Harrow User Group (HUG)

Review of NHS primary and secondary care services in Harrow 2013-14 by people experiencing mental health problems

Report Findings & Recommendations
March 2014





www.mindinharrow.org.uk

Mind in Harrow, First Floor, 132 - 134 College Road,
Harrow, Middlesex, HA1 1BQ
Tel: 020 8426 0929 Email: info@mindinharrow.org.uk
Registered Charity No 1067480 | Registered Company No 3351324

mind for better mental health
Harrow

Acknowledgements

Mind in Harrow would like say a big thank you to the Harrow User Group (HUG) Reps and NHS Harrow for supporting the coproduction of the mental health questionnaire and focus groups to review NHS mental health service in the London Borough of Harrow.

Mind in Harrow would also like to thank all the mental health service users who gave their time to answer questionnaires and take part in the focus groups.

The working group that made this was review possible included:

Raksha Pandya, User Involvement Coordinator
Harrow User Group (HUG) Reps, Mind in Harrow
Christine Knights, NHS Harrow Clinical Commissioning Group (CCG) Lead
Rajvi Kotecha, HUG Data Analyst Assistant

Report produced: March 2014

What is the Harrow User Group?

The Harrow User Group (**HUG**) is a collective of mental health service users seeking to improve mental health services in Harrow in a way that reflects their needs, wishes and expectations. HUG also actively promotes a positive image of mental health in the community to push for equal rights and opportunities for people with mental health needs. The Harrow User Group reflects the diversity of our community.

Why the Harrow User Group?

The Harrow User Group is based on the principle that service users, through their contacts with mental health services, have become **experts by experience**. In this respect, it promotes the idea that service users have a valuable contribution to make to services and society.

What are the benefits?

- Invitations to the Quarterly Users' Forum
- A free Quarterly Newsletter
- Opportunities for volunteering, trainings and develop new skills and paid sessional work £18.00 per session.
- Opportunities to become a User Representative at health or social care initiatives with regular training, support for meetings attended.

Contents

Executive Summary

In April 2013, Mind in Harrow's User Involvement Project, funded by NHS Harrow and Harrow Council, was approached by the Harrow Clinical Commissioning Group (CCG) Lead to undertake a consultation with mental health service users. The aim of the consultation was to enable Harrow CCG to capture the experience and ideas of Harrow mental health service users' to shape their local Mental Health Strategy and implementation plans.

During April and May 2013, the User Involvement Coordinator supported Harrow User Group Reps (HUG Reps) to devise a questionnaire based on the North West London CCG Adult Mental Health Strategy priorities. The three areas agreed to be consulted on were
1) 'Hospital and inpatient care' with a focus on Care Programme Approach (CPA),
2) 'Enhanced mental health care in primary care' and
3) 'Recovery and rehabilitation'.

The views and feedback from over 150 service users via questionnaires and focus groups have been collated and summarised in the form of charts and key themes. This report outlines the main findings from the quantitative and qualitative data and sets out a number of recommendations against the three areas consulted on, to support the development of a robust local Mental Health Strategy for Harrow CCG.

The key issues that have arisen from this report indicates that mental health service users want more choice and control over their lives and to be treated as equal partners in their road to recovery. Arbitrary boundaries of health and social care appear to hinder the service user's recovery and in this report mental health service users unequivocally call for a more holistic package of care at every stage of their journey. Essentially they want to be seen as real people rather than conditions.

Key recommendations to promote quality of life for people with lived experience of mental health include:

- Provision of a holistic approach focusing on the health & social care needs of the client
- Shared decision making
- Provision of a range of community support such as alternative therapies, counselling and social groups
- Training & education of staff

Harrow mental health service users want the views and needs voiced in this report to improve and shape a responsive mental health strategy for the residents of the London Borough of Harrow. The next step is therefore how Harrow CCG and mental health service users will continue this dialogue and work together to make this a reality.

Methodology

Data Collection Tools

Two evaluation tools were used to consult service users to ensure the experience and ideas of Harrow service users' were captured to shape the local Mental Health Strategy and implementation plans. They were a 1) questionnaire and 2) focus groups.

The semi structured questionnaire, was designed by HUG Reps under the guidance of the User Involvement Coordinator and the Harrow Clinical Commissioning Group (CCG) Lead. A small sample of service users tested out the questionnaire, which was completed to test the validity and efficacy of the questionnaire design. It was based on NWL CCG Adult Mental Health Strategy themes
1) 'Hospital and inpatient care' with a focus on Care Programme Approach (CPA),
2) 'Enhanced mental health care in primary care' and
3) 'Recovery and rehabilitation'.

