

EXPERIENCE OF CARE

Service Users Experiences of Mental Health Care

in the

Scarborough, Whitby and Ryedale areas.

The VOICE Project



January 2011



Scarborough Survivors



For better
mental health

Scarborough, Whitby and Ryedale Mind

INTRODUCTION

The voice project was set up, after issues were raised regarding mental health services, by members and service users of Scarborough Survivors, Scarborough, Whitby and Ryedale Mind and Carers Resource. The group then set out to look at these issues.

The project received funding from North Yorkshire County Council and Adult Community and Community services. This is integrated with Tees Esk Wear Valley NHS Foundation Trust. Two service users were employed as co-ordinators. Their remit was to collect and collate views and responses of service users and carers of mental health services, to identify areas of good practice and any areas of concern. They would then take this information back to that area of the service, in order to improve mental health service provision, in the way service users and carers wish. Its emphasis was on recovery focused care.

This piece of research is the result of that work, which commenced in September 2009 and the research concluded in September 2010. It is acknowledged that there have within this time frame been improvements and changes made within the secondary services.

PREVIOUS RESEARCH

In recent years government policy on mental health service provision and recovery has geared towards putting the patient first as the expert on their own care. There is increasing interest in the concept of recovery, both nationally (CSIP, 2007; NIMHE, 2004) and locally. It requires new approaches by staff, to support people in settings of their own choosing, enable access to community resources including housing, education, work, friendship or whatever an individual sees as critical to their own recovery (Department of Health, 2001). National priorities of engagement, choice of treatment pathway, personal care plans and choice of professional are fundamental to working within a recovery-focused approach (www.kcl.ac.uk 2010). One example of this is direct payments. Direct payments are where the service user is encouraged to manage their own care by paying for treatment themselves through a payment given to them for these purposes.

The current NHS encourages patient opinion and liaison. This is seen in the established PALS (Patient Advice and Liaison Service) and the patient opinion organisation (www.patientopinion.org.uk). The mental health charity Rethink calls it personalisation: *“It involves thinking about public services in an entirely different way – starting with the person rather than the service”* (Pattison, S 2009). Which is now high on the governments agenda.

Previous studies have assessed the recovery focused care approach. Where the patient is the expert in their own care, where treatment matches their own wants and needs taking account the whole person and not just the mental health problem or symptom.

The Sainsbury Centre for Mental Health has criticised mainstream mental health services for being preoccupied with medication and symptom control, rather than recovery. In their report "Making Recovery a Reality", the charity called for a revolution in services to allow people to "get their lives back" (March 2008). The National Mental Health Development Unit has a project-led partnership with the Centre for Mental Health (CMH), supported by the NHS Confederation, to promote and support recovery-focused organisations and services. This work builds on the recent CMH programme, "Making Recovery a Reality". The project pilots recovery-focused organisational development across selected local NHS sites to demonstrate and evaluate outcomes for providers and commissioners (www.mnhdu.org.uk).

The voluntary sector already has mechanisms in place taking the recovery focused approach. SWR Mind in Scarborough is a mental health charity with a successful befriending service. Whereby a 'friend' (a person with mental health difficulties) is linked up with a 'friend' to cater for their own specific social, emotional and practical needs. Befrienders also provide information and advocacy. Several schemes of this nature are set up around the country. For example, in Weymouth and Portland they have a personalisation scheme, like the befriending in Scarborough, Whitby and Ryedale. All of the services offered by Scarborough, Whitby & Ryedale Mind operate in a recovery focused way. A three year research project has been set up to look at the effectiveness of personalisation. Rethink have published a report on "100 ways to support recovery. A guide for mental health professionals" (Slade, M 2009). The information is a guide based on two beliefs:

"Recovery is something worked towards and experienced by the person with mental illness. It is not something services can do to the person. The contribution of staff is to support the person in their journey towards recovery".

"The journey of recovery is individual. The best way of supporting an individual's recovery will vary from person to person".

Recovery is also seen as:

"Recovery is seen within the model as a personal journey, that may involve developing hope, a secure base and sense of self, supportive relationships, empowerment, social inclusion, coping skills, and meaning" (Wikipedia 2010).

Our study builds upon this ethos. In this project we aim to further investigate the recovery focused care approach and build upon this previous research. This has been undertaken by asking the service users of the Whitby, Ryedale and Scarborough their own opinions in the needs and wants in their own care.

METHODOLOGY

Development

Two individuals were appointed as Voice group Co-ordinators as a job share. They were appointed at interview by: the MIND Chief Executive Officer (Julie Nichol), Scarborough Survivors General Manager (Andrea Woolcott) and Commissioning and Development Manager at Cross Lane hospital (Jacki Tonkin). It was deemed essential that the Voice group co-ordinators had experience of working in mental health and an understanding of mental health issues. Both coordinators are mental health service users. They are:

Jacqui Hall

Jacqui has had a vast experience of working in the mental health field. Indeed her past vocation was as a psychiatric nurse. At present she is a service user volunteer at the SWR Mind drop-in and has been chair for SWR MIND. In her role she has attended several mental health forums. She has undertaken presentations at MIND mental health awareness training events and is a MIND be-friender. She has also been a representative at service user tribunals.

Katie McNulty

Katie also has had a vast experience of working in the mental health field. This consists of her involvement in an evaluation of a service user research course ('Developing Partners' with the then TNEY NHS trust). She has been a MIND trustee which led her to attend several local and national mental health seminars and conferences. Like Jacqui, she currently does presentations at MIND befriending training events to generate awareness of what it is like to have a mental health problem. She has co-run drama workshops at the MIND drop-in. She also works part time as a research interviewer for Viewpoint (for Rethink mental health charity and Kings College). This involves questioning service users by telephone about their experience of discrimination when having a mental health problem. Katie's background in social research (MSc Social Research) brought valuable expertise to the project.

The job share proved helpful in that we could apply our own levels of knowledge and expertise in all aspects of the project. Jacqui focused on the MIND SWR and Whitby drop-ins and Scarborough Survivors because she already knew people there. Katie accompanied her on a number of occasions. Jacqui also attended a number of meetings to publicise the project. Aswell as this Katie focused on Next Steps. We both played our part in the analysis of results and Katie compiled the majority of this report, with feedback from Jacqui and Andrea, the manager of Scarborough Survivors.

Methodology

The fact that both researchers themselves were service users and had good contacts in the field proved invaluable in the running of this project. Indeed it is widely acknowledged that research about service users should be undertaken by the service users themselves. Service user researchers are indeed 'experts in our own care'. This is known as emancipatory research (research with the aim of empowerment at its core) and has been used in the disability field for some time (Barnes and Mercer 1997).

