population, they do raise a number of important issues which may be of relevance to other patients.
References


Faulkner, A. & Morris, B. (2003) User Involvement in Forensic Mental Health Research and Development. Expert paper commissioned by the NHS National Programme on Forensic Mental Health Research and Development


Reflections  (by Research Training and Support Worker)

This project has proved to be one of the most challenging of the projects I supported. Many of
the user researchers we supported had no previous experience of research and often no
previous academic background. Geraint had additional barriers to conquer; having spent
many years in hospital he had not had an opportunity or reason to do any reading, writing or
any other intellectual type activity for a long time. His medication made it difficult for him to
concentrate and he sometimes experienced periods of distress which further affected his
ability to concentrate and take things in. At first I was concerned that he would not be able to
grasp the basics of conducting research. It is to Geraint's credit that he persevered, and we
found that with additional meetings, training and a lot of work on both our parts Geraint was
able to plan the research, write the interview schedule, undertake practical tasks around
arranging interviews and also to complete some of the interviews.

It took us approximately 8 months to put together the interview schedule. It was a slow
process and it was sometimes tempting for me to go ahead and write parts of it. However,
one of the most valuable aspects of the research was that the questions being asked would be
coming from the perspective of a patient, therefore I had to hold back and make sure that the
ideas came from Geraint. I sometimes made suggestions and Geraint would agree to a topic
or question if he felt it was relevant. Although it sometimes took us considerable time to
explore and articulate Geraint's ideas, they often concerned issues which I would have never
have thought of asking about which I think confirms the value of looking at situations from
the perspective of someone who has 'been there'.

Before becoming involved with this project I had no experience of a secure hospital
environment and my first visits to the hospital were rather disconcerting. I was taken from
the reception of the building to the ward through a number of doors which would have to be
unlocked and then locked again behind me. I found myself rather depressed after hearing
about patients' experiences of being in this environment for many years. I began to feel angry
on their behalf for the years of their life spent out of touch with the real world, missing out on
many of the things that make life worth living - all because of an illness which was not their
fault. However, a few patients chose to confide in me about serious offences that they had
committed and occasionally feared that they might do again. This was very difficult to listen
to and I sometimes felt very uncomfortable, and glad that they were being cared for in a
secure environment. I didn't expect to have to deal with these difficult feelings and to be
forced to explore my views and feelings so deeply.

Despite these difficult aspects of the project, I have learnt a lot, and now have a much more
informed insight into the complexities of caring for (ex)offenders who have mental health
problems. There are a huge number of values and viewpoints to take into consideration and
finding the right balance between rights and risk is a formidable task.
Appendix 1: Interview Schedule with prompts for interviewers

Interview Schedule

Section 1 - Basic Information

Age

Diagnosis

Home Town/village

How long have you been in this hospital?

Have you been in any other hospitals?

Where were you before this hospital?
Have you ever spent time in another hospital?
Have you ever been discharged and had to come back into hospital?
Why do you think that was?

Contact with family/friends?

Which family members?
How often do you see them on home leave?
Do you have to travel to visit them?
Are there any friends you visit?

Section 2 - Knowledge about Parole

1) Do you know what rights you have as a patient under Section 37/41?

Could you explain a bit more about what you think your rights are?
Have you read the patients charter?

2) What do you understand by the term 'parole' - what do you think it means?

3) Do you know about any rules to do with your parole?

4) What do you think might happen if you don't keep to those rules?
5) Do you think the parole you have is sufficient in relation to your section?

Why?
What do you think would be fair/unfair? (depending on answer)

Section 3 - Leave History

1) How long did it take you to get leave?

Do you remember when you first came into this hospital?
Have you always had the same RMO?
Can you remember when you first had leave? - what type was it?

2) What stage are you at now and how did you get to this stage?

What type of leave do you have at the moment?
Can you remember how long it has taken you to get to this stage?
Have you found it difficult getting to the stage you are at?

3) Have there been any 'backwards steps' in the process of gaining leave?

Have you ever had parole and lost it?
Have you ever moved wards?
Why do you think this was?

Section 4 - How does the person feel their behaviour has affected their parole status?

1) Have you ever absconded or thought about it?

If they have actually absconded - when/how - was it planned?
Why did they abscond? What were the consequences?
If they have thought about it - why were they thinking about it? Why didn't they?
For everyone - what do you think would happen if you did abscond?

2) Are you keeping to the doctors instructions with regard to medication?

Do you take medication?
Are you happy taking medication?
Do you find it helps with your illness?
Do you have side effects? - what?

If you refuse your medication do you think it would have any effect on your leave pass or parole entitlement?

