Support after leaving mental health hospitals...

7 Day Follow Up Patient Experience Evaluation

May 2013

Your voice in health and social care
Foreword

“Inclusion from the start is important. Inclusion is as an end itself regardless of the results.”

Bill Ellison, Service User and Carer Steering Group

This is a significant piece of research, in that it investigates practice well after Delivering the Bamford Vision (DHSSPS 2009) sets out the specific requirement for a 7 day follow up after discharge from a mental health hospital. It looks at people’s experience of the service they receive and how it fits into their life experience of recovering their mental health and well-being after a crisis severe enough to hospitalise them.

The initial post-discharge visit is critical: it is intended to be the bridge between intense care and support in hospital and the transition to recovery in the community. When a person feels this support is non-existent, inadequate, or simply does not meet their recovery needs, it raises profound doubts about the meaning, provision and efficacy of “care in the community” in Northern Ireland. Here the report speaks for itself, and it is a matter for concern.

As stated at the outset, inclusion is an end in itself. How beneficial was this research process? While producing this research was useful, we feel that in terms of providing service users a voice that must be reckoned with, it has been challenging to reflect the richness of the service user experience in a report. This is in not the fault of the researchers, but more a limitation of investigating a specific aspect of services recommended in an action plan (DHSSPS, 2009).

Good research raises further research needs. Qualitative research which stimulates the person to reflect on their recovery needs on discharge from hospital would be helpful. People are rarely encouraged to reflect on their recovery needs, and to articulate them as equal partners with anyone, particularly health care professionals. A care plan (when
people get one) often amounts being told the services they can get. Investigating experiences that prompt a person to devise a recovery plan of their own post-hospital, with the support of staff and any other relevant people or organisations, would be research worth doing: What would the elements process of this be for you, the person?

We will work to ensure positive changes are made to services as a result of what we have learned from the people who took part in this research. As experts by experience we will also be reflecting on how we found this research process and how we can continue to undertake research from a service users and carer perspective.

Martha McClelland,
On behalf of peer advocate researchers

This study provides a valuable insight into the experiences of people with mental illness regarding the support available to them after leaving hospital. It highlights the importance of good support for vulnerable people who, having suffered a difficult period in their life leading to a stay in hospital, need continued support for their recovery in the community.

The findings clearly identify that people want the opportunity to be supported in their own home, by a professional that they know and have a therapeutic relationship with. The connection between discharge planning, understanding of the 7 day follow up arrangements and care planning appear weak which is contrary to the process of agreed support for recovery. It is also concerning that some of the people we spoke to could not identify any support after leaving hospital and this is something that service providers should immediately address.

I would like to acknowledge all of the people who shared their experiences with us as part of this study. Although they have not been named in this report, their voices are
clear and important to pay attention to. We endeavour to ensure changes are made to mental health services learning from their experiences.

**Maeve Hully**
Chief Executive, Patient and Client Council
Summary

Background
‘Delivering the Bamford Vision’ (DHSSPS, 2009, p.82) states that from April 2009, “all mental health inpatients discharged from hospital who are to receive a continuing care plan in the community should receive a follow up visit within 7 days of discharge”.

Aim
The purpose of this study is to understand people’s experiences of the follow up that takes place within 7 days of leaving mental health hospitals and the immediate period post discharge from hospital leading up to this. Do people get a follow up within 7 days of leaving hospital, what is it like, what happens and do people feel the appropriate help and support they needed was provided? The focus is on the quality of the care and support available based on the views and self-reported experiences of people with mental health problems.

Our Approach
All people over the age of 18 years discharged from mental health inpatient hospitals within the Western Health and Social Care Trust and Belfast Health and Social Care Trust areas from 12th May 2012 to 9th November 2012 were eligible to participate. 12 people chose to take part in a structured face to face interview with a trained mental health peer advocate as part of this study.

Our Findings
Key findings from the study include:

- Nine of the twelve people interviewed said that they did get a 7 day follow up appointment or visit after leaving hospital. Three people said that they did not;
- Of the nine people who had a 7 day follow up, most took place in the person’s own home. Most people expressed the desire to be supported in their own home, and where this did not occur or could not be facilitated it proved distressful;
- Issues regarding lack of clarity regarding who people were seeing for their 7 day follow up were evident;
Seven of the nine people who said they had a 7 day follow up said that they were given details about the follow up before leaving hospital;

Four people of the twelve people interviewed said that they had no preparation for discharge; two people were unclear or unsure. For the six people who made some mention of discharge planning issues regarding notice of discharge and family involvement were evident;

Although there was a common focus to the 7 day follow up, the experience of the discussion at the follow up was not always viewed positively;

Lack of knowledge, understanding and ownership of care plans was evident. Ten people did not know what a care plan was. Only two people spoke about care planning.

The main themes identified from the qualitative interviews regarding if people thought the support after leaving hospital helped and met their needs include:

- Importance of trusting relationships;
- Feeling supported by the follow up provided;
- Choice, control and flexibility for the individual.

1.0 Introduction

Evidence shows that people are most vulnerable the immediate period following discharge from mental health inpatient hospitals. Post discharge suicides are most frequent in the week after leaving hospital and 24% of post-discharge suicides take place
before first follow-up (NCISH 2011). The National Confidential Inquiry into Suicide and Homicide Northern Ireland report recommends that patients discharged from hospital should be followed up within seven days. *Delivering the Bamford Vision* (DHSSPS, 2009) sets out specific actions that Government Departments and their agencies are committed to take during the period 2009–2011 to improve mental health and learning disability in line with the Bamford Review of Mental Health and Learning Disability. Included is an action to establish procedures to ensure people leaving hospital who need continuing mental healthcare receive it. Therefore, from April 2009 “all mental health inpatients discharged from hospital who are to receive a continuing care plan in the community should receive a follow up visit within 7 days of discharge” (DHSSPS, 2009, p.82).