We took a qualitative approach in our methodology in data collection and analysis. A qualitative methodology was determined by the exploratory nature of our research question: in general service user's experience of their care. Where: *"The goal of qualitative research is the development of concepts which help us understand social phenomena in natural settings, giving due emphasis to the meanings, experiences and views of all participants"*.

Indeed this holistic approach was deemed appropriate for the very reason that we were looking for service users opinions on holistic care. This was Recovery focused care *"An approach that sees the person as the centre of their care, they are the expert in their own condition...it takes into account the whole person, mind, body and spirit, not just a symptom or problem"* (Voice leaflet). Qualitative research involves delving into the lives and opinions of service users. Some questions were quantitative, seeking numerical information, such as 'Have you got a GP?' or 'What service did you use?' However, on the whole the questions were open-ended, such as "What was your experience". These qualitative questions were: exploratory, involving how people feel or experience something, where their opinions are at stake. Thus providing a rich answer. Therefore we aimed to understand the experience from the subject's point of view, for instance their quality of care.

Data Analysis

We undertook qualitative data analysis. We did this by thoroughly reading the answers several times over. Then, by coding the answers into different themes. Answers to both questions were recorded and emerging themes gathered from the data. Data analysis is the process of bringing together structure and meaning to the mass of collected data (Marshall and Rossman 1995). In qualitative research, analysis tends to be associated with a more 'open', unstructured approach in which progressive focusing occurs once fieldwork has begun, allowing the researcher to remain responsive to their subjects views and benefits and to ascertain factors which are not envisaged at the onset" (Bryman 1988). Using data from the questionnaires, the researcher followed Silverman's process of analysis (2000), based on Glazer and Strauss (1967) grounded theory. Where, two types of category were created to assist with the indexing and retrieval of data. The first was descriptive, a list of the key topics and the second was analytical or conceptual.

Access Selection of participants

The researchers contacted GP surgeries in the Scarborough, Whitby and Ryedale area. We gave a letter and leaflet explaining what the Voice project was and our contact details for people to get in touch. Unfortunately the response rate was very poor.

We also put up posters in GP surgeries, Ellis Centre, Trafalgar Square, Next Steps and Scarborough Survivors, along with the two SWR Mind drop -ins.

We used the media. Scarborough Evening News wrote an article about the Voice project aiming to let service users in the area have their say. Unfortunately, we only got a few responses.

We also publicised the Voice project at different Mental health meetings.

The most promising method of response was when we visited different mental health establishments. We visited these on several occasions. At Scarborough Survivors (particularly the Craft group) Jacqui spoke to service users who completed the questionnaires. Katie visited Next Steps on several occasions to speak to service users there. We both went to Cross Lane psychiatric hospital on the male (Esk) and female (Danby) ward. We made visits on a monthly basis. We visited the MIND Scarborough and Whitby drop-ins on a regular basis too to speak to service users.

Therefore in order to contact participants we used a purposive sampling method, which *"...applied to those situations where the researcher already knows something about the specific people or events and deliberately selects one because they are seen as instances that are likely to produce the most valuable data...and their relevance to the topic of the investigation"* (Dunscombe 1998). We also obtained access to participants through snowball sampling *"...with snowballing the sample emerges through a process of reference from one person to the next"* (Dunscombe 1998 16). Indeed the help of Jacqui Tonkin at Cross Lane, Andrea Woolcott at Survivors and Mike Dickson at Next Steps was invaluable to gain access to participants. For which we are very grateful.

Response Rate

We had a low response rate from the advertisements put in GP surgeries and posters put up in the mental health establishments listed above.

However, we had a pleasing response rate when we actually went to these establishments in person. In total 160 questionnaires were answered. A breakdown of the totals per questionnaire are listed below:

Questionnaire	*Theme	Forms returned
1	GP experience, mental health service referral, key worker experience, care plan.	69

2	Type of mental health worker, frequency of visits and contact.	38
3	Experience of person-centred care. How could the care you receive from mental health services be improved?	33
4	General experience of mental health services. Excellent service? what has not been so good?, Could things have been done better?	20
	Total:	160

The Questionnaires

All the questionnaires were conducted by Jacqui Hall and Katie McNulty. This either involved the participants filling in the questionnaires themselves or the coordinators filling the question in for them when it proved difficult for them to fill in the form themselves.

In terms of preparation, when the coordinators visited the different venues, they would introduce themselves to the service users saying who they were and why they had come to talk to them about the voice project. Before approaching the service users with a questionnaire, the coordinators would strike up a conversation about any subject matter to establish rapport and trust. At Cross Lane, usually the nurse on duty would introduce us to the patients before we spoke to them about the questionnaires.

Service users were informed from the onset that the questionnaire would be completely confidential, and a record would be made of what they said but not who said it. They were also informed that the interviewer was a service user themselves and not a service provider. Full information was given about the way that their feedback would be used and the purpose of the research. On these occasions, we gave the participants our leaflet explaining the project.

The structure of the interviews was deliberately uncomplicated. The interviewer asked 4 questionnaires, with the question areas above (in response rate section). The interviewer used 4 basic questionnaires which had semi-structured questions. Respondents were asked to give answers under the question headings but were also encouraged to talk freely and without interruption.

Ethical considerations

Ethical issues are concerned with the moral values the researcher adheres to throughout the research: “we must, as qualitative researchers, consider the rightness and wrongness of our actions in relation to the people whose lives we are studying...” (Smith 1995).

Respondents were made aware that they would remain anonymous and their names were not recorded. They were insured full confidentiality. The respondents were given 'informed consent' whereby they were informed that they were being researched and also about the nature of the research. The reasons for doing the research and the researcher's expectations were expressed to respondents.

Our target group was vulnerable adults with mental health problems. This was taken into consideration. Where the respondent could not answer the questionnaire themselves, the researcher filled it in for them in the respondent's own words.

KEY THEMES FROM ANALYSIS

Response Rate

There were in total 4 questionnaires given to service users to tell us about their experience of care. The amount of questionnaires completed is listed below.

Questionnaire	*Theme	Forms returned
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	Total:	160

*Questionnaires are included in the appendix.

FINDINGS

The results highlight the different experiences of care the service users received for their mental health problems. Their answers from all four questionnaires demonstrate that their experiences of the care they received can be split into the following types:

- Primary care experience (from GPs)
- Referral to mental health services

- Experience of secondary care in the mental health system (Community Mental Health Teams, Crisis Resolution and Home Treatment Team, Crisis Call).
- Experience of acute care (Cross Lane Hospital)

The respondent's opinion of their care, in terms of what went well and what did not go so well is stated. They also suggest ways in which their care can be improved.

