



‘Your Story Can Change Lives’

Regional Audit of the Experience of Users & Carers within Mental Health Services

Standards 10-26: Mental Health & Wellbeing Service Framework

June 2013

Foreword

'Your Story Can Change Lives'

Welcome to this unique publication which provides the views of those who use and access our mental health services in N.Ireland. Over 700 people, including both service users and carers, responded to the regional audit which was undertaken over a four month time frame from August to October 2012. The audit was undertaken to provide information about people's experience of mental health care – this included both care provided by primary care and also by hospital/community mental health teams.

The background to the audit was the Mental Health and Wellbeing Service Framework published in October 2011 (DHSSPS). The Framework contains a range of standards regarding mental health care service provision. An important feature of the Framework is to track the 'performance' and quality of mental health service provision over time. Historically there has been a lack of good quality information about mental health services, in particular from a service users and carers point of view. This led to the *'Your Story Can Change Lives'* audit.

The issues raised by the audit, and highlighted in this report, tell us about services in 2012. The need for 'good communication', 'shared care', and 'timely information' are all amenable to action. We are therefore hopeful that progress can be made to tackle these issues.

Our plan is to act on these findings and repeat the audit in 2015. During the upcoming 2-3 year period a number of measures will be undertaken: the first step is that each HSC Trust in N.Ireland will develop and take forward an action plan – this will be developed in partnership with service users & carers. These local plans will aim to address what the audit findings tell us about services in each Trust. The action plans will be taken forward by each Trust as part of their Recovery development process (Implementing Recovery through Organisational Change - ImROC). Following this process we will then repeat the audit process in 2015.

On behalf of the regional project group, which led the audit, I would like to thank all those who responded to the *'Your Story Can Change Lives'* audit – your contribution has provided the important foundation for this work and we hope that it will lead to real change in service provision. I would also like to thank all the members of the regional steering group that helped take forward the *'Your Story Can Change Lives'* audit development work over the last year – thank you.

Dr Stephen Bergin

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EXECUTIVE SUMMARY

'Your Story Can Change Lives' is an audit of user and carers experience undertaken by the Guidelines and Audit Implementation Network (GAIN) in partnership with the Public Health Agency (PHA) and the Health and Social Care Board (HSCB). The audit which originated with the Mental Health and Wellbeing Service Framework (DHSSPS, October 2011). Standards 10-26 of the Framework cover "improving the experience of users and carers". The audit was undertaken to find out how services were performing in relation to these Standards, specifically from a service user and carer perspective.

The audit had two sections (a) a series of 9 questions developed by a regional steering group of users, carers, Trusts and other HSC organisations, along with the voluntary sector/community groups; and (b) alongside the questionnaire the audit also enabled users and carers to 'tell their story' about their experience of mental health services over the last 3 years. Between 6th August and 9th November 2012 720 experiences were collected across N. Ireland. The data was analysed using the Sensemaker software package which was able to analyse both the qualitative and quantitative information gathered. Analysis of the stories provided by service users and carers provided evidence in relation to what people value when recovering from treatment and care for mental health problems (pages 27-40). Their stories and personal experience highlights that people value:

- Being treated with dignity and respect
- Being listened to by professionals
- Having continuity of care

Next Steps

The audit findings demonstrate a varied picture of how service users and carers perceive their experience of mental health services and care in N.Ireland. This provides a baseline from which, following implementation of local action plans to address these findings (see pages 23-26), we will be able to track improvement and repeat the audit in 2015. The information from the audit will help professionals and managers within Trusts to identify what is working well and what things need to change. The local action plans that each Trust will develop will feed directly into and become an integral part of the new regional Recovery focused service project:

- *From April 2013 the 'Implementing Recovery through Organisational Change' (ImROC) programme will commence. Within this process the 5 Trusts will aim to develop more recovery focused practice in order to improve the service user and carer experience. The information gathered through this audit will therefore assist Trusts in this work.*

Given the implementation of local action plans and the ImROC development process we hope that the experience of service users and carers will improve and that this can be demonstrated when the audit is repeated in 2015.

Recommendations

- The data from this audit should feed directly into the Recovery focused service project that is being undertaken within each HSC Trust, ie. Implementing Recovery through Organisation Change (ImROC).
- Each HSC Trust should consider the information provided by the audit and develop a local action plan to address the issues highlighted – the actions in these plans should be implemented in conjunction with the local ImROC development process.
- There should be a re-audit of services user and carer experience by 2015.

INTRODUCTION

Mental illness is one of the major causes of ill health and disability in Northern Ireland. Around 1-6 people in the province will have some form of mental illness during their lifetime⁽¹⁾. Most of these people will receive care and treatment in Primary Care but some will on go to have their care delivered by specialist mental health services in the community or in hospital.

Everyone who receives care whether in the community or in hospital has a story to tell about their experience. Some people have a good experience, some a bad one, and others have a mixed experience. It is important to listen to what people say so that services can be improved.

Policy Context

The 'Bamford' Review of Mental Health and Learning Disability was launched in 2007 and set out the vision for mental health services for the proceeding 10 to 15 year period.

The Department of Health and Social Services and Public Safety (DHSSPS) first 'Bamford' action plan followed in October 2009. This signalled the formal date for implementing the Bamford Review. The second 'Bamford' Action plan was agreed in 2012.

The Mental Health and Wellbeing Service Framework was launched in October 2011. The Framework has 58 standards which are consistent with the Bamford vision and is being implemented in parallel with the Bamford action plans.

The PHA and HSCB are both responsible in partnership with Health and Social Care Trusts (HSCT) with implementing the standards over a 3 year period from April 2012.

Measuring the Mental Health and Wellbeing Service Framework

Gathering information to measure and monitor the mental health and wellbeing framework has proved to be very complex.

Each standard has performance indicators (PIs) along with quantifiable measures that assess/measure the extent that each standard is implemented. (Appendix 1)

Developing the performance indicators has been very challenging for several reasons which include:

- The relatively high proportion of information required is qualitative not quantitative - this is potentially more difficult to objectively measure.
- Consideration of the time/lengthy timescales that it may take to collect information.
- The relative lack of good/robust information systems and standardised databases within Health and Social care.

- The need to avoid duplicating efforts in terms of collecting data.

Essentially many of these PI's have not previously been measured and while some information systems are available, these are limited and likely to provide only a fraction of the quantitative data required. There is relatively little data collected routinely within the HSC that reflects the largely qualitative data required by the Framework's standards.

During the first year of implementation it was agreed by the DHSSPS that two monitoring exercises would take place. These will provide baseline information that could be re-audited in 2-3 years' time. This will assist in monitoring the service to see what is working well and what needs to be changed.

The two monitoring exercises are:

1 - Baseline mapping exercise

This is a self-assessment by Trusts to see what actions, programmes, activities and training has already commenced that will contribute to the implementation of the service framework. This work also encompassed a scoping exercise of what information systems are currently being used in mental health services.

2 – Audit

An audit of the experience of users and carers of services they have had over the past three years since the 1st Bamford action plan was launched.

Methodology Selection

The audit was developed using Sensemaker Software. This enables people to describe their experience by telling their 'story' and then answer some questions (triads) prepared by users and carers.

Audit Design

An audit tool, questionnaire and additional material such as flyer/poster information was designed and developed by the project group which involved users, carers and professionals from all 5 Health & Social Care Trusts and other HSC organisations, along with the voluntary organisations and community groups. These tools were used to capture the personal stories of users and carers who had experienced mental health services over the last 3 years. This included prompts for storytelling and 'signifiers' that would help filter the information such as a story title, keyword to describe the experience and questions which would provide demographic details about the respondents.

Data Collection

A pilot of the questionnaire was facilitated by the Patient Client Council (PCC) and involved users and cares who had not previously been involved in the development of the questionnaire.

Data was collected across Northern Ireland from 6th August through to 9th November 2012, and participants were encouraged to tell as many stories as they felt able to.

When participating online respondents had an opportunity, on the final screen, to submit or delete the story or to tell another if they wished. Of the 720 stories collected 90% of questionnaires were paper versions and were uploaded to the website by GAIN.

Data Analysis

At the end of the data collection period, 720 questionnaires were collected and uploaded to the Sensemaker Software which analysed both the qualitative and quantitative information. The analysis process also involved reading all 720 stories to capture themes and trends to provide raw evidence for the final report.

Results - (Demographic Information)

Figure 1 – Age Profile of Participants

Age Range	Return (n=720)
12-19	4 (1%)
20-29	84 (12%)
30-39	115 (16%)
40-49	189 (26%)
50-59	200 (28%)
60-65	76 (10%)
66+	52 (7%)

Table 2 – Returns by Gender

Gender	Return (n=720)
Male	322 (44%)
Female	393 (54%)
Transgender	2 (1%)
Prefer not to Comment	3 (1%)

Table 3 – Sexual Orientation

Sexual Orientation	Return (n=720)
Heterosexual	589 (82%)
Gay	11 (2%)
Lesbian	14 (2%)
Bi-Sexual	11 (2%)
Prefer not to Comment	95 (12%)

Table 4 – How Common do you think your experience is?

Commonality	Return (n=720)
0 (Rare)	16 (2%)
1	13 (2%)
2	35 (5%)
3	126 (17%)
4	146 (20%)
5 (Very Common)	234 (33%)
Don't Know	150 (21%)

Table 5 – Ethnic Group

Group	Return (n=720)
British	323 (45%)
Irish	311 (43%)
Any other White Background	37 (5%)
Chinese	2 (0.5%)
Traveller Community	3 (0.5%)
Other Ethnic Group	6 (1%)
Not Recorded	38 (5%)

Table 6 – In which setting did your experience occur?

Setting	Return (n=720)
At Home	200 (27%)
Local Centre in the Community	121 (17%)
Hospital Ward	135 (19%)
Outpatient Clinic	114 (16%)
Other	150 (21%)

Table 7 – In Which Health & Social Care Trust area did this experience take place?