The Bamford Monitoring Group of the Patient and Client Council has worked collaboratively with mental health service users (experts by experience), carers, the Bamford Centre of Mental Health and Wellbeing at the University of Ulster, the Western Health and Social Care Trust, the Belfast Health and Social Care Trusts and voluntary and community organisations in the field of mental health to explore people’s views and experiences of 7 day follow up. This research study was designed with the purpose of finding out what mental health service users in Northern Ireland think about support after leaving mental health inpatient hospitals and in particular the follow up within 7 days of discharge. Do people get a follow up within 7 days of leaving hospital? What is it like; what happens? Do people feel the appropriate help and support they needed was provided?

Mental health service users have been involved in research before, but this study represents one of the first times that a group partnership process has been used from a *service user perspective* for the entire research process from designing the research, developing the approach, carrying out fieldwork, analysing and reporting findings. Service users are at the heart of this research.
1.1 Patient and Client Council

This research study was initiated by the Bamford Monitoring Group of the Patient and Client Council. The role of the Patient and Client Council is to provide a powerful, independent voice for people by:

- listening and acting on people’s views;
- encouraging people to get involved;
- helping people make a complaint; and
- promoting advice and information.

1.2 Bamford Monitoring Group

The Bamford Monitoring Group was set up by the Patient and Client Council to find out how changes being made to law, policy and services arising from the Bamford Review of Mental Health and Learning Disability are affecting people and communities.

The group works to understand if people have experienced any changes to services in their area, and if so what has been the effect of the changes on their health and wellbeing. Ultimately are changes making a positive difference in their lives or not.
2.0 Background

This section provides background information about the process for developing the research study and the partners involved.

2.1 Aim and Objectives

The aim of this research study is to explore the views of people regarding the follow up which should take place within 7 days after discharge from mental health hospitals. The objectives are to:

- examine people’s views about the 7 day follow up post discharge from mental health inpatient hospitals;
- examine the quality of care and support available post discharge from mental health inpatient hospitals, particularly in relation to the 7 day follow up, based on the views and self-reported experiences of patients;
- identify if people feel the appropriate help and support they needed was provided post discharge from hospital, and at the 7 day follow up;
- explore issues surrounding continuity of care, and communication post discharge from hospital, and at the 7 day follow up;
- gain people’s perspectives on their own needs post discharge from mental health inpatient hospitals;
- explore people’s views of how such community-based support services might be improved in the future; and
- ensure the service user views and experiences are central to the evaluation of community-based support and follow up post discharge from mental health hospitals.
2.2 Service User and Carer Steering Group

Initially local groups with professionals, service users, carers and a member of staff from the Patient and Client Council were established in both the Western and Belfast Health and Social Care Trust areas. The research approach discussed at that time involved one-to-one interviews with mental health services users conducted by a nursing professional.

Early on research partners decided that peer advocates with experience of mental illness might be better suited to conduct interviews. It was also agreed that mental health service users and carers should design the research approach, develop research tools, carry out participant interviews, analyse and report the findings.

The local groups were concluded and a new Service User and Carer Steering Group (Steering Group) was established to direct the research study from start to finish. Membership of the group included mental health service users, peer advocates, carers, voluntary and community organisations, a research coordinator from the Patient and Client Council and support from research professionals at the Bamford Centre for Mental Health and Wellbeing.

Our research process has been based on partnership and consensus decision-making throughout. Steering Group meetings were full of lively discussion, debate and often disagreement as we made the many decisions involved with the study.
Some of the key decisions in the process of the research study are outlined below:

2.2.1 Developing the research approach
The Steering Group began with a clean slate. The decision had been agreed that peer advocates would be involved as researchers and conduct participant interviews, but the group still had to decide:
- are face to face interviews the best approach to use in the study?
- how we were going to reach people who would take part in the study?
- what were we going to ask people about their experiences?

Meetings spent developing the research approach and subsequently the supporting project documentation were vital because they ensured that the study was firmly rooted in service user experiences.

2.2.2 Developing the project documentation
The Steering Group jointly developed all project documents, writing and agreeing the content together, including:
- 1st and 2nd letters to potential participants;
- Information sheet;
- Consent form;
- Poster; and
- Leaflet.

2.2.3 Design semi-structured interview prompts
We started with a blank page and an understanding of a broad idea that we wanted to know about people’s experience. Prompt questions to guide interviews were developed based on service user experience.

2.3 Research Approval Process
Formal research approval to proceed with this research study was gained through the Office of Research Ethics Committees Northern Ireland (ORECNI) and Health and Social
Care Research and Development Offices in the Western and Belfast Health and Social Care Trusts using the Integrated Research Application System (IRAS). The content of the application was agreed via the Steering Group when designing the research approach. An illustration of the research approval process for this study is given below:

**Figure 2: Research Governance Process**

- **PCC Research Committee**
  - Discussed at meeting 25th October 2011
  - Suggested amendments
  - Approval 11th November 2011

- **HSC Research & Development**
  - Western Trust lead
  - Documents submitted 28th November 2011
  - WHSCT gave favourable opinion via letter on 16th March 2012
  - BHSCT gave favourable opinion via letter on 25th May 2012

- **ORECNI**
  - Documents submitted 28th November 2011
  - REC Committee meeting 13th December 2011
  - Favourable opinion subject to minor amendments 25th January 2012
  - Amendments submitted 26th January 2012
  - Confirmation ethical approval received 2nd March 2012

### 2.4 Research Team

The research team was made up of members from the Steering Group. They include three peer advocacy organisations, Mind Yourself, Irish Advocacy Network and LAMP, and researchers from the Bamford Centre for Mental Health and Wellbeing supported by the Patient and Client Council.