PRIMARY CARE EXPERIENCE

The respondents were asked the following questions:

- Have you got a GP?
- How helpful is your GP?
- Do you use another service within the GP's surgery?

It was found that almost all the respondents had a GP. With 68 respondents who had a GP and 1 who did not. In terms of whether the GP was helpful, the vast majority, 49 stated that their GP was 'helpful' with only 12 stating that their GP was 'not helpful' and 7 in-between stating that their GP was 'sort of helpful'. Over half of the respondents did use another service within the surgery (36) and the other half that did not (33).

Many respondents praised their GP as the best source of help for their mental health needs:

"I am lucky as I have a good GP better than the mental health worker. The doctor is brilliant"

"The GP takes over secondary care, they ring to check up on me"

MENTAL HEALTH REFERRAL

The respondents were then asked the following questions about referral.

- Have you been referred to another Mental Health Service?

Over two-thirds of the respondents had been referred to another service, 42 and the remaining 18 respondents had not.

- If yes, how long did you have to wait for a referral?

The waiting times for a referral varied:

Waiting times	Amount of respondents
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Straight away	10
1 -4 weeks	6
4 -12 weeks	3
3 months and over	7
Cannot remember	19

Although a large number of respondents were referred quickly (10), more than this (16) had a longer waiting time between 1 week and 3 months. It is interesting that the majority of respondents could not remember but not sure what conclusions can be drawn from this.

REFERRAL EXPERIENCES

Lengthy waiting times were regarded as problematic:

“It has taken a long time to wait for a referral”

“Referral times are too long”

Many respondents stated that you had to be very ill in order to get a referral:

“I have to be very poorly before get referred. Care is very affected with no key worker”

“There is also a waiting list for psychiatry and in-between. You are left to your own devices and if like me, you are very high or very depressed you are pretty much left to your own devices. If you feel you are in a suicide mood, you pretty much have to deal with it”

“No, I am not getting a service. I can’t get any help from them. They say I don’t fit their criteria”

“No. No one is helping with it. Surgery would not refer me to see a psychiatrist. Only have a GP. Moved surgery. Still waiting to actually get some help”

- What service was it?

The respondents listed the services that they were referred to which were as follows:

Mental Health Secondary Care: Adult psychiatric services for Ryedale, Crisis Team, Early Intervention Team, Anchorage, Outreach care co-ordinator, counselling, Community Mental Health Team, Community Psychiatric Nurse, Psychiatrist, Cross Lane Danby and Esk ward, psychologist.

Drop-in and resource centres (voluntary sector): Next Steps, Mental Health Matters (a floating support service which is time limited based in Ryedale), Mind, Scarborough Survivors.

Other: Clinic for physical health problems, York Hospital, Health care worker, primary care (had a worker in GP practice), clinic in Malton, another professional (not stated), smoking clinic.

- What was your experience?

In terms of their overall experience this was written down underneath this question but also at the end of the whole questionnaire described below. The findings from this are explored later in this report.

EXPERIENCE OF CARE FROM THE MENTAL HEALTH SYSTEM

In terms of secondary care in the mental health system, the respondents were asked questions about their key worker and care plan in question 1. These questions were:

- If your key worker is unavailable for you for a period of time, how is the level of your care affected?
- Is it better or worse?

Most of the respondents, 12, said that the level of their care was worse in the absence of a key worker. A high number also stated that their care was the same, 8. A small number, 5 said their care was better when their key worker was unavailable. They stated:

“Never available, never get in touch”

“Very badly affected”

“Significantly worse. He was on paternity leave, annual leave. Difficult to get a hold of. Nobody there to take your call and step in. Duty CPN there in case, but I didn’t know that. Lack of information. Been 12 weeks and not able to get a hold of him”

- Are you left with no care?

A large number, 10 said they were left with no care and 14 said that their GP took over their care.

Other respondents said that they relied on Crisis Call if there was no one else available as well as their GP. Out of the respondents that said there was always somebody they can contact if their key-worker is not available they stated:

“There is the early intervention team and CPN (alternative if present one is unavailable). GP not involved but would book appointment with them if nobody else was available. Crisis Call if no one. Never left alone without any care”

“Oncall person also got access to crisis line”

“Someone else steps in, always at the end of the phone”

“Always tries to ring before going off”

“Always get a good service with a smile. If care worker on holiday there is always somebody else. Could see... at Next Steps and not left on own. Not judged”

“Key Worker is good to talk to”

Other respondents expressed their lack of care when there was no contact from their key worker:

“I just need someone to ring up to ask if I am okay but they won’t. They expect me to ring them and I can’t always do that. I feel really rejected”

“I rang the CMHT. All I get is to be put through to the answer phone. I rang 7 times and nobody rang me back”

In the onset of a crisis, a speedy response is paramount. For example, one respondent said:

“I was not listened to after a suicide attempt – A CMHT appointment was made for the next day”

However, there were others that said that they were left with no care at all:

“When key worker is unavailable the service becomes scarce. It returns to previous carers”

“Last year, I feel my key worker was never there when I needed him”

“The Key workers don’t know all our needs, all they want to do is talk and have a cup of coffee”

“When people say they are going to do stuff they should do it. Key workers don’t know your needs they just say just have a cup of tea”

Care is affected by the type of key worker they have:

“Excellent until my keyworker changed. It was regular input, they always returned my calls. We had regular appointments. Someone covered when they were off. I felt well supported and understood. I now have no regular input. They don’t get back to me 4 or 5 times. Nothing is arranged for when they are away. I get no contact most of the time. I don’t want to keep asking. The GP offers to see me more often when he knows my key worker is not responding to my requests for appointments”

- Do you know if you have a care plan?

More respondents than not knew they had a care plan, 30 but 22 also said they had no care plan at all.

Out of those that said they did not have a care plan, a number of people said they did not need one because their care plan was in their head.

“Could do with a care plan. They say not needed but illness has ups and downs. (But patient says they could be in need of one)”

“Not aware of care plan. Just a few notes about how feeling on the day. Don’t like to feel being watched. Has problems but not recognised as such. Prefer to work out own problems at home in own way than care plan”

“Don’t know. No one ever mentioned one. Don’t think I’ve had a CPA”

“No, I have not been consulted on it”

- Have you got a copy of your care plan?

Ten people had a copy and 13 did not. Therefore more people do not have a copy of their care plan. Some therefore know they have a care plan but they have no copy. We could question this and this could be because a key worker might not have the time to make a copy for all of their clients, as one respondent stated *“I have a care plan at home where I live at. I don’t have a copy but have talked through it”*

Another stated that they do not have a care plan because they see their GP weekly. There is also an assumption that verbal plans are just as appropriate: *“But I own the care plan in my head”*. A different respondent took another approach: *“I’ve never read (the care plan) because they know what’s right”. “This is not patient care”!*

“I asked for it initially. I was only given part of it, until I asked for the rest. I don’t like the way the care plan is laid out. It isn’t easy to understand as the hand written ones”

“I have asked for a copy and not been given it yet”

- Has it been updated?