3) Do you keep to the rules about trips out - for example, sticking with the group, or coming back at the correct time etc)

If not - why?
Do you think whether you stick to these rules or not affects your parole and leave status?
4) Do you think your behaviour on the ward has affected your parole status?
Is there anything patients do or say on the ward which you think might affect their parole?

Section 5 - How do they feel about the system of getting parole?

1) Has the consultant been giving you leave which you feel is fair?
If yes - why do you think it has been fair?
If no - why do you think it has been unfair?
What do you think would be fair/unfair?

2) How did you feel about the risk assessment that you had when you first came in?
How were you assessed?
Were you allowed to read your risk assessment?
Do you think the risk assessment affected your parole - if yes - how?
Is there an ongoing risk assessment? - do you think it affects your parole? - how?

3) How do you get on with the staff?
Do you have much to disagree with where the staff are concerned?
Do you feel able to share your problems with the staff? - why /why not?
Is there anything that you do or say that you think might affect how staff feel about you?
(Do you get involved in any OT?)
Do you think your relationships with staff affect your parole?

4) Do you think other patients have had an effect on your leave or how you feel about it?
Have you talked to other patients about leave?
What have other patients said?
Has this influenced you - in a positive or negative way?

Section 6 - relationship with consultant

1) How do you get on with your consultant?
Does your consultant seem friendly?
Can you trust your consultant? - why /why not?
Can you and the consultant talk honestly to each other?
Do you feel the consultant listens to you?

2) Do you feel that the consultant helps you in getting parole?
Does the consultant give you information about how to increase the amount of parole you have?
Does the consultant get permission form the home office quickly enough so that you still have some parole when you are waiting for a reply from the home office?
3) **How do you think your relationship with the consultant affects the leave you get?**

Do you think if you have a good rapport with the consultant it might affect the leave you get?
Do you think if you don't get on with your consultant it might affect the leave you get?

**Section 7 - Do they want to leave hospital?**

1) **Are you looking forward to leaving hospital?**

If so why? Or if not - why not?
Is there anything you are worried about or not looking forward to when you leave the hospital?
(food cooked, staff to talk to, bed, security?)

2) **Do you think this affects how you feel about getting leave?**

(possibly repeat first question - how do you feel about leaving hospital?)

Does it affect your outlook on parole if you want to leave hospital?
**OR**
How does this affect your outlook on parole if you don't want to leave hospital?
What do you think about the long process of gaining increased parole and eventually leaving hospital?
(do you think it's an easy or hard process?)

**Section 8 - What are the benefits/disadvantages of parole? How could it be improved?**

1) **What are the benefits for you of having parole?**

Freedom? - what do you mean by that?
Contact with family and friends? - home visits?
Visiting home town?
Getting out of hospital environment?

2) **Are there any disadvantages?**

Returning back to hospital after having been in the community
Find leave worrying or frightening?
Stressful seeing family/friends? - need more time to get used to home visits?

3) **Do you enjoy the parole you are getting?**

Do you enjoy going on trips?
Why do you enjoy/not enjoy having leave?

4) **How could parole be improved for you?**

More parole more quickly?
Different nurse to accompany? - different person or gender?
Doesn't like other patients on group trips?
Opportunity to use public transport?
Appendix 2: Information given to the ethics committee

Full Protocol

Background

This piece of research is part of 'Strategies For Living', a UK wide supported user-led research programme run by The Mental Health Foundation. The project is supporting 15 user-led research projects, 6 of which are in Wales.

User-led Research

User-led research is research in which service users decide on the issues to be addressed and then design and carry out the research themselves. Most research in the field of mental health is carried out on people with mental health problems, does not include them and very often does not address the questions or issues they consider to be important. User-led research takes a person-centred approach, going beyond a narrow focus on services and considering the context of people's lives, taking into account peoples mental, physical, emotional and spiritual needs. This means that rather than focusing on, for example, a particular set of symptoms which may or may not be important to the patient, the patient is able to say what is important to them. This person-centred approach also means building flexibility into the process, allowing for times when people are not well, or when they need extra support or special arrangements to enable them to partake in the research.

The Strategies For Living project is based on the recognition of patients/service users as 'experts by experience', acknowledging that service users have a unique insight and perspective on issues, which can enable them to gather different sorts of information than that which may be by more traditional research approaches. Previous work by The Mental Health Foundation has found that often service users or patients feel more able to give honest answers to researchers who they perceive as service users who are completely independent of services, rather than professionals or academics.

User-led research has an emphasis on process. The process of enabling service users to participate and have an opportunity to express their views and share their experiences is considered as important as the overall outcome of the research. Findings are shared in accessible, 'user-friendly' ways, enabling them to be understood by a wide range of people including service users, carers and the general public, as well as professionals and academics.