Trust Area	Return (n=720)
Belfast	184 (25%)
Northern	115 (16%)
Southern	166 (23%)
South Eastern	138 (19%)
Western	104 (14%)
Regional Service	1 (1%)
Don't Know	12 (2%)

Table 8 – What best describes your condition, or the person you care for’s condition at the time of this experience? (Please note some patients had one or more condition):

Condition	Return (n=720)
Depression	362 (56%)
Anxiety Fears Phobia	178 (28%)
Schizophrenia	144 (23%)
Self Harm	121 (19%)
Psychotic Illness	117 (18%)
Bipolar Disorder	96 (15%)
Bereavement/Grief	84 (13%)
Alcohol Misuse	69 (11%)
Obsessive Compulsive Disorder	61 (9%)
Personality Disorder	56 (9%)
Eating Disorder	55 (9%)
Post Traumatic Stress	53 (8%)
Don’t Know	49 (8%)
Other	33 (5%)
Substance Misuse	31 (5%)
Postal Natal Depression	16 (3%)
Gambling Addiction	13 (2%)
No Reply	33 (5%)

Table 9 – Which of the following Professionals and Support Services were involved with you? (Please note some patients had one or more services):

Services	Return (n=720)
Psychiatrist	433 (60%)
GP	390 (54%)
CPN	274 (38%)
Social Worker	223 (31%)
Nurse	215 (30%)
Voluntary Organisation	129 (18%)
Counselling	107 (15%)
OT	102 (14%)
Psychologist	97 (13%)
Other	90 (13%)
Day Hospital	86 (12%)
User Support Group	56 (8%)
Helpline	55 (8%)
Advocacy	55 (8%)
Church/Faith	49 (7%)
Dietician	34 (5%)
Community Group	27 (4%)
Health Visitor	21 (3%)
Don't Know	20 (3%)

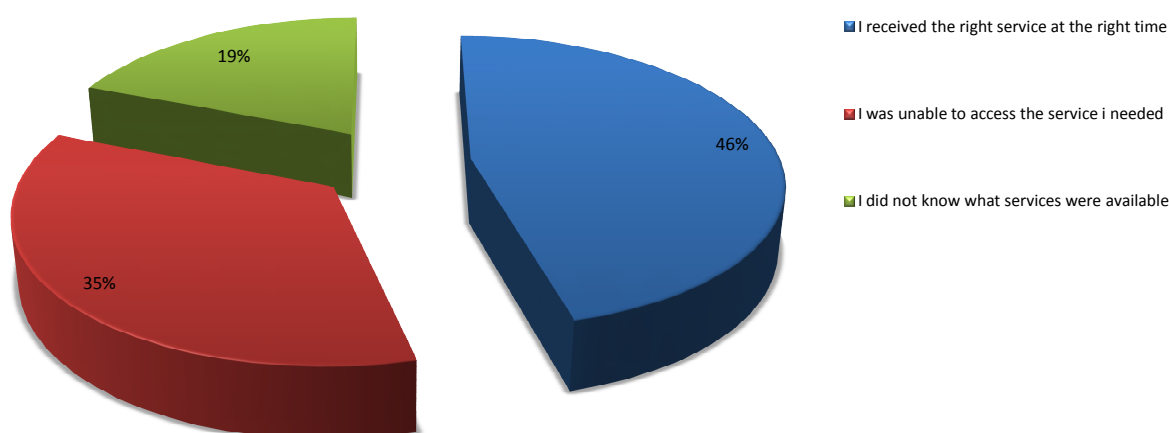
Regional Results of the 9 Questions

A number of questions were illustrated by triangles (triads) with a statement at each angle. To answer these questions, the participant had to place a mark within the triangle, on or between the statements that best represented their response. The mark placed in the triad was given “link strength” by the software thus helping identify in analysis the strength of opinion and emotions linked to the respondents’ story. The software also allowed identification of other stories that shared similar indexing.

Question 1: Where you able to access the services when you needed them?

(Please note this was applicable to 622/720 (86%) stories).

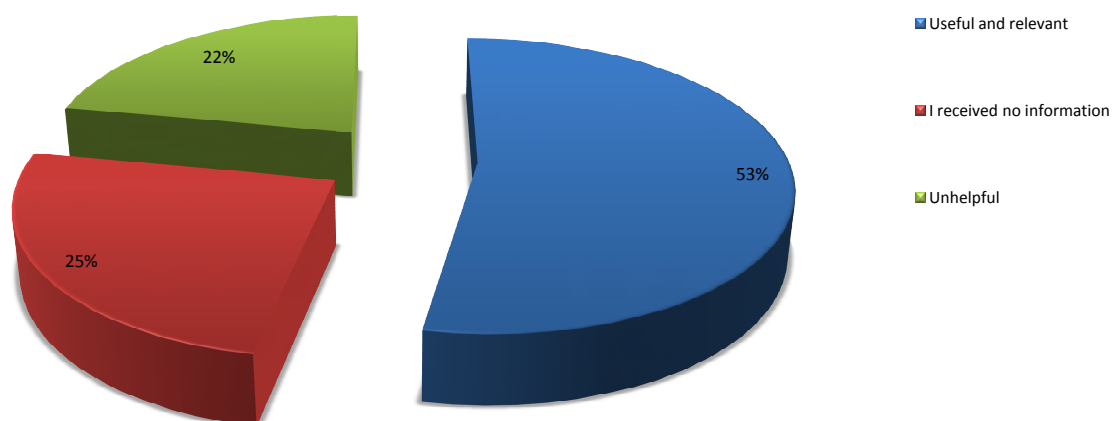
All 5 Trusts	No. of stories (n=622)
I received the right service at the right time	285 (46%)
I was unable to access the service I needed	216 (35%)
I did not know what services were available	121 (19%)



Question 2: How was the information provided to you by staff in mental health services?

(Please note this was applicable to 645/720 (90%) stories).

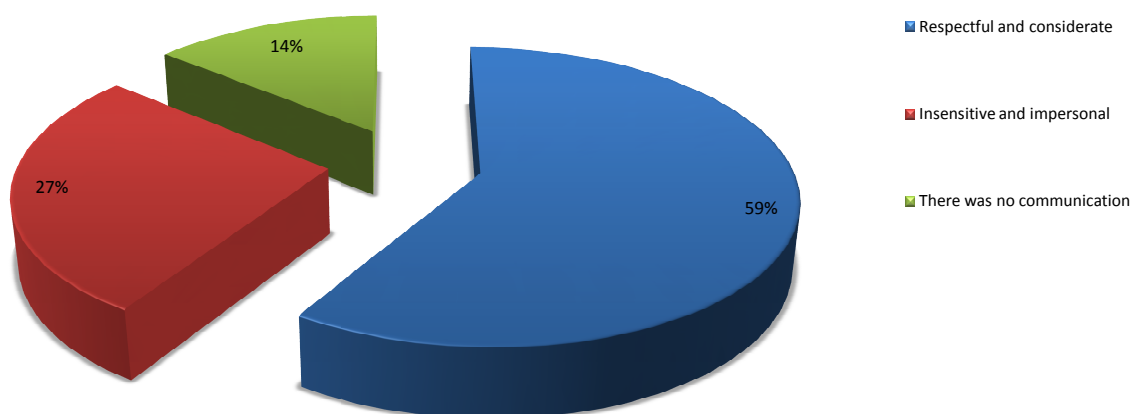
All 5 Trusts	No. of stories (n=645)
Useful and relevant	344 (53%)
I received no information	162 (25%)
unhelpful	139 (22%)



Question 3: How did the staff in mental health services communicate with you?

(Please note this was applicable to 658/720 (91%) stories).

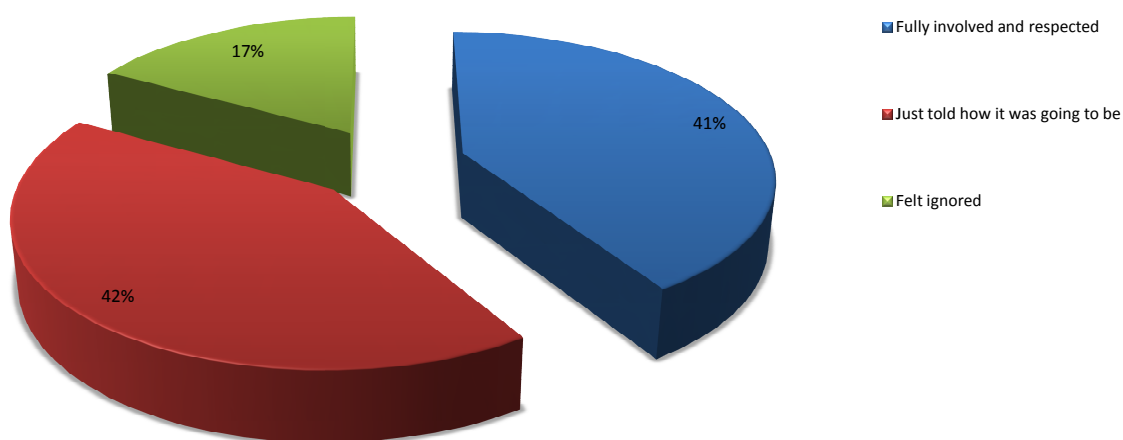
All 5 Trusts	No. of stories (n=658)
Respectful and considerate	391 (59%)
Insensitive and impersonal	177 (27%)
There was no communication	90 (14%)



Question 4: How involved were you in care planning and treatment?

(Please note this was applicable to 657/720 (91%) stories).

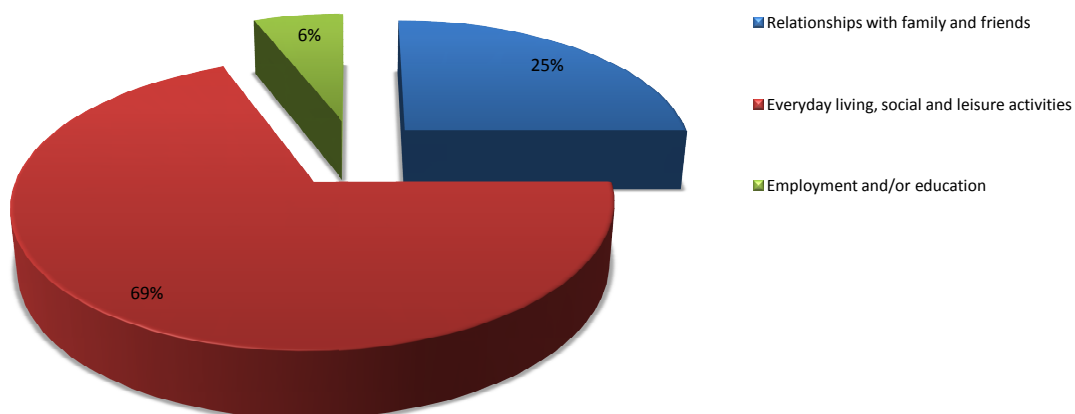
All 5 Trusts	No. of stories (n=657)
Fully involved and respected	272 (41%)
Just told how it was going to be	274 (42%)
Felt ignored	111 (17%)



Question 5: Which area of your life was impacted most in this experience?

(Please note this was applicable to 652/720 (91%) stories).