The format used a five point Likert scale which ranged between 'not at all' and 'fully met' or multiple choice questions which allowed service users to choose a number of options in their response.

There were 19 questions split across the above three themes:

- Theme 1 had nine questions, theme 2 had seven questions and theme 3 had three questions.
- There were comment boxes attached to eight of the 19 questions and there was a general comment box at the end of the questionnaire in order to elicit qualitative feedback.
- Demographic data was also collated to assess the representativeness of service users completing the surveys.

There was a cover sheet attached to each questionnaire to transparently explain:
1) the purpose if the questionnaire,
2) the mental health strategy,
3) what would happen with the feedback from the questionnaire and
4) information about focus groups.
The questionnaire was anonymous and used easy read language to increase completion rate.

Data Collection via Questionnaire

The questionnaire was disseminated by HUG Reps to all the main mental health day centres, inpatient services, Black, Asian Minority Ethnic Refugee Groups (BAMER) and at service user events such as the Harrow User Group Forum. By December 2013, 151 service users had completed and returned a mental health strategy questionnaire.

Data Collection via Focus Groups

The two focus groups held in July 2013 were led by Mind in Harrow staff. The focus groups explored central issues which were identified across the three key themes from the initial questionnaires collated. Participants self-selected to be a part of the focus group by expressing an interest to the User Involvement Coordinator. Five service users attended each focus group. Although the sizes of the focus groups were small the groups were representative in terms of gender, ages and ethnicities and provided rich feedback, which corroborated the findings collated in the questionnaires.

Data Analysis

The quantitative data collated from the questionnaires was evaluated, analysed and presented in a variety of charts, with an analytic summary of the key results. The themes from the focus groups were coded and thematically analysed for common issues which were discussed by service users.

Research Limitations

To increase the number of valid questionnaires HUG Reps were tasked with explaining the questionnaire and scanning incomplete sections before the questionnaires were collected in. Incomplete questionnaires were withdrawn from the analysis.

Key Findings and Recommendations

Section 1: Hospital and Inpatient Care - Care Programme Approach (CPA)

Key Statistics:

- 46% of service users reported they would like a family member to be involved in developing their care plan.
- 50-70% of services users reported they were partly or not involved in the CPA in areas such as 'being informed who would attend, 'developing the care plan', 'addressing social/cultural/religious needs, 'meeting their expectations for help'.

Key themes from focus groups:

- Service users want choice and control over who attends the CPA meetings
- To be informed of their rights and receive copies of CPA notes on the day
- GP's to be involved in CPA's
- To use CPA's as a mechanism to integrate service users back into society by focusing on social care aspects more holistically with health care needs

Service User comment (2013)*:*
"Consultants should lead the discussion with the patients, but in her experience they talk over the client…to other people in the room."

Recommendations:

- To ensure a more holistic way of working with service users which integrates social care and health needs
- Involvement of the GP from the beginning to aid the service user's transition from secondary to primary care
- Empowers service users to be at the centre of the CPA by treating them as equal partners who share in decision making
- Provide notes from CPA on the day

Section 2: Enhanced Mental Health Care in Primary Care

Key Statistics:

- With the exception of medication and referrals to counselling, in the main support offered by the GP was approximately 50% lower than what service users felt would be helpful e.g. help in a crisis, physical health care.
- Over 50% of service users felt their GP's knowledge could benefit from more information at the surgeries and mental health awareness training for all staff and over 40% felt outreach workers based at GP surgeries would support GP's knowledge

Key themes from focus groups:

- Physical health care of mental health service users to be promoted within primary care
- Stigma and misunderstanding experienced from staff in primary care
- Increased knowledge of community resources

Service User comment (2013)*:*
"Stigma busting and general awareness training to increase knowledge and reduce discrimination."

"A drop in surgery once a week for example, run by a mental health nurse. They have special diabetes nurses and clinics, why not MH ones?"

Recommendations:

- To introduce Training for all staff covering stigma and cultural issues
- To discuss mental health and physical health with mental health service users
- Offer longer consultation sessions to mental health service users
- To provide outreach sessions with specialist staff and trained mental health service users at GP surgeries to support mental health clients
- Seek alternative ways to meet service users' needs e.g. offer alternative therapies.

Section 3: Recovery and Rehabilitation

Key Statistics:

- 60% of service users felt quick and easy access to talking therapies would help prevent admissions.
- 58% of services users felt that they were partly or not involved in the discussion about their treatment and discharge plans.