One respondent said they got a care plan after 4 months. A large majority said their care plan had been updated. With only 2 saying they do not know.

- Were you consulted on the updates?

Significantly, most of the respondents had been consulted on the updates of their care plan (12) and 5 had not.

Questionnaire 2 asked respondents about their experiences of contact between themselves and their mental health worker. These questions were:

- Do you have a mental health worker?

Type of Mental Health Worker	Amount of respondents who see this worker
CPN	19
Social Worker	6
Psychologist	3
GP	3
GP's counsellors	3
Crisis call usage	1

A significant number have a mental health specific worker (28) and 6 use a GP for their services.

- How often do you see your mental health worker?

How often?	Amount of respondents
More than once a week	3
Weekly	13
2 Weekly	6
3 weekly	2
monthly	3
2 monthly	2
Rarely	1

The frequency of visits with their mental health worker appears satisfactory with most of respondents saying they see their worker weekly.

Methods of contact vary. One respondent preferred to have letters sent to him to show the time and date of appointment.

However, the frequency of visits with a key worker is clearly an important issue, which can have a detrimental effect on one's present mental health and needs. As one respondent indicated:

“Long term input is important”

“(Key worker) used to help set out what most achieve. To get out of the house etc”

This is also an important issue for discharge. At what stage do the service user and key worker come to an agreement about either seeing each other more or less? This was indicated by one respondent's comments:

“First I had her every week, fortnight and now nothing. I'm supposed to have CBT, it's not happened yet”

A lack of continuity in appointments was also cited by one respondent who stated that this can have a detrimental effect on their mental health:

“An appointment every three weeks is very unreliable. Every single appointment is cancelled/postponed every 2 – 4 weeks. Having to wait for the next meeting is a dreadful experience”

“No notice is taken of me when I state my issues. I have not had a meeting with my care co-ordinator for 5 weeks. When I do see him it is only for a few minutes and he just says I am okay. I want more meetings with my care co-ordinator compared to at least once a month where the meeting lasts at least an hour. For my care co-ordinator to emphasise with my problems and not just ignore them”

- Is this appropriate for your needs?

The highest number of respondents (25) stated that the amount of time they see their mental health worker is appropriate to their needs, as 'just right'. Under half this number, 9 said it was 'not enough' and only one said 'too often'.

- If you ring them, how quickly do they contact you back?

How often	Amount of respondents
Straight away	11
Later that day	25
Within two days	2
Not at all	2

A significantly high number of respondents are therefore contacted on the day they ring their mental health worker.

- If your mental health worker says they will contact you, does this happen?

Almost all respondents said that when their mental health worker says they will contact them they do (31) and only 1 said sometimes. Interestingly no respondents said no.

- How easy do you feel is it to get a message to them?

A majority of the respondents said it was easy to get a message to their worker (24), with 7 saying it was not easy and 2 saying it was okay.

Out of those that said contact was difficult, they said:

“Getting through can be impossible”

“It is difficult to leave messages”

“Contact can be very difficult”

“I can’t get a hold of them because she is always busy and never returns my calls. Excuse is we’re very busy”

An important issue to arise from this and which was referred to a number of times was that if the patient does not ring the key worker they will assume that they are okay. However, sometimes the patient may not want to ring or be too ill or not have the confidence. Or they simply might not have enough credit on their phone. This is illustrated by one service user:

“I don’t ring. Feel I’m pestering her if I do”

“Key Worker should make contact with me, not other way round”

In this sense it is up to the service user or the key worker to make sure the patient is okay?

“If the key worker doesn’t hear from me, they assume I am well – but I could be too unwell to make contact”

“It feels like that unless I am smashing the place up, they assume I am fine”

“When I am ill I am told to ring my CPN. But I feel that this is impossible. It is just how my illness affects me. So if they don’t hear from me they presume I am well. I think if they don’t hear from me in a while, they should ring me to check I am okay”

“They said I was fine, but they have never seen me when I can’t get out of bed. They said I was getting enough help”

“Did not really listen. They just wanted me to say that I was okay”

Anger through lack of contact from their key worker was expressed by this respondent:

“The service is not good because there is not enough staff to help everybody. We are labelled and put in boxes. I have been waiting since September 2009 to see and have an appointment with the psychiatrist team. It is now February 2010. That they do this to me is absolutely disgusting. I feel like consulting my MP to complain about the service”

One of the difficulties that some respondents that had moved from a different area expressed was their difference in care to what they had been used to in a different place:

“In Manchester I had a psychiatrist/psychologist, CPN support worker and OT. Then moved here...”

OVERALL EXPERIENCE OF CARE

Questionnaire 3 and 4 consisted of more generic questions asking services users the following:

Q3: Do you feel your care is personal to you? If not, why not? How could the care you receive from mental health services be improved?

Q4: Do you use mental health services? Have you had an excellent service? What has not been so good? Could things have been done better?

From the respondents' discussion of their overall experience of care from mental health services, the following themes can be identified:

- Further discussion of **primary care**, including GP support, counselling and psychologist.
- **Person Centred Care** – actual experience, lack of and need for improvements.
- Experience of **acute care in a hospital** setting (Cross Lane, Esk and Danby Ward) – The wards, staff support, friendship support, practical support (Hospital activities) and support for rehabilitation back into the community.
- Experience of other **secondary care** – Community Mental Health Teams, Crisis Call.
- **Voluntary sector support** – Mind, Survivors, Next Steps and Mental Health Matters.
- **Alternative therapies** – CBT, stress management and problem solving.

PERSON CENTRED CARE

Lack of person centred care

Numerous respondents expressed that their care was not central to them, where they felt like a 'number'. For example:

"Just a name on a file to them"

"Labelled into a tick box, not treated as a person"

"People should be treated as human beings and not just a tick box"

"I feel part of the system, but care-coordinator does not know how I feel"

"More meetings with care co-ordinator requested"

"Firstly people should not be viewed as a tick box situation. People should be treated as humans and all diagnosis should be backed up as I have heard untold stories of people who have had to fight for their rights and are suffering on top of their illness"

"Feel like a piece of machinery in the system. Care co-ordinator does not take into account of how I feel. (I want them) to really listen to how I feel. Care co-ordinator to actually comment on what I say are my problems"

"I want the best people as possible to deal with me. I am a highly intelligent person. I dig into the rights and wrongs and stand up for myself. I am half way through my life and I know what's best for me. I have different levels in mood and have mood swings cos I can no longer go on for the next 40 years. I am not going to be just part of the system. Possibly without medication I would harm myself or others and or to bypass this I move address frequently. (He feels lied to by system (society))"

This respondent expressed anger about how he is not treated as a person but how it is up to him to help himself:

"It is the 'fight of my life' and I have to put all my effort into it. Otherwise it will become an avalanche if I don't do the right thing"

An indication of the need for a person-centred approach is expressed by one respondent:

"Have not really thought about it. They were there when I needed them. Less than some. Moral support. I've just lost my mum. I need someone to do shopping with. Like a support worker. I have to rely on friends"

Another respondent expressed the need for practical support from the services. Their needs again are person centred in that they have moved and need a 'friendship' based support.