#### 2.4.1 What is a peer advocate?

Peer advocates are people who have first-hand experience of using mental health services, and have gained a level of personal recovery which has enabled them to go on to complete specialist training and support others with mental health problems.
Peer advocates are there to speak with, rather than for, people wherever possible. The advocate should make no decisions or choices on behalf of the service user. Advocates should not give advice or counselling; they support and encourage empowerment of the service user at all time. Peer advocates hold a belief in the individual’s right to autonomy rather than someone else’s idea of what is “in their best interest”. Peer advocates are a good role model for current users of services and give hope. Peer advocates are independent of mental health services and should, at all times be user-run and user-led, with supervision provided by their peers.

All peer advocates of the organisations partnered in this study have completed training which has been developed, designed and delivered by service users. The training is an accredited course through the Open College Network. On completion of the course all qualified peer advocates have to abide by a code of practice as required as part of their duty.

Brief information about the peer advocates organisations partnered in this study is below:

### 2.4.2 Mind Yourself and Foyle Advocates

Mind Yourself was established in 1996 as an independent mental health charity wholly led and run by people in recovery from mental health crises. It now provides peer advocacy throughout the North West of Northern Ireland. Mind Yourself and its project Foyle Advocates provides a supporting atmosphere and opportunity in which to explore and self-define recovery in one’s life.

Mind Yourself trains peers advocates throughout the North and indeed provides the only accredited training for fully independent mental health peer advocacy services in the North (e.g. wholly user led, run and supervised.) This is in contrast to “peer advocates” who have a limited role in hospital or in the community and are supervised by non-service user professionals or organisations. In addition to such peer advocacy, Mind Yourself as a broader mental health charity provides service user representation on health boards, training and awareness for students, professionals and is involved with organisations and initiatives in the broader community and voluntary sector.
2.4.3 Irish Advocacy Network
The Irish Advocacy Network was established as a result of a mental health service user conference held in Northern Ireland in 1989. The Irish Advocacy Network, which is peer-led, was set up to offer peer advocacy services throughout the island of Ireland. The peer advocates work in the majority of counties throughout Ireland and regularly meet with people in acute psychiatric unity, training centres, day centres and day hospitals etc. In the Belfast Health and Social Care Trust, the peer advocates work as part of teams within Home Treatment, Resettlement and Unscheduled Care, offering independent peer advocacy.

2.4.4 LAMP (Life After Mental Health Problems)
LAMP is a voluntary organisation formed in 1998 by users or ex-users of mental health services who wanted an input into the services. LAMP challenge the stigma surrounding mental health, provide peer advocacy through New Way Advocates, provide a listening ear service in a safe and confidential environment and provide an input into staff training and delivery of services.

2.4.5 Bamford Centre for Mental Health and Wellbeing
The University of Ulster established the Bamford Centre for Mental Health and Wellbeing, on the Magee campus of the university in 2011. It has been established to develop new fields of joint study with academic colleagues who work across a wide range of disciplines on the University’s four campuses. The Centre coordinates the work of 40 academic and post-graduate students. Studies currently under way include the economic impact of depression, patterns of post-traumatic stress, incidence of suicide and factors in self-harming.

2.5 Training
The next stage in the research process was training. Training ensured that peer advocates were equipped with the appropriate skills and techniques to carry out the interviews in an unbiased and consistent manner. Interview skills training were provided by Dr Sam Murphy, Bamford Centre for Mental Health and Wellbeing based on World Health Organisation interview training.
Peer advocates also took part in two additional role play training sessions. Peer advocates interviewers had the opportunity to test out being the interviewer, the notetaker and the participant. It allowed peer advocates the opportunity to test out each role, learn how to ask questions and pace the interview so it was a comfortable discussion for the participant but that the notetaker could keep up.

Feedback sessions were held as part of each training session to capture the lessons learned, and highlighted any queries, concern, or issues requiring further explanation and if necessary training.
3.0 Our Approach

Summary
All people over 18 years of age discharged from mental health inpatient hospitals within the Western and Belfast Health and Social Care Trust areas 2 – 8 weeks prior to 6th July 2012 were eligible to participate in the research. Thereafter, letters were issued to patients discharged from hospital on a rolling cycle until sufficient numbers were recruited to the study:

- Health and Social Care Trusts issued letters of invitation to patients, on behalf of the research team, to recruit participants;
- Patients contact peer advocates on the research team directly if they wished to take part;
- Two weeks later a second letter issued encouraging participation;
- Posters displayed and leaflets distributed by peer advocates on hospital wards.
- Interviews conducted with people who wanted to participate – two peer advocates (interviewer and notetaker).

3.1 Who was eligible to take part?
All people over 18 years of age discharged from mental health inpatient hospitals within the Western and Belfast Health and Social Care Trust areas were eligible to participate. Initially people discharged 2 – 8 weeks prior to 6th July 2012 were invited to participate in the research. Thereafter, people were invited to participate on a rolling cycle of recruitment i.e. the total period of recruitment lasted from 12th May 2012 to 9th November 2012. It should be noted that not everyone discharged from mental health hospitals in the Western Health and Social Care Trust area were assessed as requiring continuing care after leaving hospital. Therefore, some of those people invited to take part may not
have received a 7 day follow up. Participation in the study was limited to people in the Western and Belfast Health and Social Care Trust areas due to time and resource restrictions. However, it could usefully be completed across all other Health and Social Care Trust areas in Northern Ireland.