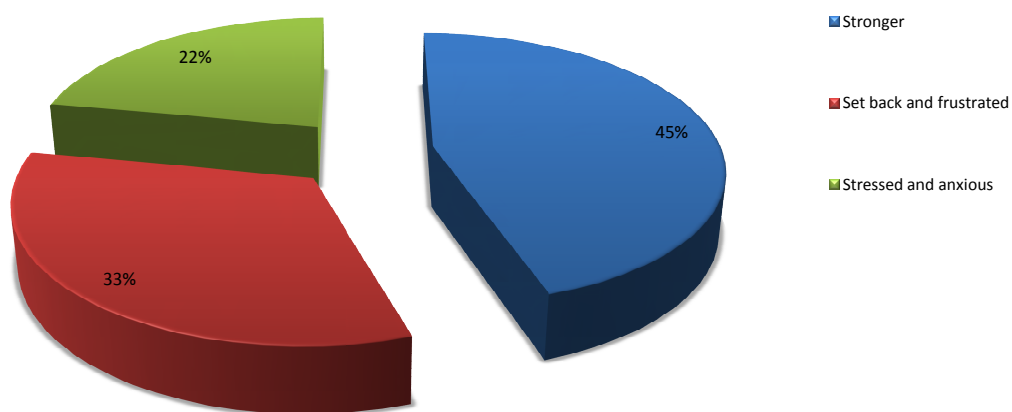
All 5 Trusts	No. of stories (n=652)
Relationships with family and friends	160 (25%)
Everyday living, social and leisure activities	453 (69%)
Employment and/or education	39 (6%)



Question 6: How has this experience of mental health services left you feeling?

(Please note this was applicable to 679/720 (94%) stories).

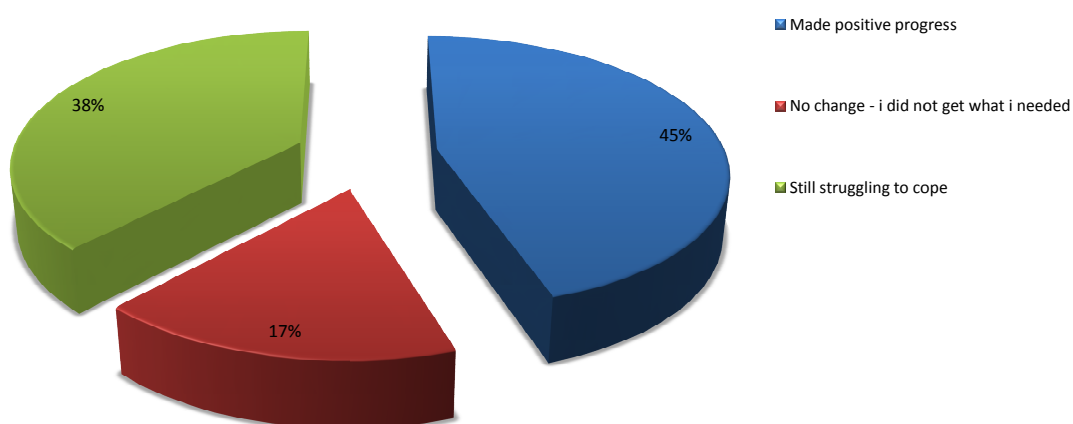
All 5 Trusts	No. of stories (n=679)
Stronger	308 (45%)
Set back and frustrated	224 (33%)
Stressed and anxious	147 (22%)



Question 7: What was the outcome of this experience for you?

(Please note this was applicable to 662/720 (92%) stories).

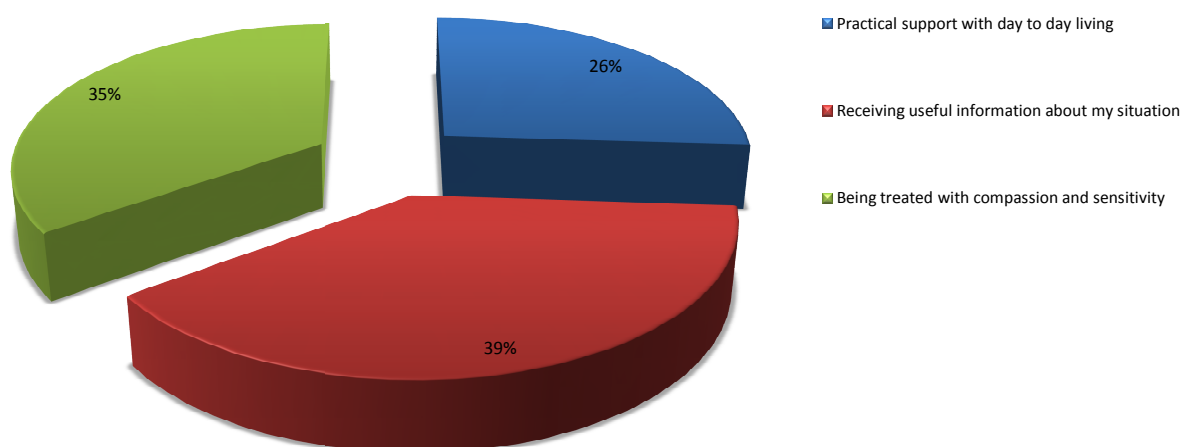
All 5 Trusts	No. of stories (n=662)
Made positive progress	300 (45%)
No change – I did not get what I needed	113 (17%)
Still struggling to cope	249 (38%)



Question 8: What would have made the biggest difference to you in this experience?

(Please note this was applicable to 619/720 (86%) stories).

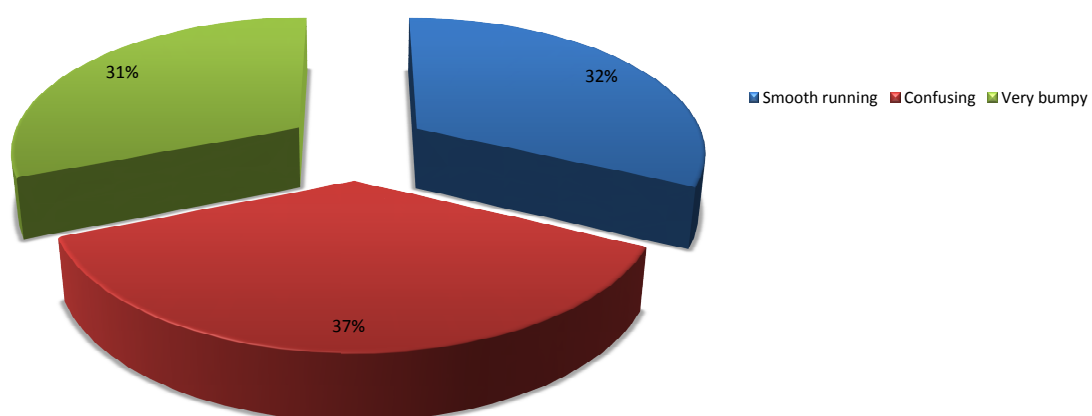
All 5 Trusts	No. of stories (n=619)
Practical support with day to day living	160 (26%)
Receiving useful information about my situation	240 (39%)
Being treated with compassion and sensitivity	219 (35%)



Question 9: Thinking about this experience how would you describe your journey within mental health services?

(Please note this was applicable to 672/720 (93%) stories).

All 5 Trusts	No. of stories (n=672)
Smooth running	215 (32%)
Confusing	249 (37%)
Very bumpy	208 (31%)



Summary of Regional Results

Question 1: Where you able to access the services when you needed them?	Overall NI Figure (CI's)
I received the right service at the right time	46% (42%-50%)
I was unable to access the service I needed	35% (31%-38%)
I did not know what services were available	19% (16%-23%)
Question 2: How was the information provided to you by staff in mental health services?	Overall NI Figure (CI's)
Useful and relevant	53% (50%-57%)
I received no information	25% (22%-29%)
Unhelpful	22% (18%-25%)
Question 3: How did the staff in mental health services communicate with you?	Overall NI Figure (CI's)
Respectful and considerate	59% (56%-63%)
Insensitive and impersonal	27% (24%-30%)
There was no communication	14% (11%-16%)
Question 4: How involved were you in care planning and treatment?	Overall NI Figure (CI's)
Fully involved and respected	41% (38%-45%)
Just told how it was going to be	42% (38%-46%)
Felt ignored	17% (14%-20%)
Question 5: Which area of your life was impacted most in this experience?	Overall NI Figure (CI's)
Relationships with family and friends	25% (22%-28%)
Everyday living, social and leisure activities	69% (66%-73%)
Employment and/or education	6% (4%-8%)
Question 6: How has this experience of mental health services left you feeling?	Overall NI Figure (CI's)
Stronger	45% (42%-49%)
Set back and frustrated	33% (30%-37%)
Stressed and anxious	22% (19%-25%)
Question 7: What was the outcome of this experience for you?	Overall NI Figure (CI's)
Made positive progress	45% (42%-49%)
No change – I did not get what I needed	17% (14%-20%)
Still struggling to cope	38% (34%-41%)

Question 8: What would have made the biggest difference to you in this experience?	Overall NI Figure (CI's)
Practical support with day to day living	26% (22%-29%)
Receiving useful information about my situation	39% (35%-43%)
Being treated with compassion and sensitivity	35% (32%-39%)
Question 9: Thinking about this experience how would you describe your journey within mental health services?	Overall NI Figure (CI's)
Smooth running	32% (29%-36%)
Confusing	37% (33%-41%)
Very bumpy	31% (28%-34%)

Summary of Results for each individual HSC Trust *

<u>Question 1: Where you able to access the services when you needed them?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	Overall NI Figure CI's
I received the right service at the right time	40%	46%	42%	57%	49%	42% - 50%
I was unable to access the service I needed	37%	46%	41%	23%	24%	31% - 38%
I did not know what services were available	23%	8%	17%	20%	27%	16% - 23%
<u>Question 2: How was the information provided to you by staff in mental health services?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	CI's
Useful and relevant	45%	57%	43%	68%	65%	50% - 57%
I received no information	31%	27%	25%	19%	20%	22% - 29%
Unhelpful	24%	16%	32%	13%	15%	18% - 25%
<u>Question 3: How did the staff in mental health services communicate with you?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	CI's
Respectful and considerate	50%	59%	53%	77%	68%	56% - 63%
Insensitive and impersonal	37%	26%	32%	16%	19%	24% - 30%
There was no communication	13%	15%	15%	7%	13%	11% - 16%
<u>Question 4: How involved were you in care planning and treatment?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	CI's
Fully involved and respected	35%	39%	36%	58%	45%	38% - 45%
Just told how it was going to be	45%	40%	44%	33%	46%	38% - 46%
Felt ignored	20%	21%	20%	9%	9%	14% - 20%
<u>Question 5: Which area of your life was impacted most in this experience?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	CI's
Relationships with family and friends	26%	24%	23%	31%	16%	22% - 28%
Everyday living, social and leisure activities	65%	71%	68%	64%	81%	66% - 73%
Employment and/or education	9%	5%	9%	5%	3%	4% - 8%
<u>Question 6: How has this experience of mental health services left you feeling?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	CI's
Stronger	38%	47%	33%	58%	57%	42% - 49%
Set back and frustrated	37%	33%	46%	23%	21%	30% - 37%
Stressed and anxious	25%	20%	21%	19%	22%	19% - 25%

<u>Question 7: What was the outcome of this experience for you?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	CI's
Made positive progress	39%	48%	42%	56%	54%	42% - 49%
No change – I did not get what I needed	23%	17%	23%	6%	12%	14% - 20%
Still struggling to cope	38%	35%	35%	38%	34%	34% - 41%
<u>Question 8: What would have made the biggest difference to you in this experience?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	CI's
Practical support with day to day living	25%	25%	25%	34%	17%	22% - 29%
Receiving useful information about my situation	40%	39%	37%	34%	49%	35% - 43%
Being treated with compassion and sensitivity	35%	36%	38%	32%	34%	32% - 39%
<u>Question 9: Thinking about this experience how would you describe your journey within mental health services?</u>	BHSCT	NHSCT	SHSCT	SEHSCT	WHSCT	CI's
Smooth running	23%	33%	29%	41%	39%	29% - 36%
Confusing	36%	39%	40%	40%	32%	33% - 41%
Very bumpy	41%	28%	31%	19%	29%	28% - 34%

* Projects rely upon a sample of the overall total population; Confidence Intervals (CI) are often used to identify the likely range within which the true/real population response would lie. Therefore from a statistical perspective the CIs provided in the below table identify the likely range within which we can be 95% certain that the true/real population response to the relevant question lies.