Key themes from focus groups:

- Offer practical support such as training/key worker to reduce readmission
- To take a holistic approach when reviewing support for service users preparing for discharge
- Access to talking therapies and activity based groups in the community

Service User comment (2013)*:*

"Someone to help with the transition period at initial phase of release from hospital would be good. Interim support."

Recommendations:

- To use a person centred approach to involve service users in their treatment and discharge plans
- To invest in more accessible and wide ranging community support
- To bolster the resources in A&E Liaison
- To provide more intensive support during the initial stages of discharge

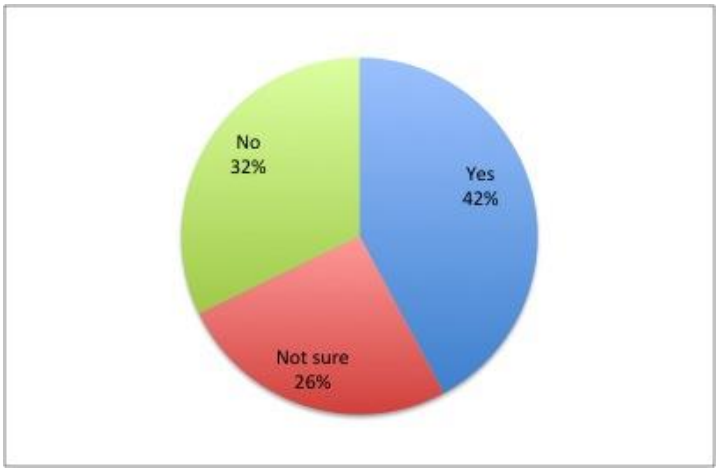
Results & Data Analysis

Each question in the Questionnaire has been included in the 'Results and Data Analysis' section. For ease of reference the question is stated and the data is presented in the format of a graph with a summary explanation of the pictorial data directly underneath it. Where appropriate the qualitative data collated from the questionnaire or Focus Groups are included to enhance the quantitative summary of the data.

Section 1: Hospital and Inpatient Care - Care Programme Approach

In total 140 responses were collated from this section.

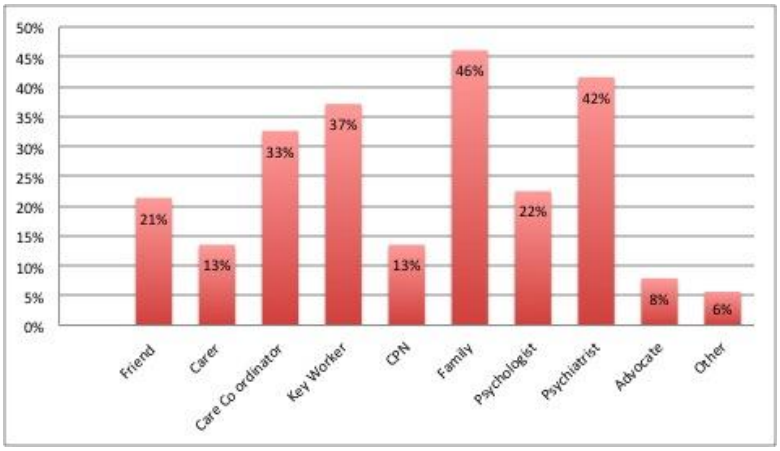
1. Are you currently on a Care Programme Approach?



Graph Interpretation

140 participants answered this question. The results indicate 42% are on the CPA, 26% were not sure and 32% were not on a CPA.

2. Who are the people you would like to be involved in developing your care plan?



Graph Interpretation
89 participants answered this question. Those who answered 'not sure' to the Question 1, but filled in the subsequent section pertaining to care plans have been included in the analysis.

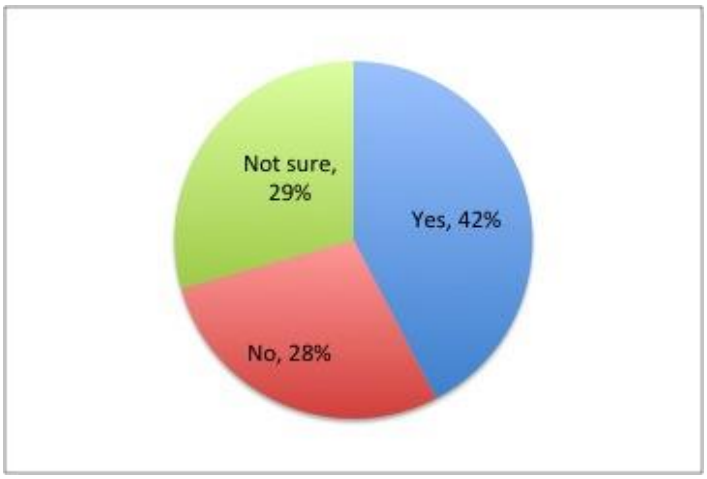
The results indicate that the most favoured people to be included in development of a care plan are family (46%), psychiatrists (42%) and key workers (37%).