3.2 How were people invited to take part?
The Western and Belfast Health and Social Care Trusts sent a letter from peer advocates in the research team to potential participants informing them about the study and inviting them to directly contact peer advocates if they wished to participate. This approach in communicating with people ensured that their anonymity was protected and their identity was not known by the research team until such times as they made contact and indicated they wished to be involved. Furthermore, the Health and Social Care Trusts had no knowledge of who chose to respond and participate. The letter sent to people made clear that:

- The letter had been sent by the Health and Social Care Trust, their details have not be shared with peer advocates on the research team;
- The Health and Social Care Trust was assisting peer advocates to contact people who may wish to participate. The Trust would have no further involvement and would not know who chooses to participate in the study i.e. responses would be anonymous;
- Participation was entirely voluntary and the decision not to participate would not affect the persons current or future mental health care and services;
- A full and detailed information sheet about the study would be explained if they contacted the peer advocate;
- People could contact the research team at any time to find out more about it and were under no obligation to proceed and be involved; and
- Peer advocate name and contact details were provided should they wish to get involved.

People were given two weeks to respond to the initial letter, and a second letter was then sent to encourage participation. The second letter was sent to all people in each cycle to ensure that the Health and Social Care Trusts did not know who had responded and who
had not, maintaining the anonymity of participants. If after two weeks there was no response to the second letter, no further correspondence was issued. It was assumed that anyone who did not respond did not want to be involved in the study. When people contacted peer advocate organisations with an interest to get involved, further information about the research and what taking part would involve was shared with them and an initial meeting arranged.

It was determined that this was the best approach for several key reasons:

- People invited would have had a 7 day follow up, and that the experience would be in the recent past. This would improve the likelihood of clear recollection;
- A time lag of a further week after the 7 day follow up was allowed to ensure the participant was more likely to be well enough to participate; and
- The rolling schedule of ‘cycles’ to invite participation allowed for the possibility that it would take time to recruit enough people who wished to participate in the research study.

In addition to the main approach to recruit study participants outlined above, the Service User and Carer Steering Group decided that it would be beneficial to use a poster and leaflet to encourage participation.

**Poster and leaflet**

The poster was placed in mental health inpatient wards. The purpose was to make patients aware the study was on-going and perhaps be more likely to choose to participate when they leave hospital. The leaflet was developed so that peer advocates could give information to patients when visiting wards, again potentially increasing the recruitment of participants.
3.3 What did taking part involve?

Participants took part in a semi-structured face to face interview about their experiences of support after leaving hospital and the 7 day follow up. The interview was carried out by a trained mental health peer advocate, with support from a second peer advocate to act as a ‘scribe / notetaker’ to maintain a record of the interview.

To begin the interviewer asked the participant a broad question “What happened after leaving hospital?” Prompts were then used to guide discussion and ensure all aspects of the person’s experience were appropriately explored. Prompts were used as necessary to focus the participant on areas of interest and ensure discussion did not divert from this.

All interviews took place in a location convenient to the participant, either in their home or at a mutually agreed neutral location. Peer advocate offices were primarily used for conducting interviews as they provided a supportive, neutral environment. Facilitating the participant’s choice about where the interview took place was important. Each interview lasted approximately one hour on average, although duration varied depending on the participant.

Formal, written consent was gained from each participant. Peer advocates gathered informed consent from participants prior to the interview commencing. Each participant was taken through the study information sheet and was encouraged to freely ask questions or raise any issues relating to the study. If they chose to be involved, they signed a consent form. Each participant was given the option to proceed directly to interview or schedule the interview for a separate day; this was at the discretion of the participant. The purpose of two separate sessions was to allow a ‘cooling off period’ so that the person could take time to consider if they wished to take part. Such arrangements were flexible to the needs of the participant and the peer advocates.

Interviews were recorded in writing by the ‘scribe / note taker’ and where consent was given by the participant, interviews were voice recorded. Digital interview recordings were then transcribed. Each participant was offered a copy of their interview record.
3.4 Data Analysis

Interview records were subject to qualitative data analysis. Responses to prompt questions were analysed thematically and the key trends explored.

3.5 Ethical issues

Given the sensitive nature of this area of study, it was important that several ethical and design issues were addressed.

Recruitment of participants was based on gaining ‘informed consent’. Potential participants were identified and sent an invitation letter that explained, in detail, the nature of the study and value of their involvement. The letters were sent by Trusts on behalf of the peer advocates in the research team and people were asked to contact peer advocates directly if they wished to participate. Whilst it is thought that this method of approaching people limited uptake, it ensured participants remained anonymous to the research team unless they chose to participate. Anonymity was also upheld with the Health and Social Care Trusts as there was no awareness of who chose to respond and take part in the research study. Peer advocates gathered informed consent from participants prior to the interview commencing. Each participant was taken through the study information sheet and was encouraged to freely ask questions or raise any issues relating to the study. If they chose to be involved, consent form was signed.

It was acknowledged that people participating in the study had recently been unwell in hospital and may have continued to be unwell, so were vulnerable to being adversely affected through participation. Safeguards were put in place in order to minimise the impact and effect that the interview might have had on participants.

Names of participants were only available to the research team when patients made direct contact with peer advocates or the Patient and Client Council indicating they wished to be involved. This avoided sharing of patient information, and placed the service user in control. All information held about participants was managed securely and maintained in a confidential manner. Participants’ names and personal information were known only to the research team; personal details or identifying features were
stored in a secure database accessible only to the research team, and were not used in any report arising from the study. Names and any other identifying features were removed from the interview transcripts. Specific details that might compromise the anonymity of the participants have been edited from the findings section of this report. Care has also been taken to avoid the inclusion of details that could impact on third parties who may have been involved in or affected by the events described by participants.