Key Themes & Trends identified from the 720 stories

This section contains extracts from the stories as they have been told by the users or carers. A number have been edited to maintain anonymity and to reduce length. These stories were read and themes taken from them.

There are many ways that this section could have been presented. We have chosen to theme the stories in two ways:

- 1 – What is valued or not valued across the service by users and carers
- 2 – Experiences of users and carers in different parts of the service.

Respect & Dignity

People valued being treated with respect and dignity.

Quote – *My recent admission to hospital was positive; I felt I was treated with respect in the hospital and in the community. Since discharge there has been better support from my Key Worker and have had referrals to support agencies which give me a focus and structure to each day.*

Quote - *I've a good relationship with my CPN although I can't talk to my consultant as he is aloof and doesn't seem to have time. I found that I felt the consultant wasn't listening to me, he wanted me in the door and then out. I felt belittled and humiliated by this experience, but i kept thinking at least I'm not going into hospital as it can be scary.*

Quote – *My Key Worker was very insensitive, unsupportive and made me feel I have no real problem, to which I even doubted my own diagnosis, discharged soon after. Crisis occurred, attempted to take life.*

Quote – *Staff can be judgmental and tactless.*

Communication

People valued being **listened** to.

Quote – *Staff attitudes were excellent and staff very supportive and reassuring. I felt supported and listened to by all members of the care team. Felt involved in all aspects of my care, had a very positive experience.*

Quote - *I attended a local restaurant for a cup of coffee with my social worker. We had a talk about current affairs and how i am managing my condition. The outcome was a better understanding of what im going through for my social care worker. Learning how to cope with my condition had a big impact on me and my family.*

Quote – *I feel like I've been talked to, not listened to. Feel like am being pushed to the side or I'm problematic.*

Quote – *The Doctor in question did not make eye contact, not even once, while I was relaying to him how ill my husband was. I brought this to his attention; he assured me he was listening to me. **I WONDER!!***

People valued Information especially in relation to medication & services

Quote - *I was not given any information on necessity and side effects, because of this I did not encourage my relative to continue to take his medication. Consequently he had a relapse. I do not blame myself but staff. I was never told medication needed to be ongoing.*

Quote – *When my loved one tried to access services and information, he constantly hit brick walls.*

Quote - *While an inpatient my medication was increased from 60mg per day to 90mg as a result of this my blood pressure dropped severely after discharge. I started fainting and ended up in a general hospital for 6 days before my BP was stabilized. When asked the Psychiatrist and CPN about the affect of the increase of meds on my blood pressure no one could give me an answer.*

Quote - *I suffered from a series of traumatic events over a space of several months. I went to my GP who listened and offered me medication. On the course of visiting my GP the asked me if I would like to see a CPN. Whilst apprehensive I went and had a really positive experience. She was patient and understanding and left me feeling that she really cared. She also signposted me to other services that has been a lifeline to me and continues to be. I don't think I would have recovered as quickly without the GPs or CPNs expert help.*

People valued Continuity of Care

Quote – *My consultant has moved to the Wards, following this when I go for my 3 month appointments I see a different consultant each time. This has led to me seeing 5 different consultants. There is definitely a lack of continuity of treatment. The doctors were going to make changes to my medication but I felt these were not informed choices since they did not know my case as fully as I would like.*

Quote – *I have been using mental health services for years. At first I had my own CPN but over the last 2 years I have had nurses and social workers coming but not staying for long. Now I don't even try to get used to them and I wouldn't even tell them how I feel. **You just feel like a number!!***

Need for consistency in Outpatient Services

Quote - *I went to see psychiatrists on numerous occasions. Each time I went, every single time was a different doctor. Every time you would have to start over from scratch, which was very frustrating. It felt I was never moving on and given more medication each time I went. I feel if I had seen the same doctor a relationship could have developed and I would have felt like I had been listened to.*

Quote - *I have been using the MH services a long time. It has been in last number of years the CPN's are not staying. I get used to one then they move. I am not saying that they are bad, most of them are so nice and do a great job. It is when a new one comes i have to tell them everything again. I know it is not their fault. That is how they get to know us but do they need to ask the same thing all the time. Do they not read my notes or do they have to talk to you first before reading them? I know this sounds bad but i feel some time they just want to see the pain. I am sorry but that's how it feels to me. It would be far nicer if they knew a bit about me and came for a chat. I hate doing that list thing.*

Quote - *Psychiatrists appointments. You wait 2/3 months to obtain one. Then 40 minutes in waiting room. Then a 2 minute "consultation". In 2010, I had 6 appts, 6 different female locums or students. All just were over my history for their files/studies. Then 'Are you okay', then out of the door. One doctor even continued walking when I started telling her my story of my crisis. CPN more use monthly.*

Quote - *I go to see my consultant every 3 months. I be sick the night before I go. He will bring you in and ask how you are. When you start to tell him. Just say things are not good or there is something worries me. He does not want to know. You can see it in his face as if to say here we go again. My CPN would till me talk to the Dr (consultant) then he will say are you talking to your CPN. Why do they not talk to each other. I feel I have no one who understands. It is only when I come to this group, you know they get what you are saying.*

Quote - *I'm a service user involved with one of the psychiatrists and I feel like I have been regularly accommodated by my psychiatrist and have been fully involved in my care planning and treatment. I get regular appointments when I feel like I need to see my psychiatrist. I can ring him at any time if I ever need him. I can sort out my medications over the phone and it allows me not to have to travel far. It's of great help to me.*

Quote - *Times I visit the physiatrist he calls me by the wrong name even though my files were in front of him. My CPN had to constantly remind him of my proper name. This left me with no trust or interest as I felt he had no interest in me if he couldn't even read my name.*

Quote - *When I go to the psychiatrist, I never get to see him, I only see a student who is strange to me.*

Quote - *I find myself wanting to attend certain psychiatrist's appointments because I feel an overbearing lack of understanding and empathy on their part. While some are actually quite good, some lack basic common life skills and lack of understanding of someone that lives a normal different life to theirs. Some seem unable to relate to everyday life stresses of patients like myself.*

Need to reduce variation in Inpatient Services

Quote - *I have had a good experience with mental health services. Being a long term patient I can talk particularly about the nursing care I have received. The nurses always do their best to get you out and about, for example cinema and going for meals. The nurses have a good understanding about my illness therefore when I have my ups and downs they know exactly what to do. When I am having a bad day staff tolerate me, talk to me and offer me reassurance and that's important.*

Quote - *The experience that stands out the most is the help and support I received from hospital staff when my mother passed away. At this time I was on a continuing care ward and felt able to talk to nursing and social care staff about my experience and grief. I felt the knowledge and experience of staff helped me greatly and that staff were always available to listen and support.*

Quote

-I was admitted to services in the early hours of the morning

-I was welcomed by a nurse and made tea and toast

-A nurse then sat with me while the doctor examined and admitted me

-I was then shown to my bed area, and made comfortable by staff

-Next morning I was taken to the dining area and shown how the system works

-I was then seen by another doctor who asked how I was feeling and if I had any questions and was I happy to stay in hospital, I said no I didn't want to stay and the doctor then reassured me I was safe from harm and that staff were there to help me

-The staffs are brilliant at their jobs, always calm, kind and considerate

Quote – *I like the security of being in hospital. I like being treated in hospital and not in my own home when I have a crisis.*

Quote - *I have used the mental health services a number of years as an outpatient and as an inpatient. When on the hospital ward you left on your own most of the day the only contact you may have with anyone is being told to come for your medication or that is was time for you for your meals. There is very little interaction from the staff the clients are just left to their own devices.*

Quote – *The admission was very formal and had to fill out forms and check my belongings. I felt completely depersonalised.*

Complaints

Quote - *When in hospital I made a complaint re a consultant. After I did this I felt that I was ostracized by staff and ignored. I then made a complaint about this. The reply was that I was abusive even though I had not been.*

Quote - *My son had taken an overdose. Neither he nor I were treated with care or compassion. Staffs at that time were indifferent and seemed annoyed to be bothered with us. He had to have a blood test within 4 hours. We were left 4 hrs 15 mins and I had to search for staff to take a blood test. Finally a male nurse agreed to do it and he wasn't given privacy to get blood test. (While waiting 4 hours patient was suicidal and wanted to leave and I was left to struggle to keep him in A+E alone) Blood test was taken 15 mins outside of 4 hour period. We were left again hours and had to finally leave around 5am, Later on letter of complaint with help of cause, after investigation - staff lied and said test was taken 4 hours. However with experience of lab testing I knew the time of test was different and proved my story. Very shocked that hospital lied. Felt blamed by investigation for having to leak.*

Primary Care – Reduce variation in Primary Care Services

Quote – *Went to the GP out-of-hours services when I was suicidal and felt like self-harming. There were very good at listening to what I had to say, then the GP got me to see the CPN who was on duty who was also very helpful. I had to go to hospital.*

Quote - *I was introduced to lithium (a new drug) years ago. Initially i was so grateful; my illness was known now as Bipolar. They claimed i would be on this drug for life. Years of blood tests insured but finally approx fours ago lithium went wrong for me. It proved toxic and i was in hospital lots of times. This period of my life was terrible, i was so ill, finally my GP's wrote to psychiatrist, stressing their concern of this drug on my physical health. The tides have finally turned, i have been lithium free from 22nd February, coupled with my social worker and community support worked, my life is now so much better and brighter. My dark cloud is lifting and for the first time i am feeling joy and happiness. I know i will always be on medication for depression, will always have up and downs but am now feeling more confident for my future.*

Quote – *When I first went to the doctors to talk about my mental health, the reaction I had my very upsetting. When I began to get upset she offered no consolation what so ever. The only help she offered was a leaflet on depression and anxiety and asked if I want to go on anti-depressants. She didn't even suggest counselling. I was shocked at how little empathy I received.*