Service User comment (2013):

"A trusted friend. If a person cannot articulate things, a friend could do this for you. This could be a carer or relative too."

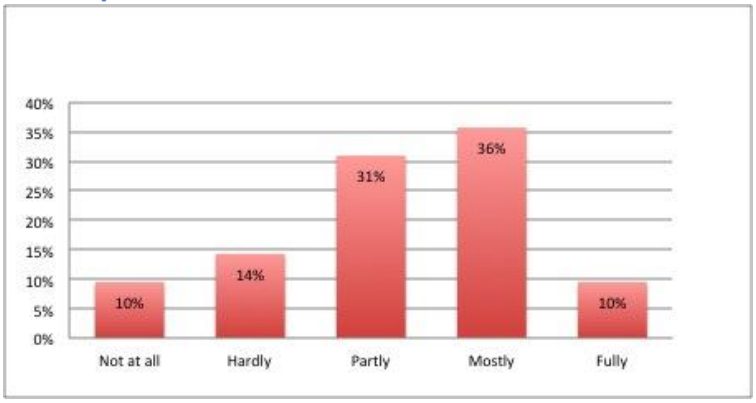
"Would like service user choice as to who is there and need to discuss why"

3. Are you informed in advance which professionals will be present at your CPA/Care planning review meeting?



Graph Interpretation
85 participants answered this question. The results indicate that 42% were aware of who would be invited in advance and over half of service users (57%) either do not know or are unsure of who will be present at their planning or review meetings.

4. How far are you actively involved in the development of your care plan?



Graph Interpretation
From a total of 84 responses, 46% of participant's felt they were mostly or fully involved in the development of their care plans, whilst 55% felt they were partly, hardly or not involved in the development of the care plan.

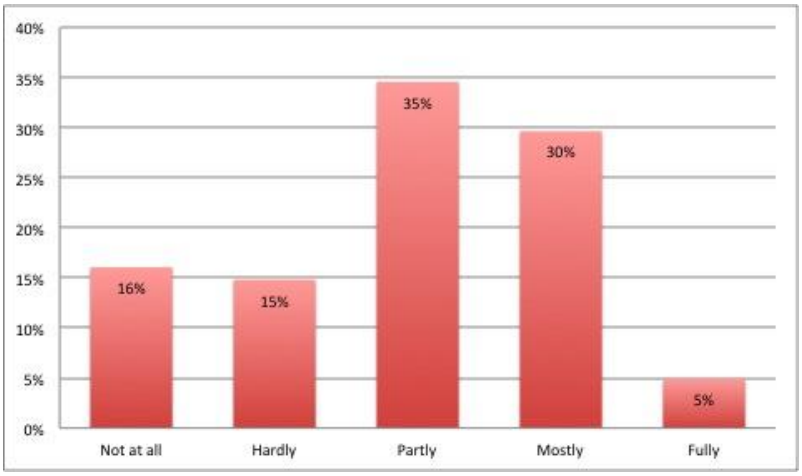
Service User comment (2013)*:*

"CPA is challenging, intimidating and overwhelming"

"It's also about being timid, when you are just coming out of primary care/time of distress you are extremely vulnerable and people in CPA seem to forget that. That one needs space to be expressive."

"CPA should not be tick-box exercise"

5. How much are your social care needs discussed and covered in your care plan, for example social activities, taking steps towards employment?



Graph Interpretation
From 81 participant responses, 35% believed their social care needs were fully or mostly discussed and covered in their care plans and 66% thought their social care needs were partly, hardly or not covered in their care plans.

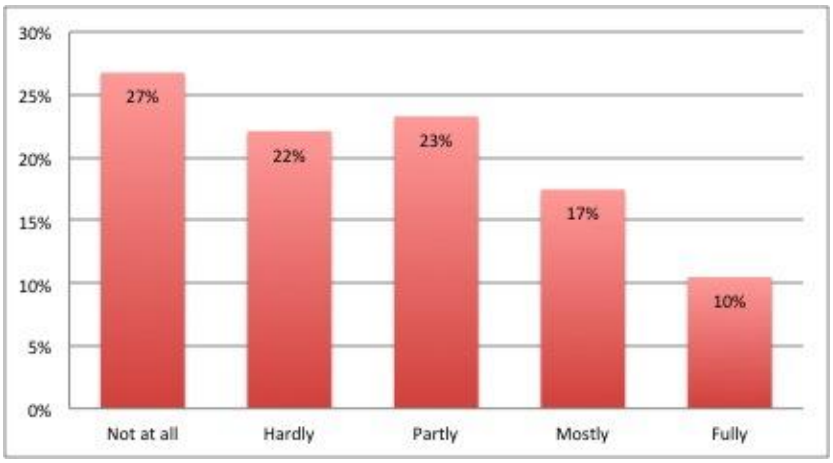
Service User comment (2013)*:*

"Social needs have been addressed, should be holistic approach, we want person-centred approach."