Peer advocates are themselves people who have experienced mental health problems and may potentially be adversely affected by the interview process. To reduce this risk peer advocates were subject to post interview debrief with a peer and supported through peer supervision throughout the study (as is required by the peer advocate code of practice).
4.0  Our Findings

This section details the findings from the 12 interviews completed as part of this research study. Whilst this is a relatively small number of interviews, in the context of the number of people discharged from mental health hospitals during the period of study, the findings give a valuable insight into individual experiences and highlights views shared by the people who spoke to us.

Most of the interviews took place in peer advocate offices. However, a few people preferred to be interviewed in their own home. The interviews lasted on average one hour, and most people preferred not to have their interviews voice recorded, but were happy for the interviewer to make notes. Responses to the prompt questions used in the study are discussed and direct quotes are used to illustrate the experiences. Section 4.9 includes a discussion of the main themes which emerged throughout the interviews regarding participant views about support after hospital and whether or not it met their needs. Appendix 1 shows how responses to prompt questions were broadly categorised when analysed.

Brackets and three dots [...] indicate that irrelevant material has been removed to aid clarification or save space. Brackets containing text are used to anonymise data or to include explanatory text. Quotes that include explicit detail or, which compromise anonymity have also been edited and care has been taken to exclude details that could impact on third parties.

4.1  Did you get a follow up after leaving hospital?

Nine people said that they did get a 7 day follow up appointment or visit after leaving hospital, and three people said that they did not. One person didn’t recall specifically getting a follow up mental health appointment but said that s/he did see her GP and had involvement from the Home Treatment Team. It was interpreted by the research team that this person did have a 7 day follow up, provided by the Home Treatment Team; this experience was discussed as part of the interview. The three people who identified that they did not have any follow up said:
“I didn’t get anything… no one came to see me.”

“I had a follow up appointment for primary care. I was offered day care which I didn’t take up.” [This was interpreted that this person did not have 7 day follow up.]

“I was told at hospital that a letter would be sent to me but one was not sent. I was told I would get a follow up visit but one was not made”.

4.2 Where did the follow up take place?

The nine people who said that they had a 7 day follow up appointment or visit told us where it took place:

Table 1: Where the follow up took place

<table>
<thead>
<tr>
<th>Community Mental Health Team Offices</th>
<th>Hospital appointment</th>
<th>Own Home (inc. Home Treatment Team)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>6</td>
</tr>
</tbody>
</table>

Table one shows that the majority of people identified being seen in their own home, which includes two people who left hospital and were discharged to the Home Treatment Team; one of whom said that the Home Treatment Team called at her home for “three days in a row after leaving hospital”[but then reverted to visits every other day], the other had a visit “two and then five days after leaving hospital”.

One of the people who had their follow up in their own home said that it was not their preference to have the visit at home, but because it was with the particular social worker it was ok “with him it was fine.” This person asked the social worker if they were obliged to attend outpatient appointments after discharge and was “relieved to find out that this was my own choice.” The trusting therapeutic relationship, with a choice of support from
whom and from where was very important here and this issue is further discussed in section 4.9.

In contrast, another person was extremely distraught recounting their difficult experience after leaving hospital, particularly trying to reschedule their follow up appointment at the hospital. Their preference was that the follow up would take place in their own home as they didn’t feel able to make it to the hospital:

“Within the 7 days it was difficult for me to make the appointment, I tried to reschedule the appointment but they wouldn’t reschedule the appointment. And I did request could I have the appointment at home, could a CPN or staff member of community mental health visit me, and I was told no […] I didn’t think I would be able to go in because of the way I was feeling […] I wanted to talk to someone in my own home I would’ve felt more comfortable […] I felt very let down and isolated […] I couldn’t make the appointment cause of the side effect of medication that made me really ill, I didn’t have any transport, I couldn’t manage buses […] eventually I had to go in and keep my appointment.”

This person experienced difficulty due to having to travel into the appointment. The importance of being close to help and support was echoed by another person:

“It was really helpful that the help was local and the hospital was close to where I live. When I’m psychotic I get confused easily so it helped that I knew where to go.”

It is important to remember that the standard for 7 day follow up (DHSSPS, 2009) stated that people discharged from mental health hospitals should have a follow up visit i.e. the professionals should go to the person. It appears from the people spoken to as part of this study that this has been the experience for most, and the experiences detailed above would support this approach.
4.3 Who did you see?

Of the nine people who did have a 7 day follow up, two people identified that it was a social worker who they saw, two people saw a Consultant Psychiatrist or a Doctor, and two people were visited by Home Treatment Team, although one person said that they knew they were from the Home Treatment Team but could not recall what profession they were.

One participant described a “Counsellor” visiting them. One participant had staff from the hospital visit them at home and said “the woman was a nurse from [hospital] and I don’t know who she was.” Similarly, another person did not know who it was that they saw at their 7 day follow up “I seen somebody that I never knew before. I don’t know who it was.”

Lack of clarity about who people were seeing for their 7 day follow up is concerning, and appears to conflict with the principle of therapeutic relationships. If the professional undertaking the 7 day follow up is not known to the person, it brings to question issues of continuity of care. This is further discussed in section 4.9.

4.4 How long was the appointment or visit?

For the people we spoke to as part of this study there was not a connection between time and benefit from the 7 day follow up. However, other factors were particularly important and these are identified and discussed in section 4.9.

One person whose visit lasted about an hour said this was “longer than the allotted time the social worker had for the visit […] he overstayed his time, he stayed on.” This time was greatly appreciated by the person who identified this was despite the social worker running late for another appointment.