Quote - *My doctor just didn't seem to have the time to listen - it was do you need more medication? If not see you in 2 months! I didn't know if i needed more medication, that was not my job, i seemed to be taking up their time for all the wrong reasons.*

Community Mental Health Team

Quote – *I was thankful to the CPN and mental health team that I could stay at home.*

Quote – *I have a CPN who is very good to me. He listens to me and my husband. When I go into hospital he phones my husband to see how he is. When I listen to others talk about their mental health workers I am horrified about some of things they tell me. I feel so lucky to have mine. **Why do all the workers not do the same?***

Carers valued being involved in their families care and treatment

Quote – *As a carer I was well supported in my efforts to care for my wife and was also kept in the picture in how to deal with things as they came up. My counsellor also made me aware how to look after my own mental health as matters like this have know to be a trial for everyone being involved. My wife was in a dark place and without the professional help of mental health services I don't know what we would have done.*

Quote – *After caring for someone with serious mental illness for a long time we were allocated a new social worker who changed everything with her attitude and creative thinking towards problems, and open attitudes to trying things and working closely with the family.... She helped me and my family understand the illness, but most importantly helped us see how the person we cared for had many strengths and got to feel proud of her again, instead of thinking of problems all the time. Our personal relationships improved with understanding and released a lot of pressure for everyone.*

Quote – *We have problems going to the psychiatrist and giving legitimate concerns as this would break patient/client confidentiality.*

Quote – *With consent the Carers need to know about medications. What the problems are etc... since they really carry a burden and maybe devastated.*

Quote - *I was being treated at home by the home treatment team they came to me every day for about 2 months. Although there input was great I felt they could have included my carer in my treatment more as when the team left my carer was the person looking after me. I did not get referred to the community consultant for quite some time after the team finished with me.*

Need to improve experiences in other areas of Physical and Mental Health Care:

General Acute Care

Quote - *I recently had to see a consultant about a physical illness. Because i also had a mental illness the consultant and other medical professionals ignored a lot of the physical medical evidence and repeatedly suggested that my condition was psychosomatic. I was faced with this attitude every step of the way, and i was only listened to when it was too late and i am now having to live with a serious physical condition that could have been avoided had their judgement and actions not had been affected by their inability and unwillingness to put the fact that i had a mental illness to one side. I was also angered by the way i was spoken to as if i was less intelligent than someone who didn't have a mental illness. I regret ever seeking help for any mental illness as i feel that simply having it on my medical records has disadvantaged me and will do in the future. Do these professionals not realise that someone with a mental health illness is every bit as lucky to have a physical illness as anyone else. This mindset must cease.*

Quote - *I had an experience when I was in a mental health hospital ward where I had a stroke; I then had to leave to go to casualty in another hospital for treatment. I then was put into a ward within the same hospital where I feel that due to the fact I suffered with a mental illness that I was treated differently by staff. I was alienated on the ward which had set me back quite a bit with my condition. I really just wanted to return to the mental health ward where people had been treating me with utmost dignity and respected my circumstances.*

Day Services

Quote - *I was worried sick because my ESA stopped and then I got a letter saying my housing benefit would stop and I phoned and left a message for my social worker and he got back to me within 10mins and arranged to come and visit me. I was also able to share this crisis with a support worker in day centre, which really helped. The day centre was a vital link to me socially for a year or so.*

Quote - *I go to the Day Centre. It helps me the staff are great. Why are they closing them. I was told they were closing all in 2 years. What am I going to do. I don't want to go to AMH this is all about the money cutback. They say it will help us. This is recovery. What is recovery got to do with me. I have been like this for years. My Dr told me I will never get better. I am on all kinds of tablets. Who do they think they are talking too. No one is asking me what I what, it's all money.*

Quote - *I was at the Day Hospital for about 4 weeks. My experience was very positive. I felt MUCH CARE AND ACCEPTANCE from the staff and other patients and was able to be a part of some baking crafting and games. I felt that I was truly accepted and valued as a person and was inspired to do craft and had a better outlook on life.*

Quote - *I attend a mental health day centre. Over the past few months there has been a reduction in staff. This causes distress as there is not the same support available. What staff are on duty are as helpful and supportive but over-stretched.*

Crisis Services

Quote - Relative agitated, insisting on walking out into dark streets fireworks going off in highly agitated state. After 5pm no recovery team support available. Phoned home treatment as relative known to HTT, standing by front door to prevent relative from leaving home. Phone answered by CPN in HTT Told I had to phone out-of-hours, Asked to speak to senior person on duty who was able to describe relative and well aware of illness Advised to contact Ex husband to take relative to him. By this stage I broke down and cried, advised to keep calm and phone out-of-hours.

Quote - I used to have a CPN who would call at my house. For a year now I have to go and see them. I don't mind but sometimes I can't get out the house. My wife phoned one time to tell them I could not go. She was told if things get worse to phone back. If it is after 5pm to contact out-of-hours. When my wife give off. They said a new appointment will be sent out. A week later I ended up being seen by home treatment. Why did they not come out when my wife ring. Is this what is called recovery.

Quote - Being in great distress and suicidal at a day care centre the manager contacted crisis response by end of the day centre closing there was still no word from crisis team. Centre Manager contacted my husband to come collect me and take me home and supervise me at all times. As day progressed I deteriorated and contacted GP explained about crisis response he contacted them then informed me to be at out of hours for 8pm. This was 5.30 and crisis response were contacted at 10am. At 8pm my family took me to see crisis response. I had to wait an hour half. by this time I was very very unwell, my anxiety levels were extremely high causing me to go into a panic attack. When I finally got to see the team I was extremely agitated and suicidal. the crisis team told me I was 40 yrs of age and an adult and I could choose which pathway to take and sent me home that night I took an attempt on my life and had to be hospitalised.

Quote - Out of hours Doctor - always willing to talk to me about my wife's illness / crisis whenever i have called in the middle of the night. Doctor at 'out of hour' surgery - responds quickly - get to see a doctor in good time after initial phone call. Feel reassured that as a carer, if something happens in the middle of the night or at weekend i can still call out of hours and get a quick response.

Voluntary Services

Quote - I come to **** for information and support. Without them i would not know what is happening in MH services. I know there is someone here to talk to who knows what it is like. My CPN is good but does not understand. He is always in a hurry. This wee place has help me out lots of times.

Quote - Since starting *** services in Belfast I have had no contact from S. Worker and little support from Mental health team. I have support - which is excellent and always there any time of the day. All I need is to pick up the phone and talk to my key worker.

Quote - the staff are very helpful, help build relationships between me and professionals, help make my goals a reality.

Day Hospital

Quote - I go to the day hospital 2 times a week. I use to go everyday Monday to Friday. I found sometimes helpful, but would like to do more stuff to help my mind and help me get better. I also found the staff helpful. But I need more help with personal issues and feel the day hospital could help.

Quote - I attend a mental health day centre. Here i get to meet other people like myself, i also get to take part in classes and go away on trips. This helps my confidence and helps my mood stay stable.

Quote - I am not happy with all the changes that have been happening in the Beacon Centre, all our classes but one has been put outside of the Beacon centre. I always looked forward to attending the centre for a chat and seeing the other clients that i have made friends with over the years. The staff have no longer the time to spend with you for a chat or even notice that maybe you're not having a good day. Cut backs has stopped all our trips and activities. I am too scared to speak out about this as I'm afraid of being dropped by mental health and having no support, really its only the fact that i still have a small number of classes that i look forward to and this is my opinion is what keeps me out of hospital taking up a bed for months on end.

Quote - My mum was referred to the day hospital a little while ago by a member of the community addictions team. She had a stroke around 6 months before due to an overdose of medication and she was very depressed, anxious and withdrawn and still drinking heavily. She was very anxious about starting at the day hospital because it meant leaving the house and meeting new people. Neither of which she thought she could cope with. The centre staff met with her on the first day and were really lovely to her and stayed with her until she felt comfortable enough to stay on her own. My mum had gone to the centre with the attitude of only going once to get her case worker off her back as she put it. If the staff had not been so caring and attentive on that first day and every other since, she would have never gone back, therefore removing the first real support system she has had for her mental health problems. My mum now really enjoys going to the centre as she has made friends there and the staff are so supportive if she is having a bad day.

CAMHs

Quote - This experience happened between the months of May 2008 - April 2009. I was 17 years old and was going through what i can only describe as a mental breakdown. One day i reached breaking point and tried to end my own life by taking a massive overdose. My failed attempt resulted in me being admitted to a adolescent mental health Ward. Throughout my 11 months there i underwent regular psychology, one to one with a mental

health nurse to discuss my mood and any worries i had on a daily basis, also weekly meetings with a consultant to discuss medication. For a lot of my time there i was seen as a risk to myself and others so was kept on 2:1 observation. My care plan every week depended on whether i was well enough to participate in OT and other activities on the Ward. Unfortunately i continued to become an even greater risk to myself and others, so the decision was made to transfer me to a specialist secure unit in England until i was well enough to return home. Throughout my time in hospital i found staff very helpful and caring, some staff may at times have been a little insensitive and unhelpful but as i was there for a long time, i got to know which staff i felt comfortable to talk to. At the end of that experience i came out a stronger person. The whole thing was a very traumatic but necessary experience.

Quote - My son became very ill with depression, psychosis and OCD .He was just 17. we were sent initially to a crisis centre where the staff were brilliant with him and myself. We were quickly referred to a CAHMS unit where we were cared for by an excellent team - a psychiatrist who was supportive, understanding, and who reviewed us as a family very frequently and involved us and all decisions. She was always at the end of the phone which gave me such comfort. A clinical psychologist who used CBT with my son for a year was amazing and had such skill and talent with young people. A specialist nurse helped my husband and I cope with the situation on a regular basis .It gave us a chance to someone who understood. The teamwork was fantastic. Eventually we went to adult services which was difficult at the start as they didn't have the same time to spend and didn't involve the whole family. After asking for support we got a psychiatric nurse with whom my son built up a good relationship and he was seen by the doctor 3 monthly mainly for medication purposes. He is much better now thanks to early intervention and great care.

Advocacy services

Quote - I care for my son who self harms and has depression. I can see the signs now and I seek help from advocate and family members. He becomes very anxious and would hit out at people then he would self harm himself. In the past I found it very hard to get help for him as it was usually A&E. I had to take him to our own GP, but thankfully now I have the support of an advocate worker who is great and can call on day or night. As before when I had to go to A&E and wait for hours to be seen to be sent home again and told to watch him myself were now I have support.