“All I have here is a CPN. I need someone to help me going out, shopping, GPs etc. It is very difficult with my anxiety. I have talked and talked about my problems. What I need is help practically to do the day to day things. I had no friends here and no one to help me...”

In this instance, their needs are emotional and practical and not being met by the services.

Person centred care

Respondents did express their own experience of their care as personal to them. Some also stated a case for more person-centred care.

In actuality these questions were answered at the end of the questionnaires and more generally involved respondents writing about their overall experience, good and bad.

There were respondents that were happy with their overall care. As this service-user states that a multi-agency approach to her care is good:

“I feel that my support from the early intervention team in particular has been excellent. I feel like my Social Worker, community psychiatric nurse, psychiatrist have a good understanding of my personality, opinions, intelligence and interests as well as my illness and treatments”

“Brilliant support and encouragement from Early Intervention Team. Continued guidance throughout hospital admission and in community support from social worker”

“GP and psychiatrist work together”

There were others which expressed the need for long term care:

“Long term input is important”

There was reference to the constraints that professionals had to work under which could hinder person-centred care:

“Doctors and psychiatrist should not have to achieve production goals, just treat each other as individuals as an individual and spend as much time as is needed”

“(They should) Call her by her name. Retain information. For me, even in one year one-to-one paying attention to her medical history and interest. Which makes you feel special. Each care worker fascinated by her personal history because they are learning about human beings at your expense”

“Yes, I feel the care I receive from everyone is acceptable by my CPN and doctor”

“I feel I get what I need. I get loads of help”

There has been much emphasis for the need for person centred care. However, sometimes this may not be appropriate if the person is so ill that they cannot judge what is best for them. This is indicated by what one respondent said:

"I saw a primary mental health worker after I visited my GP to ask for my anti-depressants to be restarted as I was feeling terrible. I got an appointment pretty quickly and she took my history in a reasonably sensitive way. But she didn't seem to want to tell me what she could do to help me – she kept saying 'It's for you to say what you want' – all I wanted to do at the time was to lay down and die that was no use at all"

There is a need for a key worker to provide practical help:

"All I have here is a CPN. I need someone to help me going out, shopping, GPs etc. It is very difficult with my anxiety"

Some do not know what help is available and 'what to do...'

"He walked to shop ten times in 6 years. He gets taxis. Has been on benefits for 20 years. He is not capable of working, he is terrified. He has physical problems (pancreatitis). He is weak and dyslexic. Does not know what allowed to do. Rather than be frightened he would prefer to be dead"

It is when people feel they are a 'whole person' and then they are faced with getting well in terms of their life. For example, when this person did not know 'what to do' when he became ill having been in a career before:

"He used to be a chef. Knows everything by the book and French terminology. Took him two years to learn. An 8 months ladder but then hospitalized"

"His belief is 'value yourself less and don't let anyone treat you like a door mat'. He feels like a victim but does not look like one. Terrified to walk"

PRIMARY CARE

Some respondents relied more on GP support than any other:

"I'm GP dependent"

"My GP is very helpful and understanding. With counselling hand in hand. Doctor talks about medication in line with her GP"

"Don't know what would have done without the help"

"GP saved my life"

"Very good"

"The whole surgery is helpful. Feel like listened to"

“He does not trust CPNs and psychiatrists but GPs are very good. Gets a postal not telephone reminder”

The importance of having GP support is expressed when one respondent stated that she was worried when her GP would have to retire.

It seems to be the case that GP support varies. Some are supportive of mental health needs and others aren't. This depends on the GP in question.

A GP can provide a backdrop to other support available, as a reassurance:

“For my mental health needs, the GP is sometimes helpful. It is a reassurance that I can see my GP but outcome not as helpful as expected...requests for further help not taken up. To continue with current mental health services”

“GP helpful within the constraints of the system”

“The consensus of doctors not voicing their opinions because of the system covering its tracks needs investigating”

“Most of the time, but difficult seeing other GPs within the practice and not seeing the same one”

“When GP has time, he is very popular”

“Discuss mental health needs before physical help. I go to him about anything”

For example, other GPs are not so supportive:

“Feels like some of his queries about mental health (depression, psychosis etc.) are not taken seriously by GP”

“GP is upsetting rather than helpful”

“Not clued up...”

“No, I don't think he understands”

“Feels like he just wants to get rid of me”

“Adequate, not really her thing”

“Took weeks before took notice”

“It took over four weeks for me to see a practice nurse at the surgery and I was getting worse”.

“Talking to my GP when I told him I was hearing voices etc. he said there was nothing to worry about but I felt like I was cracking up and did not feel at all reassured. I thought I was going to head for a complete breakdown. I didn't get the reassurance I needed”.

“For years, a GP would not listen. He has suffered all his life since 16 years. Has had ECT. He asked to see a counsellor ten years ago because of depression. He moved and saw a different doctor after original doctor said it was a waste of time. He was discharged last year. Don’t know why probably because of cut backs. ‘It is a crutch you need to go back to in case”

Sometimes the GP could not provide the correct medication. A service user was hospitalised when he had a lack of sleep. Stating that the GP was unable to prescribe diazepam and sleeping tablets on two occasions.