4.5 Were you given details about the 7 follow up before you left hospital?

Seven people said that they were given details about the 7 day follow up before leaving hospital. Four people said they were not given details about the 7 day follow up (this
includes those people who identified that they did not have a 7 day follow up after leaving hospital) – one person said “No. It came as a complete surprise when they landed at my door.”

One person was not sure and “had some recollection of being told her consultant and GP would be in touch after s/he left hospital.”

Some of the comments people who had a 7 day follow up made include:

“They told me just before I was discharged that someone would contact me within 7 days.”

“Yes, I was given details at the hospital.”

“Told in hospital that I would get follow up visit but one was not made.”

“Yes, they told me someone would be in touch within 7 days.”

“Yes I was given details.”

“Yes I was given a card with an appointment.”

It is important to highlight that the above responses are regarding being given details about 7 day follow up. People were asked about other support and contact details for someone to call if the person felt unwell after leaving hospital which is discussed in section 4.7.

### 4.6 Was there preparation for your discharge from hospital?

Four people were absolutely clear that there was no discharge planning whatsoever: “No, and I knew I would just do it again,” “Never done that. Ever.”

Six people made mention of some preparation for discharge.

Several issues with preparation for discharge and the process emerged:

#### 4.6.1 Notice of discharge

Discharge at very short notice was an issue for two people. One person who said they were only made aware of their discharge a couple of days in advance and another person went so far as to say “I guessed the right day when they were going to throw me out. There was no preparation at all for my discharge.”
Preparation for the discharge meeting itself was also mentioned by one person who said that the Consultant Psychiatrist gave no warning about the meeting. S/he was told the same day as the meeting that it would be happening and said that the nurses had to provide reassurance that “nothing would be forced on me” at the meeting.

4.6.2 Family involved
Five people mentioned experiences regarding the involvement of family and friends in discharge planning.

Three people spoke particularly negatively regarding the involvement of family and friends in their discharge planning. One of the people said their discharge was at very short notice and their friends and family were not involved in the process despite the person telling staff that they were going to be returning to an empty house. Similarly, the second person identified there was “no prompting or information” to encourage them to ask their family, friends or an advocate to attend the discharge meeting, so they had to contact their partner personally as he “needed to see that there was a care plan in place for this own reassurance.” The third person identified that they went to live with their parents after discharge but that “nobody checked with my parents that it was ok to live with them, and my father has lots of health issues.”

One person appeared to have a proactive and positive involvement of family involved in planning discharge, saying that in the week before their discharge, “family were called in to discuss what would happen.” Another person had two nights short term leave prior to full discharge home.

Two people mentioned a phone call to parents in relation to discharge, but whether or not this was helpful, or if family were involved further than this is unclear as the individuals did not give further details.

4.6.3 Other support
Nobody independently mentioned the involvement of advocates when discussing discharge planning. When prompted about support from any other sources one person said they “were aware of a patient advocate on the ward” and had occasional contact,
but did not contact the patient advocates to attend the discharge meeting as she had “no awareness of the role they could take at the meeting.”

4.7 Did you get contact details for someone to call if you felt unwell after you left hospital?

Whilst most people said that they had contact details for someone to call if they felt unwell after leaving hospital, they didn’t comment further on whether they found them to be helpful or useful:

“Yes, I was given an emergency and helpline. My flat has a buzzer if I need help.”
“Yes I did, a business card was given to me and lifeline card.”
“Yes, they gave me contact details should I be unwell.”

Three people said that they did not get contacts, and one person was rather vague about whether or not they were given contact details:

“I didn’t get any contact details but I’ve since arranged a counsellor in a private capacity.”
“I wasn’t given any contact details. I received leaflets about other organisations.”
“I wasn’t given anything.”
“They gave me a card and I think it had details on it.”

However, two people did say that they found the contacts they were given helpful. One person was given contact details for their social worker and occupational therapist, both were described as “accessible” and “do respond” when needed. Another person “found them useful, I was given the telephone number of [Hospital].”

Two people felt particularly strongly that the contact telephone numbers were inadequate and that having contact telephone numbers is not enough support. It was greatly distressing for one person when talking about their experience of repeatedly being given
telephone numbers for mental health services but real support was lacking. Support is further discussed in section 4.9.

“They say if you need us we’re here give us a ring, but when you ring in you don’t get anything back so what’s the point […]they furnish you with telephone numbers but it’s like a tape recording, it’s the same thing over and over […] They never come out. When I ring in in distress they’re busy. The duty officer has gone out, she’ll ring you back, and at that time it’s the last thing you want to hear. If I rang at 9 in the morning they ringing me back at 5 in the evening, everything thing inside of you is building up from 9 to 5 and let’s say quarter to 5 that’s basically the time they ring you, just before they close.”

“I get a lot of numbers but no support.”

“They told me to ring lifeline […] I didn’t get anything else.”

4.8 What did you talk about at 7 day follow up?
The 7 day follow up appointments / visits seem to have focused on how the person was doing at that time and their wellbeing:

“The counsellor advising me on what would keep me out of hospital. More or less saying to keep on taking medicine.”

“I talked about what I was wanting to do… I was positive about what I was wanting to do coming out and this occupied most of the interview.”

 “[social worker] made sure I was ok and not self-harming… it was very reassuring and it made me feel better. I felt that I would cope better.”

“We talked about the support they could provide and how was I. The nurse was very good. She provided a listening ear and it reassured me. She understood the pain
and agreed with me that it was better to get out and about.”

“I was asked about my general wellbeing… I felt it helped me to know that there was help there if I needed it.”