The work of the Strategies For Living Project is complementary to developments within the social research field, where 'emancipatory' research has gained increasing support within the wider health and disability fields. Emancipatory research is concerned with what research can do to facilitate the process of empowerment.
 knowing our own minds' - a user-led survey of alternative and complementary treatments and therapies was published by The Mental Health Foundation in February 1997. Over 400 people who had used mental health services returned questionnaires asking them to comment on a wide range of mental health treatments and therapies, as well as a range of other personal and self help strategies. The survey demonstrated the importance of understanding the full context of people's lives: how it is that people find ways of coping on a day to day basis, and what alternatives people seek when conventional treatments do not solve all of their problems or indeed create new ones.

Knowing Our Own Minds was the starting point for the Strategies For Living project, phase one. A second piece of user-led research 'Strategies For Living' (2000) took a more qualitative approach to explore people's experiences of different treatments and therapies in depth, in order to find out what people find helpful and why. At the same time as this large scale piece of research was being carried out, the project also supported 6 small scale pieces of user led research across England and Wales. 'An Investigation Into Drop-Ins' (Malpas & Weekes, 2001) was carried out by two service users in South Wales, and the findings have been used to successfully achieve further funding for a drop in service which was threatened with closure. The supported user researchers have talked about a large number of benefits of being a part of the project, including increased self esteem, being afforded respect and dignity (both themselves and the participants), gaining new skills, reduction of feelings of isolation, learning about oneself and managing ones mental health more effectively. (see 'The S4L User-Led research Project: An Evaluation' N.Hutnik, 2001).

The Strategies For Living Project Phase 2

In March 2000 a successful application was made for further funding from the Community Fund to continue and expand the project. Currently Strategies For Living Phase 2 is supporting 15 user led research projects across the UK. The aims of the project are as follows:

- To document and disseminate peoples strategies for living with mental distress through research, publications, newsletters and networks.
- To promote a holistic approach towards mental health, taking account of people's mental, physical, spiritual and emotional needs.
- To raise user, carer, professional and public awareness about alternative ways of living and coping with mental distress.
- To encourage and promote user-led research in mental health.

There are 6 supported user-led research projects across Wales investigating a wide range of topics:
The needs of carers of people with manic depression (Abergavenny)
Mental health advocacy in Wales (National)
Dissociation (Carmarthen)
Getting back into employment after mental health problems (Aberystwyth)
Needs of survivors of childhood sexual abuse (Wrexham)
Leave for patients under section 37/41 (Llanarth, Nr Abergavenny)

Although the UK project as a whole has an advisory committee, Wales has its own advisory group to ensure that the projects are also guided by more local concerns and knowledge.
Group members who come from across Wales include a number of people who are working in mental health services, a user researcher, and several academics. Most of this group also identify as service users and are involved in the user-movement in Wales.

**Training and Support**

Each project has a grant of up to £2000 for research expenses. Other expenses such as travel and accommodation required for attending training sessions are also covered by The Mental Health Foundation. Researchers are given assistance and guidance in managing the budget and must return any unused grant to The Mental Health Foundation at the end of the project.

User researchers being supported by the Strategies For Living project are required to attend training sessions and to make use of individual support. The training sessions cover the main steps in conducting research including introduction to research, designing questionnaires, ethical issues, conducting interviews, analysis, and writing reports. Individual support is flexible depending on the needs of the particular project and researcher. Individual support for this particular project has included (initially) fortnightly, and more recently weekly meetings with the research training and support worker to assist Geraint through each stage including deciding on aims and methodology, considering ethical issues and designing the interview schedule. Geraint has also been having weekly individual help and support from John Boardman, patient advocate at Llanarth court. We have also had access through the Strategies For Living network of contacts to a large number of interested individuals with knowledge and skills in research, including the Welsh committee members who have been involved in supporting and advising on the project.

**Geraint's project**

**Aims**

The aim of the project is to gain an in-depth insight into the perspectives of a small number of patients on the system of gaining leave for patients under section 37/41.

In particular,
what is patient's understanding of the system of gaining leave
how do they feel about this system
what do they see as the benefits and disadvantages of having leave.

**Approach**

This piece of research takes a qualitative approach which fits with the aims of achieving an in-depth understanding of participant's perspectives. A qualitative approach can take account of individual meanings and contexts in a way that larger scale more quantitative research is unable to do. The project aims to gather information from a small number of participants who are all resident in the same hospital in order to gain locally relevant information. It does not aim to be representative of all inpatients under this section or in this particular hospital, but rather to give participants the opportunity to talk about their views and experiences in depth, and to use this information to raise awareness of issues which may also be relevant to other patients.
Method

Geraint and myself will carry out 7 semi-structured interviews with patients who are under section 37/41 living in the accommodation block at Llanarth Court Hospital. The interviews will be recorded, and transcribed. The transcripts will then be analysed qualitatively. Participants will be paid £5 as a token of thanks for their contribution on completion of the interview and given written information about section 37/41, the restrictions placed on them and their rights under this section.