The frequency of GP visits are important. From *“GP monthly meeting”*

“I am speaking with human rights lawyers now in York as I am concerned about the level of professionalism of professionals in the Scarborough area”

Another respondent suggested that his GP took on a multi-agency role, doing the job that the mental health workers should do:

“I don’t see her often enough (the key worker). GP is good. Good with other things. Accommodation is a nightmare. GP is writing to all concerned. For example, council and has got bus pass. GP writes to everybody. He is very helpful. GP takes over Anchorage role”

Psychology

For some respondents having psychological help was useful:

“Excellent”

“Helped me to motivate myself, through guidance and encouragement, rather than being pressured into doing things”

“Very good”

Other services

The mental health nurse in the surgery was described as useful:

“Understanding but can't prescribe”

“Saw counsellor three times and I felt better”

ACUTE CARE IN HOSPITAL

Person-centred care in hospital

Reference to the lack of person care in hospital was raised:

“In hospital I should be told more of what is happening to me”

“There is a lack of belief in the patient and what I say – I am told to just take my medication, not given any help”

“MDT group decisions are different to what has been decided by patients and their main nurse”

“No one discusses reasons with patients”

“Ward has been very helpful. Services not that good”

“Sleep and rest in hospital”

There is a difficulty when there are no beds in Cross Lane and patients have to be referred to Middlesbrough or Durham. In this case it is difficult for a key worker to visit but the Crisis team can take over support:

“I have been very distressed when going to my care manager but he did not make any further appointments with me. When I have contacted my care manager feeling very suicidal he did not believe me. For my care manager to actually believe what I say instead of having pre-conceived ideas about me”

An over reliance on medication prescribed by doctors is not geared towards patient centred care:

“My medication has made me put on so much weight. I have tried to talk to him about it. He thinks it is a wonder drug and isn’t prepared to look at anything else. He just tells me to carry on taking them. He does not seem to be interested with it although I am worried I am going to have a heart attack”

“I do feel, I have to fit into the system”

There is a lack of self-autonomy on the wards. Some expressed the need for more time off the ward:

“Patients are not allowed self-autonomy, to run their own groups, clubs and are expected to do as they told to do and use the OT groups as provided by the hospital...”

It is difficult for patients who live far away to get the care they need from their key worker whilst they are in hospital. For example, a patient said this who lives in Helmsley and her key worker was in Malton.

Friendships

Support can come from friendships made on the wards:

“Meeting other patients in Cross Lane can be helpful”

Lack of support and activities within the hospital

Respondents stated:

"There's boredom on the wards"

"Lack of activities on ward. Therefore, I go to room after meds in morning"

"The plastic sheets on the bed make you sweat...hot drinks only at certain times..hindrance of male patients contacting females on ward"

"Not allowed to take part in table tennis. Patients after discharge should still have access to OT"

"It was in hospital, partly but there was a lot of group things which you were made to feel was compulsory"

"Faster and more OT involvement unable to go to OT or gym because there is never staff available and would like to go to the gym and or daily but can't. Left with nothing of interest on ward. Would like more activities on ward and more speedy recovery"

"There is absolutely nothing to do on the ward. You are left just with your own thoughts. Boredom is a major problem."

"There is nothing to do on the ward. You are left on your own"

"There is nothing to do. OT is non-existent. Even if you get to OT, there is nothing there. You are left on the ward to "Stew in your own thoughts". They have brought it up at the ward meeting"

Lack of practical and emotional support for rehabilitation into community

The importance of a key-worker to help people once back into the community is highlighted:

"I'm scared to come out of hospital without a key worker designated"

"Discharge is difficult with lack of help back into community with OT etc"

"If patients are expected to get into a routine for preparation prior to going home then why can't they make their own beds? And tidy up their own or others dinner plates etc as you would in the real world. Why is there no community board for the patients when there is nothing but red tape and do and don'ts plastered everywhere?"

"I am having to fit into the hospital routine and it's not the way I do things at home. ie. Getting up at set times and having meals at set times. They could leave me to do things I normally do"

Staff

Patients in Cross Lane hospital praised staff for their support and expertise:

“Staff and activities are very conducive to examining heartfelt feelings that guide us through the staircases of days. As we wonder through enduring lives”

“(There is) interest in each other and every person in cross lane are getting to know in-depth personality of each of us it is so ingenuous to our good mental health”

“They do pretty much everything mentioned in pamphlet and caring. No one incarcerates self’s in environment like this. Because can’t get out if wished locked up no way to leave”

“Medication giving me bad side effects. Told I will have to put up with it. He has put a complaint in, been good on the ward about getting certain foods for me. I feel safe on the ward. The staff are nice and helpful”

“I have had a very nice experience staying at Esk in Scarborough. I mean by this – I came in feeling scared and very depressed. The staff have been excellent. Very helpful. Always there to listen and very caring. I have been offered table tennis, exercise and cooking. Which I enjoyed. There was always tea and treats on tap. Thank you”

“I have been in Esk Ward due to a very bad urinary infection which I hadn’t been aware of. However I have been given a course of very strong anti-biotics for this infection. All of the doctors and NHS staff on Esk ward have been absolutely fantastic to me with care and attention to furthering my health in the future. I can only say how much help everyone has given me”

“Excellent. Could not fault it”

However staff were also criticised for lack of understanding of certain patient’s needs:

“Staff lack experience of the mental health system”

“Staff on the wards are just ‘jobs worths”

“Professionals don’t wanna engage you because it makes their job harder they are ‘Jobs worth”

Some patients stated that their care depended on different staff and how some rather than others were more helpful:

“Care depends on the staff on duty”

“Some of the staff are lovely but some staff are hard work with little feeling. They do not appear to have any real experience of what it is like to have a mental health problem. I wonder why they are in this job”

“When I was hungry in the night, it was fine with those good staff and I was able to get a snack but with the others I was refused”

“Some staff are really good and caring. But some are very hard. I went into the office and the member of staff shouted at me to get out. I heard her shout at other patients too. I was desperate for a cigarette in the night but it depended on who was on as to whether they would let you or not”

“They spend all their time in the office and do not enter the day room”

However, the patients did consider the difficulties staff faced in terms of resources to cater for their needs in the ways they wished:

“Staff in hospital are not able to act due to the system – too much red tape”

A respondent recognised the constraints put on staff:

“It has nothing to do with individuals but a lack of resources available”

Indicating that if more resources maybe staff would be able to be more of what patients wanted.

There was also a feeling that a patient could not talk to staff:

“I do not feel able to talk to staff”

One respondent complained that the staff she could not approach the staff and they did not treat her right:

“On the ward, the staff did not come into the day room at all. They said you could go and talk to them but I did not feel able to. If they had been around I could have spoken to them. I was accused by a senior nurse on the ward ‘Don’t talk to staff like that’. I was upset, as I hadn’t said anything to upset her”

Another suggested:

“They spend all their time in the office when they did come out, all they did was watching TV and didn’t like it if you disturbed them”

Some patients felt that the staff just did not care:

“On the ward, a patient threw a cup of coffee over me. The staff just said go in your room. They were not very helpful about it”

Each patient in hospital has a key worker inside, known as a named nurse. However, some respondents did not know who that was:

“No key worker on ward allocated to me”

“I never found out who my named nurse was all the time I was there. When I asked one day they didn’t know themselves”

"I do not know who my named nurse is..."