Although there was a common focus to the 7 day follow up appointment / visits, the experience of the discussion was not always viewed positively. Some people were clear that they did not find the 7 day follow up of benefit to them:

“The talk was about my suicide attempts and drinking. The visit made me even lower than I was… they didn’t offer me any support whatsoever. They made me feel worse and I got the impression that they were sick of me”

“How are you getting on now, what are you doing to pass your day, you should walk your dog. It was a complete waste of time.”

Being given inaccurate information that did not lead to additional support was concerning for two people. One person said that they were told various support groups would be looked into but that didn’t materialise. Another was told that they were able to call the professional anytime during the week for support if needed which was good, but was also given details about a group that was closed; “[professional] gave me wrong information and it caused me to feel panicky.”

4.8.1 Was your Care Plan discussed?

Ten people did not know what a care plan is, and when asked by the interviewer about their care plan some of the people said “what’s that?” When they were given an explanation of what a care plan is, none of these people said that they had a care plan. Some of their comments include:

“No, what’s that?”

“My mum is my carer but I don’t have a care plan.”
Two people did speak about care planning. One person was very clear about their care plan and how they were involved in reviewing this prior to being discharged from hospital. “I have a care plan which I agreed. The nurse went over it with me before I left hospital.” The second person said there was a care planning meeting prior to discharge from the mental health hospital and although they “didn’t speak in terms of a care plan”, the person was sure that this was the subject of the discharge meeting.

There is a lack of knowledge and understanding about ‘care plans’ amongst the people we spoke to. The purpose of a care plan is to agree what treatment and support is needed by the person and how it will be provided. A recovery orientated approach places the person at the centre of this process. People should be aware of their own care plan and the 7 day follow up is an integral part of this support.

4.9 Do you think the support after leaving hospital helped / met your needs?

Views about whether support after leaving hospital met the person’s needs could be broadly categorised as either positive or negative. Five people had positive views, and seven people were negative about support after hospital; these are discussed below:

**Trusting relationships**

The relationship with the professional was often a key factor in feeling supported after discharge. One person felt that the support from the social worker and occupational therapist thoroughly met their needs, and was extremely glad to avoid further contact with the CPN and Consultant Psychiatrist. The person was clear that they “wouldn’t have been confident to ask to discontinue with the doctor if [the social worker] hadn’t supported me”. The follow up was of was of tremendous benefit thanks to the “quality and integrity” of the particular social worker involved as they were “psychologically safe” for the person. Another person described the reassurance and understanding from the professional “the nurse was very good. She provided a listening ear and it reassured...
me. She understood the pain and agreed with me that it was better for me to get out and about.”

Regular contact with an individual was seen to be part of building a strong trusting relationship. Several people said that they were no longer able to get consistent support from one person throughout their journey of recovery, something that they would value having again:

“I used to get a care worker and that was help to me. I don’t get one now and I think it would have helped… A regular care worker that I could talk to. The care worker I used to have would come out every few weeks and talk to me.”

“I didn’t get key worker because they said I didn’t need one.”

“It’s all strange faces. There isn’t an allocated person that you can have a rapport with. There’s some people I can open up to and some people I can’t open up to. Need someone I feel comfortable with who have an understanding of me, my illness, how I react.”

The attitudes of healthcare professionals were referred to by some people and clearly had an impact on how supported people felt, and the likelihood they could trust them:

“Oppressive […] no care, all oppression […] glad to be able to discontinue with the doctor”.

“I felt very let down and isolated by their attitude towards someone like me that was coming out of psychiatric ward with a long history of problems.”

Feeling supported
Some people described a feeling of reassurance that the follow up gave, and this was an important factor in their positive response about support:
“It was reassuring and practical in the sense that I could be driven down to the shops if need be. I was on ‘self-harm contract’ so it was planned and really well thought out.”

“The home treatment team was very good. They didn’t smother me – they phoned at least 4 times.”

“She did say that I could call her anytime during the week.”

Of the people who made negative comments about support after leaving hospital, the key reason was simply that they had little or no support:

“You’re not getting anything from the phone and you’re not getting anybody to visit you [...] made you feel real unwanted, real isolated and makes you feel like they don’t want you, like they’re afraid of you [...] Why can they not come to see me, or what’s wrong with me? Are they taking you seriously?”

“All I got was outpatients and I found that boring.”

“They said I should come back in 2 weeks but I didn’t go because I saw no point.”

“I might never need hospital admission if I had an after care and support.”

“They didn’t offer me any support whatsoever. They made me feel worse and I got the impression that they were sick of me.”

This lack of support was described by one person as something which they tried to address in the weeks leading up to their time in hospital, they felt “ignored”, relapsed and had to be admitted to hospital. Unfortunately this continued again after hospital:

“The time I went into hospital, the weeks leading up to it were really difficult weeks, and I kept trying the mental health services for help but all I was getting were phone numbers. Basically phone numbers and helpline numbers and stuff. I never got a home visit which I needed a home visit but I was always denied it and that’s why I feel let down. Because they never acknowledged me and they never, they never took on board what way I was feeling and they kept just ignoring [...] I relapsed and
ended up back in hospital because I didn’t get no support I didn’t get no home visits I didn’t get anything. And after I was discharged the same thing happened, I was in the hospital and I didn’t get anything, they didn’t learn from that, they didn’t learn from ignoring me and they didn’t learn when I came out, things didn’t change.”

Concerns about medication contributed to people feeling unsupported after leaving hospital:

“I had a query about my medication and didn’t get the support.”

“I’ve had problems with that medication and I’ve had that medication changed by my doctor, but the medication actually gave me problems when I left but I didn’t have anybody to talk to about that.”