Informed Consent

Geraint will decide on a patient who he would feel comfortable interviewing and who he feels will be able to talk about their experiences and feelings in an interview context. He will then ask the staff on that patient's ward for permission to approach that patient.

If staff are agreeable to this, Geraint will tell the patient about the research and give them written information to take away and discuss with staff or others if they wish. Geraint will then approach them again after a few days and if they would like to be involved, Geraint and myself will then arrange an initial meeting with the potential participant.

This initial meeting will be to introduce myself, and to tell them more about the research, what will be involved in the interview, and about confidentiality issues. If the patient is interested in being interviewed we will then go through the informed consent form with them, and after checking that they fully understand it, will ask them to sign it. If they wish, the potential participant can take the informed consent form away to look at on their own or discuss with someone else.

On the day of the interview we will check with the patient that they are still willing to take part, and also with the ward staff that they are still happy for the patient to be interviewed.

Confidentiality

The interviews will be held in a private room where participants will not be overheard. The interviews will be taped, and the tapes and transcripts will be kept in a locked box, in a locked drawer in Geraints room.

The interviews will be heard by myself, Geraint and the transcribing company staff.

The anonymised transcripts may also be seen by Vicky Nicholls (S4L Co-ordinator), and Toby Williamson (Head of Strategies for Living team) for the purposes of assisting with the analysis.

The report will be written in a way which does not enable any participant to be identified. Due to the small number of participants, this will involve taking particular care not to reveal any particular characteristics which may reveal a participant's identity. The published report will be made widely available to service users, carers, service providers and professionals.

The information gained from the research will be used for this research project only.
The tapes will be destroyed immediately after transcription. After the project is completed, the transcripts will be kept in locked files at The Mental Health Foundation Offices in London for 2 years before being destroyed.

Confidentiality will be broken in the following circumstances: (This will be made clear to participants before they agree to take part).

If either interviewer believes that the participant intends to cause harm to themselves or another person and that this intention is serious enough to warrant intervention by hospital staff.

**Risks**

Possible risks have been identified by the researchers and hospital staff as follows:

<table>
<thead>
<tr>
<th>Nature of Possible Risk</th>
<th>Minimising Risk</th>
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<tbody>
<tr>
<td>Emotional upset caused to interviewee.</td>
<td>• Nursing staff to give permission for each participant to be interviewed.</td>
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<td>• Interviewee to be made aware (in advance of giving consent) as to the personal nature of the questions.</td>
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<td>• Interviewee to be able to refuse to answer any question which they find upsetting or too personal etc.</td>
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<td>• Interviewee will be able to request a break at any time during the interview.</td>
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<td>• Patient advocate (John Boardman) to be available after each interview for participants to talk to.</td>
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<tr>
<td>Emotional upset to researchers</td>
<td>• Rachel Waters (Research training and Support Worker) will be spending time after each interview to provide support to Geraint.</td>
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<td>• Rachel will have access to a member of the Strategies For Living Team after the interview and support session, for her own support needs.</td>
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<tr>
<td>Violence to researchers</td>
<td>• Nursing staff to make a decision on the day of the interview as to whether the participant is 'safe' and well enough to interview.</td>
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<td>• Researchers will be given an alarm which alerts staff if there is a problem - and gives location of problem.</td>
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<td>• Staff will be aware of where researchers are, who with and how long they expect to be there.</td>
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</tbody>
</table>
| Geraint having personal information about other patients. | • Researchers to inform staff when interview has been completed.  
| Geraint being excluded by other patients - due to no longer being seen as a 'proper' patient. | • Clear confidentiality policy to protect researchers and participants.  
• Ward staff to be made aware of the type of information which researchers will be asking for, and to be agreeable to this.  
• Make clear to participants that the research is user led, and that the research is entirely independent from the hospital.  
• Geraint to be open with participants about his reasons for wanting to do this particular research.  
• Geraint to be offered support if he should feel that he is being excluded by other patients.  
| Breach of Confidentiality | • Clear confidentiality policy to protect researchers and participants.  

**Benefits of Research**

Geraint's personal experience of being detained under this section for many years has led him to believe that many patients do not fully understand the system of leave for this section, and as a result have difficulty in keeping to the various rules and restrictions which are placed on them. This then leads to further restrictions on their freedom, causing frustration for both the patient and staff involved in their care. We hope that gaining an in-depth insight into patient's understanding of and feelings about the system will enable staff and patients to work more effectively together within the system to improve patient's quality of life.