Other staff on the ward, namely **psychiatrists** and **doctors** were also criticised:

"Doctor on ward was not helpful with physical issues"

"Doctors are unreliable. They don't always turn up on the day. They turn up and expect patients to turn up on the day they say"

"They turn up and expect patients to forgo their plans"

The doctors were described as being *"Disrespectful consultants"*.

Patients suggest that when the care is decided by the psychiatrist it is not patient centred:

"Psychiatrists decide everything"

There is a difficulty with prescribing medication:

"By not changing the dose without the doctor telling you first. As this is where confrontation happens"

A doctor was criticised for not understanding the patient's physical health needs:

"The doctor on Danby Ward did not check my own medical records from my GP's when I requested cream for my psoriasis. Instead he prescribed some everyday cream with 1% hydrocortisone which does nothing for my psoriasis. Which shows he could not be bothered to check my own personal records".

Practical Support

"Practical support is lacking"

There is a need for more staff.

Support to get back into community

Patients suggested that there was a lack of support available to them to help them get back into the community after a hospital stay:

"It depends on GP care – what is happening when they leave?"

"Need for more self-autonomy. To make my own bed, organise OT activities to help me re-adjust before going home from hospital"

"More action taken whilst you are actually in hospital as to what is going to happen to you, the patient, on leave, even temporary leave"

There was a fear that there would be no help available from a key worker once a patient had been discharged from hospital:

“When I came out of hospital I was scared I would be abandoned. My key worker was off sick and I would have really valued someone to come and see me and check if I was okay. But no one has been to my house”

“When I went home, I rang the ward. They promised to ring me later but no one ever did”

SECONDARY CARE

Praise for a key worker was noted:

“Excellent. Very caring and understanding and probably saved my life”

“CMHT do not answer the phone”

“Very disappointed with Anchorage...under crisis team following overdoses. Very supportive. Ringing and visiting 3 to 4 times a week and not letting her down. Expect similar service from Anchorage but did not happen”

“At GPs surgery, the PMH worker works for Anchorage. Supportive and helpful”

“Crisis team are very helpful. I was in Durham hospital for two weeks because there was no bed in Scarborough. Cross Lane staff are excellent. Durham apologised about referral”

“Crisis team was very good but visits for a week before became so unwell needed to be admitted and were patchy and felt could have used more support”

“Crisis team are very good and to phone. They come out if no one else. Doctor rescued her and got her out”

“Did not change medication, too infrequent appointments (psychiatrists)”

In contrast, the crisis team were criticised for not responding soon enough:

“When I was discharged from Cross Lane in October, the last time had seen old care-coordinator and had two phone calls before xmas and was informed on 18th December that she would get in touch and never did. Care coordinator now changed. It was in A and E and there crisis team was informed. Care co-ordinator said she would get in touch and she never did. Had a temporary crisis team member that he was seeing every day. He phoned me on a Sunday to ask how I was and I told him I keep cutting my wrist and his answer was I’ll make an appointment to see you tomorrow. I phone him back to say I am about to gas myself and his answer was that he would have to phone police to cover himself”

“The Crisis team tells me they will ring back but no one does”.

“Very bad. Made complaint to PALS. Better now”

“The Anchorage and psychologist. I ended up even more depressed”

"I stopped using the Anchorage as they had nothing to offer me"

"In the community, partly, it was just about okay but I was given two care coordinators, who turned up at my front door unannounced and I did not know who they were. This made me feel worse and anxious"

Someone said about the whole system:

"In every single way. Fools running organisations that aren't competent"

VOLUNTARY SECTOR SUPPORT

Next Steps

Most of the respondents from Next Steps, a mental health resource centre in Malton stated that they used Mental Health Matters, (a floating support service which is time limited based in Ryedale) regularly as additional to the support they already had in place and a number of people stated that they could rely on this service when no other help was available. Mental Health Matters is located in the very same building as Next Steps.

"Help and support here. Mental health matters upstairs. In station way there is the mental health team. They help together and work together "If not one came out both come out and decide what best for us". I'm happy with things and they couldn't be any better"

"Mental health is a barricaded community. There are Mental Health Matters with a support worker... made life slightly more bearable"

"MH matters have guidelines about what you are supposed to do and have small goals"

"He feels anxious not having a key worker but Next Steps helps 'something to do, part of the furniture'. Does not want to be on own in the house. Talks to someone from next steps if need be and mental health matters for support"

"Had a CPN. Next steps referral has had fantastic care. "Don't know what I would have done without this place"

It therefore occurs that having an additional support service in the same building is very beneficial to service users. This model could be used elsewhere if possible.

Mind

"Mind drop-in at Whitby is better than the support from the Anchorage"

"Mind drop-in is helpful. (named staff) is very supportive. I'm waiting for a befriender which will be helpful".

“In contrast Mind’s drop-in has helped as the people understand me and give me confidence. I take that confidence out with me. I feel understood”

Scarborough Survivors

Is a mental health resource centre; As a service user-led charity aiming to give “the provision of support and information for the relief of persons who have or have suffered mental health difficulties”

It is run as a self-help organisation with people who have in some way been personally affected by mental health issues, either personally or as a carer or friend.

The Resource Centre offers people a ‘safe’ environment where they are not judged by their condition, but treated as an individual in a supportive environment, where they are part of a community. Members offer practical and emotional support to each other by being able to understand each other’s issues from their own personal experience, or be signposted to the appropriate agency where you will be able to receive the service you require. Within the Resource Centre members can take part in activities which are designed to promote mental health well-being and social inclusion, alternatively you can just come in for a chat and a cuppa in the ‘drop-in’ style coffee bar.

Comments from service users spoken to at Scarborough Survivors are incorporated into the report.

ALTERNATIVE THERAPIES

Problem solving

One particular lady was offered problem solving techniques when she was depressed and suicidal. It made her angry:

“What did she (PMH worker) think I had been doing? Sitting there wringing my hands waiting for someone to come and rescue me? I had tried every kind of problem solving, positive and negative, that I could think of and had come to the conclusion that there was no way out except suicide. Her blithely suggesting that after knowing me for two hours we could ‘solve my problems’ together was completely patronising and offensive”

Stress management

“Problem solving and stress management in hospital”

“Has been forced to use self-help groups for alcoholics. Social services tell her she has to be hospitalised”

“Psychotherapeutic work now is not particularly useful. Problem solving support is okay in the short term”

“for support given in past which had long term benefit and insight building value to be reinstated. Afraid I may relapse without it”

“Working on our personality defects”

MAIN FINDINGS

The following points represent, in the researcher’s opinion, the main issues to emerge from all of the questionnaires.