Accident & Emergency

Quote - While I know A&E is understaffed & under pressure someone could have taken a few minutes to let this young girl know she was important. I work with young homeless people 16-25. In 2011 I spent 5 hours in A&E with a young girl in crisis she was taken to a cubical where the curtains were closed and during that time no one come to speak to her or reassure her that she would be seen soon. I feel that this is too long for someone in despair to wait. If I had not stayed I believe she would have left & the consequences may have been tragic. (There was no illicit drug use with this young girl)

Quote - One night i went to A&E, just felt terrible didn't want to be here anymore and wanted some kind of help. When i went in and seen the nurse i told her how i was feeling and she asked me do i use mental health services and when i said yes her attitude changed. I know i have a diagnosis of a mental illness but that was not the reason. I was there; i just wanted someone to help me with how i was feeling. She said she would get someone to see me and would i wait outside. 6 hours later i was still waiting, someone from the mental health team came, i spoke with him, he said he'd get me an appointment with my doctor i told him it was not my mental health. He asked me did i have a plan, i told him i didn't need a plan. He said he'd phone me the next day then he left. On my way home i met a friend, told him what had happened, he made a plan with me on how he could help and I'm still here today. Why cant mental health professionals do simple things like that.

Quote - Nurses should not treat people who self harm as time wasters or feel they can pick on them. My daughter was admitted to hospital after an overdose of paracetamol and was placed in an ER cubical on a chair. She was drowsy and very sore as she also has FMS so she lay down on the floor. When a nurse saw her she was roughly pulled to her feet and told to sit up on the seat, she couldn't possibly be feeling drowsy. Was taken to see a CPN and asked if I could come along, but was told no. She can't remember what was said and was sent home without knowing what happened.

Quote - I self harm and have tried to kill myself a few times. I have been to A+E I have sat for 12 hrs at a time and then been sent home without real help. The nurses in A+E were not very nice to me and were very rough when they were cleaning my wounds. One nurse told me I should be ashamed of myself as there were people who were really sick and needed help. She made me feel really bad. When the psychiatrist came to see me I could not make him understand how ill i was and how much I needed to be somewhere that was safe. He kept asking me stupid questions about my childhood which had nothing to do with anything now. The commented on how I was dressed and asked if I did drugs even though I told him I didn't. By the time I saw the mental health people I was very angry and frustrated and stressed. I needed to self harm again. He would not give me anything to calm me + just said I was aggressive. He didn't listen to me that I waited so long without treatment and this was why I was annoyed. My friend was very upset they had to wait with me for so long + was annoyed at me also. I got fed up with the questions + waiting + had to leave. I needed help when I first got there + by the time they came to me I was made to feel really bad. When I left A+E I cut myself right away - I didn't go back- I wouldn't go back to A+E for help in crisis again.

Community Teams – Home Treatment

Quote - I have not a lot to say - My CPN is great, he helps me all the time. I do not know what i would do without him. I know he says where he works is moving. He told me i will be staying with him. I am happy; i would be lost without him. My doctor is good too. The day centre helps me to get out. MH Services is great.

Quote - *The home treatment team stepped in after this, they were rubbish, because of it being the holidays they were always different people and they never remembered my name. They asked me the same questions every day and they were quite personal and the whole experience was quite harrowing. I felt like I was being interrogated by the staff.*

Quote - *I recently had a bad experience and it happened in a public place. An incident happened and alarm bells rang that i needed help. I was sent to the home treatment team at the Mater hospital where the staff were courteous and helpful. I was sent for rest bite and i had access to a doctor quickly. The medication was then started quickly. The outcome was good; the treatment was effective and efficient. The home treatment team were perfect.*

Quote - *I was in hospital a long time. Not sure how long I'm out now and I live in a wee fold. I have a wee fella comes to me. We go for a cup of tea and have a talk. I love my wee place but I am on my own. That is hard sometimes. I miss the staff in the hospital. Their good people you know. I hope my friend gets out soon.*

Quote - *I was not good but this time i did not want to go to hospital. So i said i would take home treatment. They would come to my house and ask things and tell me things. All i wanted to do was sleep. So i said i do not want to take sp many tablets. They told me i had to take them. No one would listen to me. So i just stopped taking them. Things were bad but i did not want to sleep all the time. When the CPN found out i was not taking them, the doctor came out to see me. He said i needed to go back on them. I said i would like a new tablet or not so much of the one i was on. He said i would become unwell. I told him i could not live like this. He told me if i did not listen to them they could not help me. I said you are not listening to me. He went away when the CPN came again, she told me i was being discharged. My life was falling apart and all they wanted me to do was take tablets and sleep. Home treatment my bum!*

Quote - *During a time of extreme depression I was to have a visit from a CPN he phoned to say he not coming he said he would call another day. He did this several times - cancelling and not coming and he never came. The psychiatrist came once put me on anti depressants and I never seen anyone since and that was 2 years ago.*

Quote - *I was in need of help from Home Treatment. I found them to be very helpful and supportive - they worked with me encouraging me to keep going and that despite feeling so unwell they kept calling and supporting me and reassuring me throughout the process. One member in particular was extremely good; she gave me a kick up the ass when i needed it and a hug and gentle reassurance when i needed it.*

Quote - *Basically after a long time caring for someone with severe mental illness we were allocated a new social worker who changed everything with her attitude and creative thinking towards problems and open attitude to trying things and working closely with the family. It was wonderful and I wished we had met this individual at the beginning of our journey rather than 12 years into it. She didn't have extra time or resources or a magic wand but she changed everything. She saw the person I cared for as an individual and respected her rights and wishes. She persevered. She helped me and my family*

understand the illness but most importantly, helped us see how the person we cared for had many strengths and we got to feel proud of her again instead of thinking of problems all the time. Our personal relationships improved with understanding and released a lot of pressure from everyone.

Transfer to Hospital

Quote - *My son had a very bad turn years ago. We phoned the hospital and they told us to ring out-of-hours. The doctor came out with an ambulance; the doctor would not come in without the police coming into the house. They would not come in without the riot squad, 8 men in full riot gear came into the house to take my son out of the house to an ambulance to the hospital. I hope that things have changed since then.*

Quote - *My son was in hospital, he was allowed out a few hours a day and weekends if he was well enough. He would not return on one of his visit home back to hospital. He was becoming very unpredictable and I knew he had to go back to hospital to finish his treatment. The staff at the hospital were very good at helping me. The problem was that I had to wait all day until 8 O'clock at night before a GP and social worker could be found, the police of course as well. I was shocked to see my son being handcuffed like a criminal being removed from the house. I think something more sensitive and caring should have been explored. My son was never in trouble in his life or had ever been arrested by the police. I think for someone to be so ill and confused needs compassion not treated like an animal or criminal. I was very grateful at the same time for my son to go back to hospital as we were in a state of crisis and had nowhere else to turn. Most of the staff very helpful and did their best to help me and my son, there was only one person at the hospital who was in charge of the ward. He asked to speak to me and was very harsh and hard and told me my son's behaviour was very unacceptable and I felt so scared that I thought they would throw him out of the hospital and we would not had have anywhere to turn. I was lead to believe that people with mental illness, such as schizophrenia when they were unwell their behaviour could become very hostile, unreasonable and very paranoid. I don't think he was very professional for someone running a ward.*

Comments in relation to PSYCHOLOGICAL SERVICES:

Counselling

Quote - *I was struggling to cope with an experience from "The Troubles" and it was having a negative impact on my life. I contacted the Trust and received counselling. For the first time i felt listened to and that i was able to tell my story. The experience was positive, through counselling i was able to see that i was a survivor and not a victim.*

CBT

Quote - 2011 change of GP meant change of health care provider. My husband required CBT however the session started could not be transferred to the new Trust. Result my husband became suicidal GP referred him to an online system of support - 'Beat the Blues'. This was unsatisfactory due to my husband's illness. Impractical infact. GP saw him as emergency and through help and change of medication things did eventually settle somewhat. However, one year on still awaiting referral to CBT. Husbands mental health status has in the mean time fluctuated and the only support he has is myself or the GP. Very unsatisfactory level of support in the Trust. Can only praise the support and help given in Trust. It is sad that your post code dictates the level of care available and provided.

Quote - After trying many brands of prescription drugs, which had little or no effect on my mental state. My consultant suggested another strategy.

Quote - She suggested that we try CBT. This method is in use at my local day centre. She arranged for me to attend this centre. I have found that this method achieves better results for me than the drug method.

Summary Table in relation to Themes & Trends

Trust	Positive	Negative	Mixed	Other*	Total
Belfast	65	90	16	13	184
Northern	50	41	17	7	115
Southern	67	69	27	3	166
South Eastern	68	33	17	20	138
Western	63	25	13	3	104
Regional/Don't Know	3	6	1	3	13
Total	316 (44%)	264 (37%)	91 (13%)	49 (6%)	720

*(**Other** – No story given or story only contained 2-3 word – insufficient details).

Summary

The audit has provided evidence in relation to what people value when recovering from treatment and care for mental health problems.

People value:

- Being treated with dignity and respect
- Being listened to by professionals
- Having continuity of care

The stories also show that this evidence matters regardless of what part of the service you use.

Recommendations

- The data from this audit should feed directly into the Recovery focused service project that is being undertaken within each HSC Trust, ie. Implementing Recovery through Organisation Change (ImROC).
- Each HSC Trust should consider the information provided by the audit and develop a local action plan to address the issues highlighted – the actions in these plans should be implemented in conjunction with the local ImROC development process.
- There should be a re-audit of services user and carer experience by 2015.

The Way Forward

From April 2013 the ImROC programme will be progressed in each Trust. This aims to develop more recovery focused practice and therefore improve the service user experience. The information gathered through this audit will assist Trusts to benchmark themselves across the three service lines (acute, rehabilitation/recovery and primary care) and against the 10 ImROC organisational challenges..

Creating recovery-focused services requires fundamental cultural change. The promotion of recovery must underpin all treatment and support provided and guide the work of every mental health worker. A series of workshops conducted across England in 2008/9 reviewed the available literature and practice and identified ten key organisational challenges for mental health service networks seeking to become more recovery-focused⁽³⁾:

1. Changing the nature of day to day interactions and the quality of experience of people using services and those close to them.
2. Delivering comprehensive service user led, co-produced, education and training programmes.

3. Establishing a Recovery College to drive the programmes forward.
4. Ensuring organisational commitment – creating a recovery-focused culture at all levels.
5. Increasing personalisation and choice.
6. Changing the way we approach risk assessment and management.
7. Redefining service user involvement.
8. Transforming the work force to include peer workers.
9. Supporting staff in their journey of recovery and transformation.
10. Increasing opportunities for building a 'life beyond illness'.