“The only support option I was given was medication which didn’t work. Several times this has happened. I arranged for my own counsellor to help me through my issues.”

“They didn’t try me on different medications.”

Choice, Control and Flexibility
Occasions where people had the opportunity to be in control of their support and were offered choice and flexibility seem to affect satisfaction. An example where this worked well was when a person was informed at their care planning meeting in hospital prior to discharge that a visit would be organised. The appointment offered didn’t suit the person so an alternative was offered and confirmed via letter to the person’s home after discharge. This flexibility was greatly appreciated. Another person commented that:

“i thought it had improved to when i was last in, over 6 years ago. i felt that the staff
in particular better trained and more inclined towards empowering and offering choices to the patient. I thought the psychiatrists more empathetic than I remembered.”
5.0 Conclusions

This report shows that for the people we spoke to support after leaving hospital and the ‘7 day follow up’ was not consistent and not always good. It is concerning that some people did not have any follow up at all, but for those who did they have identified what made that support good or not.

People really value the support from a trusted professional and throughout the findings section difficulties in continuity of care through the journey from hospital, follow up on discharge and ability to seek help as needed are alluded to. Where support worked well it appeared to be grounded in trusting relationships with professionals, the person was involved in decision-making about their own care and support, there was clear communication about help available, the person was in control and their choices facilitated. A lack of involvement in discharge planning both of the person and their family, seeing different professionals and being unaware who you are meeting at a 7 day follow up, along with a lack of awareness of a care plan point to what could be the underlying problems in support available.

The intention of the 7 day follow up is to support people in the community after leaving hospital, and the personal stories of those participating in this study provide a valuable insight into the support available. However, addressing the issues highlighted in this report are not confined to this one aspect of support and perhaps encouraged us to think about the broader implications for the way in which people with mental health needs are supported to stay well.

Key findings from the study include:

- Nine of the twelve people interviewed said that they did get a 7 day follow up appointment or visit after leaving hospital. Three people said that they did not;
- Of the nine people who had a 7 day follow up, most took place in the person’s own home. Most people expressed the desire to be supported in their own home, and where this did not occur or could not be facilitated it proved distressful;
- Issues regarding lack of clarity regarding who people were seeing for their 7 day follow up were evident;
Seven of the nine people who said they had a 7 day follow up said that they were given details about the follow up before leaving hospital;

Four people of the twelve people interviewed said that they had no preparation for discharge; two people were unclear or unsure. For the six people who made some mention of discharge planning issues regarding notice of discharge and family involvement were evident;

Although there was a common focus to the 7 day follow up, the experience of the discussion at the follow up was not always viewed positively;

Lack of knowledge, understanding and ownership of care plans was evident. Ten people did not know what a care plan is. Only two people spoke about care planning.

The main themes identified from the qualitative interviews regarding if people thought the support after leaving hospital helped and met their needs include:

- Importance of trusting relationships;
- Feeling supported by the follow up provided;
- Choice, control and flexibility for the individual.

The Patient and Client Council will disseminate the findings of this study with all Health and Social Care Trusts in Northern Ireland, and will work to ensure that mental health services are enhanced and developed in accordance with the issues identified. This is particularly important given that Transforming Your Care (HSCB, 2012) is proposing a vision to continue extending the care provided in the community rather than in hospitals. This change in emphasis from providing care in hospitals to community based support has several implications that learning from this study highlights:

- There must be a recovery-orientated focus to the development of services and support for people with mental illness;
- People with mental health problems value relationships with trusted professionals and continuity of care must be maintained;
- People with mental health problems must be involved as partners in planning their own care and support, with participation of their family carers. Each person should have a care plan which they hold personally.
Further investigation is required to provide an understanding of the continuing support needs of people with mental illness. Members of the Service User and Carer Steering Group and research team will identify further research which arises as a result of this research study.
6.0 Recommendations

The Patient and Client Council make the following recommendations based on the findings of this project:

- The Health and Social Care Board and Trusts should work to ensure that everyone leaving mental health inpatient hospitals have a “7 day follow up” visit after discharge;

- The Health and Social Care Board and Trusts should consider how best to improve continuity of care and in particular patients should have access to a named professional (“trusted professional”);

- The Health and Social Care Board and Trusts should ensure that all mental health service users and their carers / family (where appropriate) are fully involved in decisions regarding their discharge; and

- The Health and Social Care Board and Trusts should ensure that all mental health service users are involved as partners in planning their own care and support, with participation of their carers / family (where appropriate). Each person should have a care plan which they hold personally.
7.0 Bibliography and References


NCISH (2011) National Confidential Inquiry into Suicide and Homicide by People with Mental Illness: Suicide and Homicide in Northern Ireland. Published by The University of Manchester (June 2011).
Appendix 1– Interview analysis response tables

The following tables show how responses to some key prompt questions were broadly categorised when interview responses were subject to qualitative data analysis:

**Did you get a follow up appointment / visit after leaving hospital?**

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<th>Don’t know / Not sure*</th>
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<td>3</td>
<td>1</td>
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* One participants’ recollection was unclear, although the researcher was able to interpret from further information provided whether the person had 7 day follow up or not.

**Where did the follow up take place?**

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<th>Hospital appointment</th>
<th>Own Home (inc. HTT)</th>
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**Were you given details about the follow up appointment / visit before you left hospital?**

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</tr>
</thead>
<tbody>
<tr>
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<td>4</td>
<td>1</td>
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</table>
Did you get contact details for someone to call if you felt unwell after you left hospital?

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<tbody>
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Was there preparation for your discharge / leaving hospital?

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Do you think the support after leaving hospital helped / met your needs?

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