Primary Care

- Almost all respondents had a GP and a majority stated that their GP was helpful towards their mental health needs.
- Some respondents expressed that their GP was the best source of help to cater for their mental health needs and at times took over what is the role of the key worker.
- However, the help of a GP varies dependent on who they are. Some GPs are described as inadequate and having a lack of understanding of their patient’s mental health needs. This can effect referral waiting times.
- Service users are aware that GPs work within the constraints of the system.

Referral to mental health services

- Two thirds of the respondents had been referred to another mental health service.
- Out of these, a higher number of respondents were seen straight away. However, a large number of respondents had a longer waiting time between 1 week and 3 months.
- Some service users stated that they had to be acutely ill in order to be referred.
- Lengthy referral waiting times are damaging to service users who need to be seen immediately owing to the nature of their illness.

Experience of care from the mental health system

Keyworkers

- Most respondents said that the level of their care was worse in the absence of a key worker. A high number said that they were left with no care in this instance.
- Service users are aware that if their key worker is away they can contact another professional: mental health worker, GP or crisis call.
- There are problems when their key worker changes.
- A lack of a key worker is damaging to service users who need to be seen immediately owing to the nature of their illness. This is also important in terms of the frequency of keyworker appointments. With the need for continuity and long term input.
- Key workers should not expect their patients to ring them if they need help and should not assume that if the service user has not made contact that they are well.
- Some respondents stated that they were not getting a good service from their key worker because they do not understand all their needs and just go for coffee all the time.
- Most respondents had a mental health worker.
- The benefits of the crisis team were recognised. Particularly that it is a service they can rely on in crisis when their key worker is not available.
- Although, there was reference made that the crisis team are not immediately responsive to acute crisis such as suicide attempts.
- The frequency of visits is satisfactory, with most respondents seeing their key worker either weekly or fortnightly. Out of these, most respondents said that this time is 'just right', with under half saying it was 'not enough'.
- A significantly high number of respondents that leave a message for their key workers are contacted later that day. Almost all respondents are contacted by their key worker when they say they will contact them. A majority of respondents said it was easy to get a message to them, with a third saying it was 'not easy'.
- There needs to be support at the time coming up to discharge. Where the service user needs to know the level of support available and frequency of visits.
- There are differences in care when services users have recently moved to the area compared to where they used to live.

Care Plan

- Most respondents knew they had a care plan but a third of these stated that they had no care plan at all.
- A number of people said they did not need one because it was 'in their head'.
- Some respondents also said that they did not need a care plan because the professionals 'know best'.
- More respondents than not did not have a copy of their care plan.
- Most respondents had been consulted on the updates of their care plan.

Person-centred care

- Many respondents expressed that their care was not central to them, where they just felt like a 'number'.
- Respondents wanted more emotional and practical support which considers their individual needs.
- Some respondents are happy with the care they receive which is a multi-agency approach.
- Professionals were praised for their understanding of the patient's personal history.
- Long term care is important.
- Is person-centred care necessarily a good approach? Where one respondent stated that so much emphasis was put on her to solve her own problems that the professional could not tell the patient what she could do to help her.
- Some service users do not know what help is available.

Acute Care in Hospital

- Some patients in hospital are unaware of the help that is available.
- There is a lack of belief in the patient helping themselves to get better.
- There is an over-reliance on doctors prescribing medication which does not consider the patient's overall needs. Where too much of the patients decisions are made by the psychiatrist who expect to see patients in their own time.
- On some occasions in hospital, the doctors would not look at the physical health of patients and know what their medication was through a lack of insight looking at their records.

- There is a difficulty when no beds are available close to home and patients are referred to Middlesbrough or Durham. Also when they live far away from Scarborough. Where it is difficult for a key worker to visit.
- Lack of self-autonomy and independence from patients to get themselves better, with the view to going back into the community. Where they are only told what to do in hospital.
- Friendships made in hospital can aid recovery.
- Boredom due to lack of support and activities is damaging for recovery.
- The need for a key worker to support people to get back into the community is important, in and out of hospital.
- Hospital staff were praised for their support and expertise. Some say they understand the patient's individual needs.
- However, others suggested that they lack experience of being mentally ill and are 'jobs worths'. Where they spent too much time in the office and not with patients.
- Hospital treatment such as having a cigarette or snack depends on staff on duty.
- There was recognition by patients that staff have to work within the constraints of the system and available resources.

Voluntary sector support

- The Mental Health Matters service was invaluable to people that went to Next Steps resource centre, because it was located in the same building.
- All respondents that were questioned at Next Steps agreed that it was extremely helpful and supportive in helping those with mental health problems.
- Mind Drop in is helpful with people that understand and gives you confidence.

Alternative Therapies

- Problem solving techniques were beneficial but also patronising.

CONCLUSION

Our central aim in the VOICE project was to listen to service users' experience and knowledge of their care. Respondents expressed their experience of: primary care, referral to mental health services, secondary and acute care. They spoke of their good and bad experiences and how services could be improved and developed.

As this year's VOICE project has come to an end with the results highlighted in this report we have learnt a great deal about the care of numerous service users. Most respondents stated that their GP was helpful towards their mental health needs but some more than others. They are also aware that their GP support can only work within the constraints of the system. Referral waiting times vary and lengthy waiting times together with a lack of a keyworker affect the care they receive. This is owing to the nature of a mental illness. Keyworkers are useful and without them the level of care received is greatly affected. Keyworkers should not expect the service user to ring them and assume they are okay. It is sometimes impractical for a service user to maintain contact and they might be so ill that they cannot contact them. The Crisis team were praised but the urgency of support is paramount owing to the nature of mental illness. A majority of respondents did not have a copy of their care plan. Many stated that the care they receive did not consider their individual emotional and practical needs. Not all service users know what help is available. This occurs also from hospital patients. In hospital, patients want more self-autonomy and independence to help them back into the community. Staff were praised and patients are aware that they work within the constraints of the system. Voluntary sector support was invaluable and geared towards understanding service users' individual needs. Occurring more so than in statutory care because they have to work within the constraints of the system.

There is room for development. For example we took a bottom-up approach to our investigation. There could be scope in the future to also speak to mental health professionals. In order to listen to their views so improvements can be made. We also have some limitations on reaching out to those with mental health problems that don't have connections to the places where we have gone to, to ask their opinions. It has been very useful to have two service users as VOICE project coordinators. This could be developed further by asking more service users to become involved in the research design.

This is just the beginning. We aspire to develop the VOICE project even further through disseminating these current results to both service users and professionals alike. We hope that the VOICE project will become widely publicised so that professionals actually listen to the needs of the service user in their treatment of care. So that managers and service users alike understand the current situation of person-centred care and the Recovery model. We have obtained funding for another year and the main issues arising from this first cohort of the project will be addressed more thoroughly in the future.

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