References

1. Bamford Review of Mental Health and Learning Disability (2007)
2. The Mental Health and Wellbeing Service Framework (October 2011)
3. Sainsbury Centre for Mental Health (2010) *Implementing Recovery. A Framework for Organisational Change*, London: Sainsbury Centre for Mental Health

Steering Group Membership

Name	Job Title	Organisation/Trust
Stephen Bergin (Chair)	Dr Stephen Bergin	PHA
Aidan Murray	Deputy Director Social Services	HSC Board
Maureen Ferris	Project Coordinator	PHA
Briege Quinn	Nurse Consultant	PHA
Nicola Porter	Manager	GAIN
Ronan Strain	Regional Clinical Audit Facilitator	GAIN
Rosa McCandless	Senior Information Manager	PMSI , PHA
Rosie Kelly	Children's Services, Child Health	PHA
Adrian Walsh	Finance Representative	HSC Board
Martin Quinn	PPI Representative	PHA
Anne McMurray	Consultant	Sensemaker Lead
Trevor Fleming	Head of Mental Health and Disability Nursing, Hospital services and Acute mental health treatment services.	NHSCT
David Olphert	Service Improvement Manager	NHSCT
Joy Hammond	Head Of Conditioning Management Programme & OT	NHSCT
Eileen Bell	Service User Representative	NHSCT
Mary O'Brien	Service Manager Recovery	BHSCT
Conor McCluskey	Projects Admin Support	BHSCT
Martin Daly	Service user consultant	BHSCT
Karl Hughes	Manager - Mental Health Service User Forum	SHSCT

Francis McConnell	Quality and Patient Safety Manager	SHSCT
Bryan Rhodes	Operational Support Manager	SETrust
Pat McGreevy	Service Improvement Manager	SETrust
Amanda McFadden	Assistant Director Adult Mental Health	WHSCT
Ciaran McKenny	Service Improvement Manager	WHSCT
Gillian McMullan	Project Manager, Bamford Monitoring Group	Patient and Client Council
Marie Crossin	Advocacy Representative	BMG
Maura Cunningham	Service User	New Horizons
Cherie Davidson	Area Manager	CAUSE NI
Jackie McCaughey	Area Manager	Mindwise
Chris Tay	Advocacy Manager	NIAMH Wellbeing
Joanne Wilson	Acting Senior Research Officer	Praxis Care

Acknowledgements

GAIN would also like to acknowledge and thank the following for their help and support in completing this project:

- Cognitive Edge PTE Ltd
- Patient & Client Council

Please see below Web link to the Service Framework Standards.

http://www.dhsspsni.gov.uk/service_framework_for_mental_health_and_wellbeing_-_consultation_version_-_summary_of_standards.pdf

Standards 10 - 26
<p>Standard 10 - User Participation - A person who uses Mental Health Services should be actively involved in planning and monitoring of their treatment and care in a recovery focussed service. Users should also be involved in planning, development and monitoring of mental health services.</p>
<p>Standard 11 - Carers Carers of people with a mental health problem should be given the opportunity to be involved in the planning and delivery of services. Carers should be given information, advice and support relevant to their needs. All carers including children and young people, should be offered a carers assessment.</p>
<p>Standard 12 – Advocacy A person using specialist mental health services should have access to advocacy services in both community and hospital</p>
<p>Standard 13 - Safety/Privacy/Dignity Mental health services should be provided in an age appropriate environment that ensures the safety, privacy and dignity of those who use the services and their families and carers.</p>
<p>Standard 14 - Information sharing A person and their carers and members of the public should be provided with evidence-based, targeted mental health and wellbeing information including information in relation to their detention under the Mental Health Order 1986 if applicable.</p>
<p>Standard 15 - Effective communication between mental health services and users/carers Health and social care organisations and their staff should communicate effectively and in a timely manner with those who use or access mental health services, including their carers[if appropriate], as an essential and universal component of the planning and delivery of health and social care.</p>
<p>Standard 16 - Communication between services, organisations and professionals Health and social care organisations should ensure that effective and secure patient information systems are in place to record and share relevant information across HSC services and other agencies in line with agreed protocols</p>
<p>Standard 17 - Service Delivery A person with complex mental health needs should be treated and supported in the community and in their own home, where possible, with due regard to both their physical and mental health needs.</p>

<p>Standard 18 - Access to services</p> <p>A person experiencing a significant mental health crisis should have timely access to age appropriate health and social care services 24 hours a day 7 days per week.</p>
<p>Standard 19 - Care Pathways</p> <p>A person using mental health services should have an integrated care pathway for their assessment, treatment, care and ongoing management where health and social care[including primary care] work in partnership with users and their carers to develop the most appropriate and accessible services</p>
<p>Standard 20 - Care Planning</p> <p>A person receiving treatment and care in primary care and/or mental health services [community or inpatient] should have a care plan prepared in partnership with them that is recovery focused, evidence based and fully recorded. The shared care plan should allow for urgent access to specialist services, if required. [Where relevant this should identify the needs of children and family members]</p>
<p>Standard 21 - Occupational assessment</p> <p>A person with severe mental health needs should have a full occupational assessment, reviewed on at least an annual basis and thereafter access to a range of adequate occupational services should be arranged.</p>
<p>Standard 22 - Medicines Management</p> <p>A person should be provided with medication, if appropriate, that is prescribed in accordance with local and national guidelines. This choice should take account of the person's needs and be supported through a partnership approach between that person associated carers and health care professionals, with the opportunity to access sufficient information to enable them to make an informed decision about their medication and other treatments.</p>
<p>Standard 23 - Physical care of people with severe and enduring mental illness</p> <p>A person with severe and enduring mental illness should be offered a physical health check at least annually [normally in primary care] according to locally agreed protocols based on National Guidelines</p>
<p>Standard 24 - Domestic Violence and Abuse</p> <p>Health and Social Care staff should be aware of the signs and symptoms in relation to violence [including domestic violence] ,abuse and neglect in order to help them identify victims, and trained where necessary, to offer early help and support. Health and social care staff should also know who the lead for child protection and adult safeguarding is within their organisation and how to contact them</p>
<p>Standard 25 - Supportive Palliative care</p> <p>A person with a mental illness and their carers being assessed for supportive and palliative care should have their specific mental health needs taken into account in consultation with them and their carer.</p>
<p>Standard 26 - Psychiatric services in acute general hospital</p> <p>A person attending an acute general hospital should where appropriate have access to age appropriate psychiatry services and should include follow up arrangements if required such as the Card Before you Leave Scheme.</p>

“Your say can change lives...”



Share your recent experiences of
Mental Health Services and change
services for the better

To find out more contact:

028 9052 0629

eu.sensemaker-suite.com/gain/index.html

GAIN

Guidelines and Audit Implementation Network

1st August - 31st October 2012

Users and Carers Experience of Mental Health Services in N.Ireland

Your Story Can Change Lives

Help us to plan future changes in mental health services and staff training.

Dear Reader,

GAIN* in partnership with the **HSCB*** and the **PHA*** would like to hear about your experience of using mental health services in any setting within Northern Ireland since 2009.

It is important that the people, who rely on mental health services, receive accessible and effective support and treatment which promotes recovery. Service users and carers should be treated with dignity, respect and compassion.

Telling us about your experience is important. This is the first time that service users and carers across the whole of Northern Ireland have been asked for feedback on their personal experiences. This will help to create a better picture about the quality of mental health services across Northern Ireland and show us what areas of the service need improvement.

Please tell us about a recent experience that happened to you or someone you care for, when you were involved with mental health services in Northern Ireland. Your name or any other identifying information will not be requested. Your story and answers will remain anonymous.

All the individual contributions will be pulled together into a final report. The report will be available on the GAIN website. By completing and returning the survey you are consenting for your anonymous information to be used with that of others in the development of a study report.

Yours Sincerely,

Nicola Porter

Aidan Murray

Stephen Bergin

GAIN

HSCB

PHA

***GAIN: Guidelines and Audit Implementation Network**

***HSCB: Health and Social Care Board**

***PHA: Public Health Agency**

GAIN's website is www.gain-ni.org.



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Taking part

You can complete the survey online or by handwriting the survey and then return to us in the SAE, or by interview with a trained interviewers. Paper copies of the survey will also be available in different languages upon request.

If you would like paper based or translated copies of the survey sent to you or you would like someone to help you complete the survey via interview, **please contact the GAIN office on 02890520629.**

A member of GAIN staff will ensure that you get a copy of the survey or will contact you to make the necessary arrangements for interview completion.

How to Complete:

1. Describe a real experience that has happened to you or someone you care for
2. Complete the questions about your experience.
3. If you are taking part via interview the survey will be read to you and your answers recorded.
4. At the end you will be asked if you wish to write about another experience. You can contribute as many experiences as you wish.

The survey will take about 15- 20 minutes to complete. The survey will be open from 1st August 2012 until the 31st October 2012.

Please tick which of the following best describes you:

- | | |
|--|---|
| <input type="checkbox"/> I am a user of mental health services | <input type="checkbox"/> I am the carer of a service user
e.g. a family member or friend |
| <input type="checkbox"/> I am an informal carer of a service user – not a relative | <input type="checkbox"/> Other (please specify)
_____ |

Next Steps

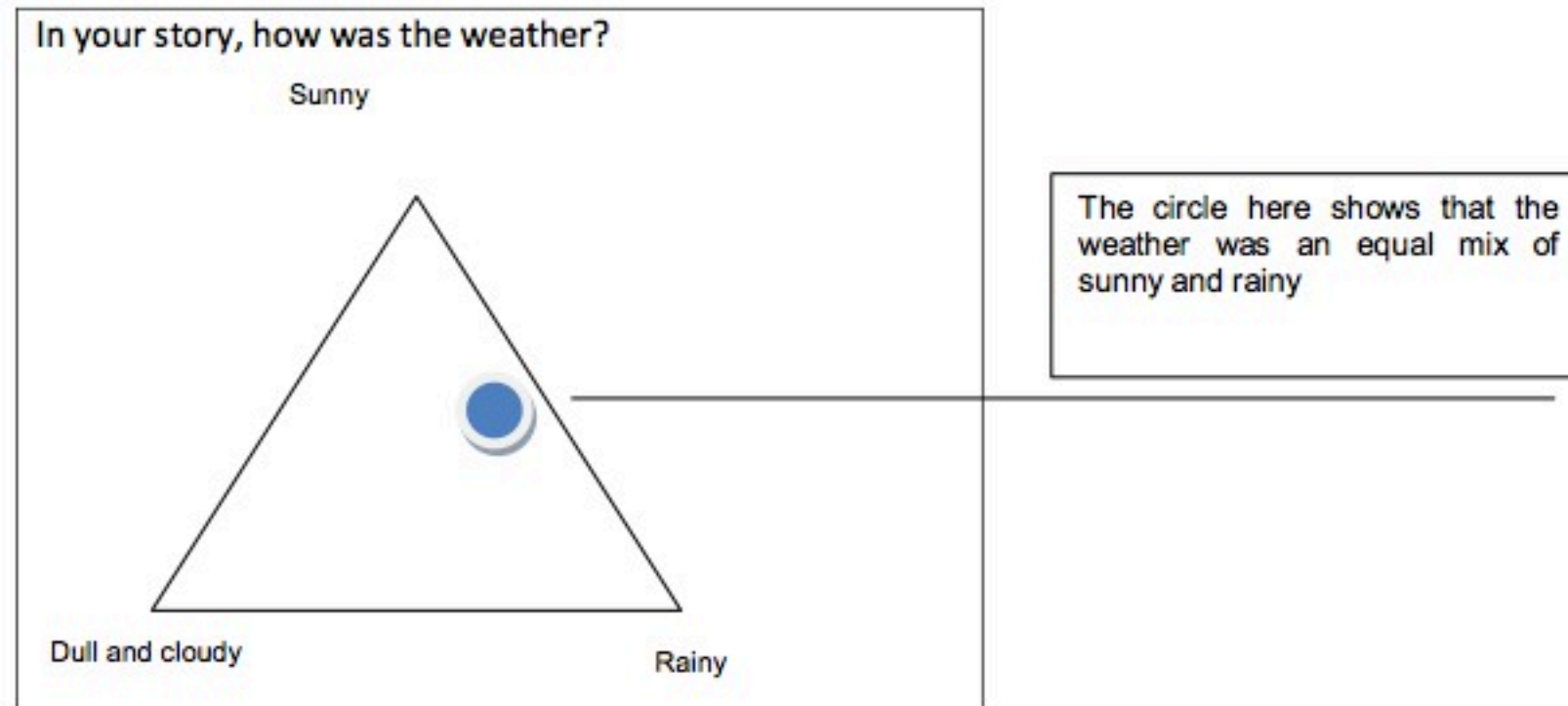
We would like you to use the triangle questions to think further about your experience.

Please mark the spot on each triangle by drawing a circle which best reflects the experience in your story.

You can choose one specific corner if that fits best, or between two corners or in the middle if it is a bit of all three.

Please see the example below about the weather.

Example:



If none of the corner answers are applicable to your experience, then please indicate N/A (not applicable).

Please describe an experience which shows what it's like to be on the receiving end of mental health services - whether as a user of the services, or, as a carer.

Of all of your experiences of mental health services, which one had the most impact on you?

Your experience may be good or bad. What matters is that it is real and recent and shows how mental health services are working today. Your experience can relate to **any aspect of services** and in any setting.

What happened? What did people do? What was the outcome or impact?

Write in the box below. Do not worry about grammar or spelling. The story must be real. You can use phrases/bullet points/ sentences. Describe the situation, what happened and the impact on the people involved. Please do NOT use real names.

Please give your experience a title e.g. the moral of your story or lessons to be learned.

Choose three words or phrases that sum up the key themes in your experience:

We would like you to use the triangle questions to think further about your experience.

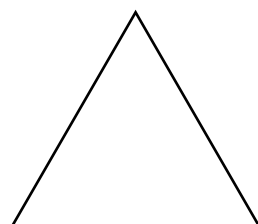
Please mark the spot on each triangle by drawing a circle which best reflects the experience in your story.

You can choose one specific corner if that fits best, or between two corners or in the middle if it is a bit of all three.

If **none** of the corner answers are applicable to your experience, then please indicate N/A (not applicable).

1. Were you able to access the services when you needed them?

I received the right service at the right time



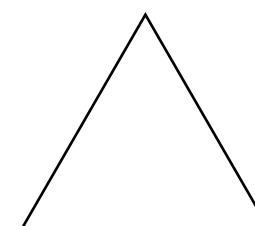
I was unable to access the services I needed

N/A ☐

I did not know what services were available

2. How was the information provided to you by staff in mental health services?

Useful and relevant



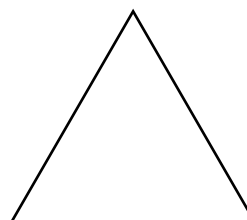
I received no information

N/A ☐

Unhelpful

3. How did the staff in mental health services communicate with you?

Respectful and considerate



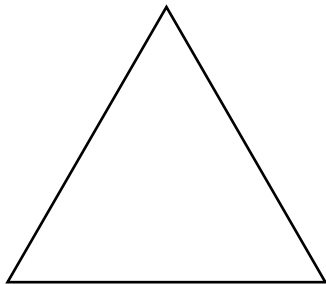
Insensitive and impersonal

N/A ☐

There was no communication

4. How involved were you in care planning and treatment?

Fully involved and respected



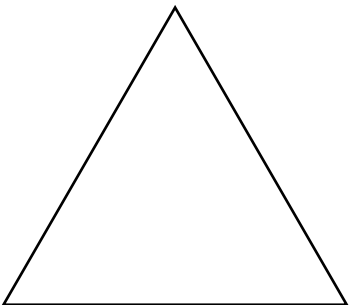
Just told how it was going to be

Felt ignored

N/A ☐

5. Which area of your life was impacted most in this experience?

Relationships with family and friends



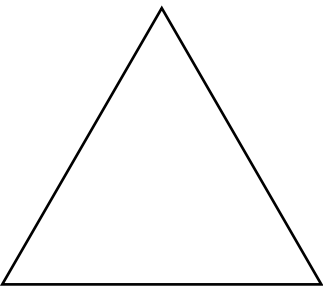
Everyday living, social and leisure activities

Employment and/or education

N/A ☐

6. How has this experience of mental health services left you feeling?

Stronger



Set back and frustrated

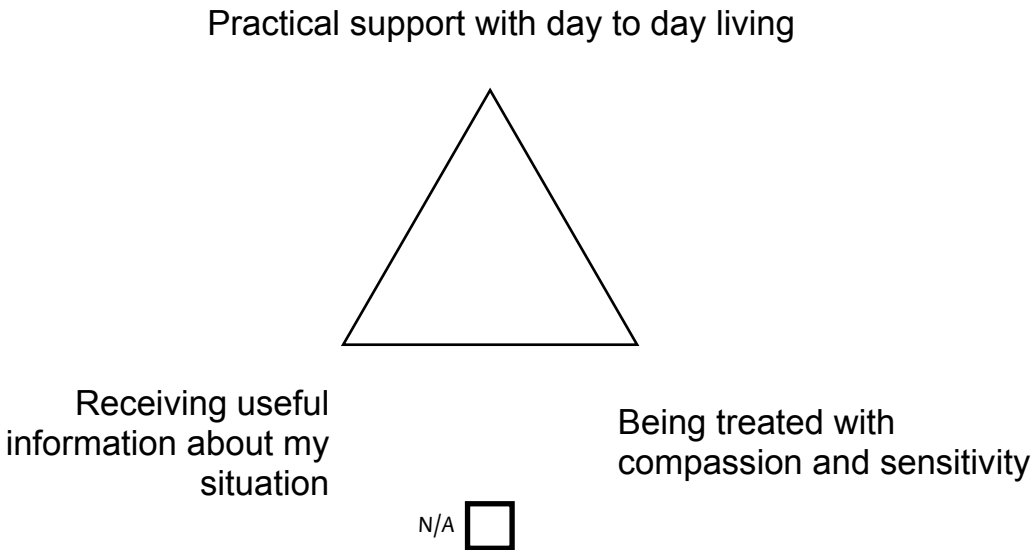
Stressed and anxious

N/A ☐

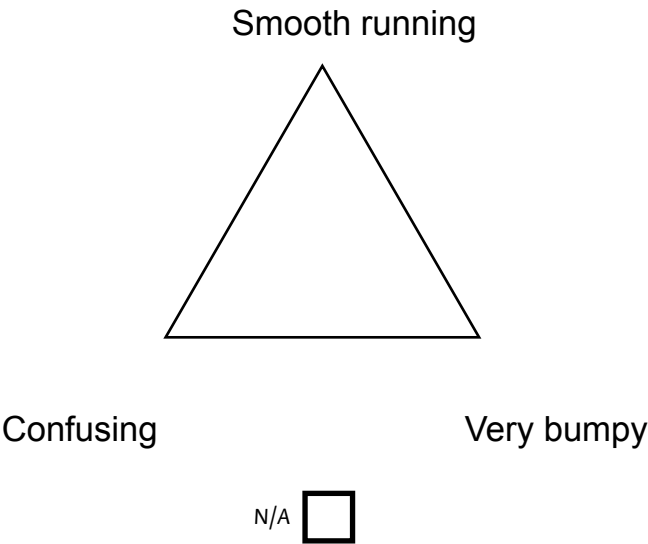
7. What was the outcome of this experience for you?



8. What would have made the biggest difference to you in this experience?



9. Thinking about this experience how would you describe your journey within mental health services?



Your age:	12 - 19 years	20 - 29 years	30 - 39 years	40 - 49 years	50 - 59 years	60 - 65 years	66+ years

Your gender:	Male	Female	Transgender	Prefer not to comment

Your sexual orientation:	Heterosexual	Gay	Lesbian	Bi-sexual	Prefer not to comment

How common do you think your experience is? Please choose (by ticking) from 0 to 5, where '0' = rare and '5' very common.	0	1	2	3	4	5	Don't know

Your Ethnic Group (please circle)	White	Chinese or other ethnic group	Mixed	Asian or Asian British	Black and Black British
	British Irish Any other White background	Chinese Traveller Community Any other Ethnic group	White and Black Caribbean White and Black African White and Asian Any other mixed background	Indian Pakistani Bangladeshi Any other Asian background	Caribbean African Any other Black background

In which setting did your experience occur? (please tick)	At home	Local centre in the community	Hospital ward	Outpatient clinic	Other (please specify below)

In which Health and Social Care Trust area did this experience take place? (please tick)	Belfast	Northern	Southern	South Eastern	Western	Regional Service	Don't know

Please give the first three or four digits of your BT code, e.g. BT6 or BT55:

BT _____

What best describes your condition, or the person you care for's condition, at the time of this experience? (please tick)			
Bereavement / grief		Bipolar disorder (manic depression)	
Depression		Self harm	
Post natal depression		Schizophrenia	
Obsessive compulsive disorder		Anxiety fears phobia	
Personality disorder		Gambling addiction	
Psychotic illness		Substance misuse	
Post Traumatic Stress		Alcohol misuse	
Other (please specify below):		Eating disorder	
		Don't know / not sure	

Which of the following professionals and support services were involved with you? (Please tick all that apply)			
Advocacy		Nurse – mental health services	
Social worker		Voluntary organisations	
GP		Church / Faith based group	
Psychiatrist		User support group	
Community psychiatric nurse		Occupational therapist	
Psychologist / Psychological therapist		Dietician	
Health visitor		Community group	
Counselling		Day hospital	
Other (please specify below):		Helpline	
		Don't know / not sure	

If you are completing a paper copy please return to the address below:

GAIN, Room C4.17
 Castle Buildings, Stormont, BELFAST BT4 3QQ

Support

You may find that you would like to have someone to talk to about your responses to the questions – a friend or family member, or someone who provides you with support. You can contact your key worker or the helpline below:

Lifeline: 0808 808 8000