"Before discussions begin, the CPA team should be aware of what things are available to clients so they can signpost with ease. Have knowledge of some services at hand that could be accessed by client. Personal budget things for example: what is available to people and how to use it is not widely discussed or available yet."

"Client needs taken into account, gentle steps, and holistic care."

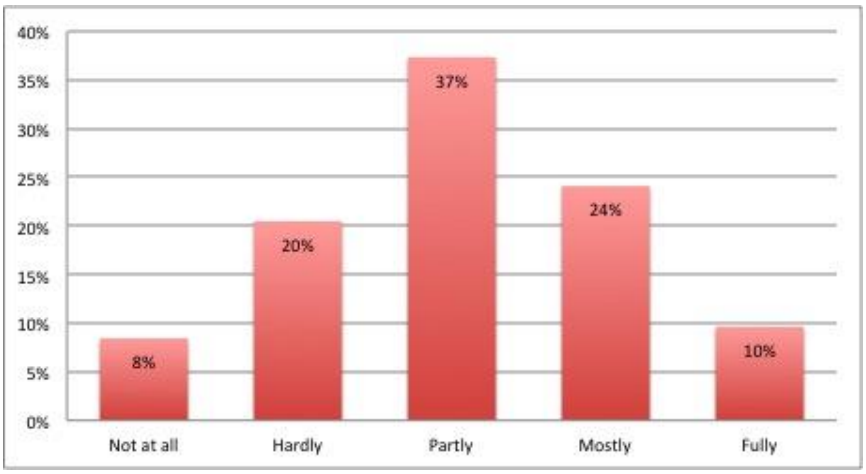
6. How much are your cultural or religious needs discussed and covered in your care plan?



Graph Interpretation

From 83 respondents, 27% thought that there cultural and religious needs were fully or mostly met and 72%, thought they were only partly, hardly or not met at all.

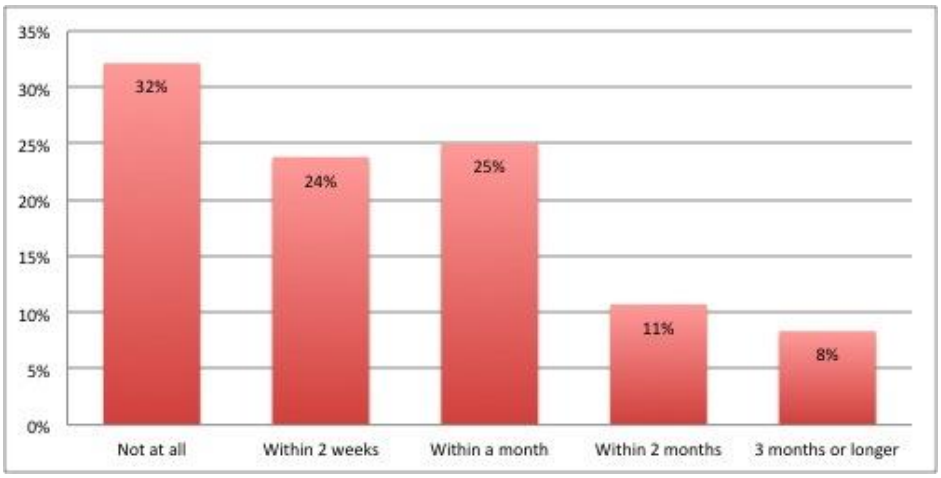
7. How far has your care plan met your expectations for help and support from mental health services?



Graph Interpretation

From 83 responses, 34% agreed that their needs were mostly or fully met by their care plans and 65% reported that their expectations for help from mental health services were hardly, partly or not met by their care plans.

8. When your care plan was last completed, how long was it before you received a copy of your care plan?



Graph Interpretation

The results indicate that from 84 responses that 32% have never received a copy of their care plan. (N.B. Ten of these respondents were not sure if they had a Care plan). 24% received a copy within two weeks, and 25% within a month. 19% had to wait between two and or longer.

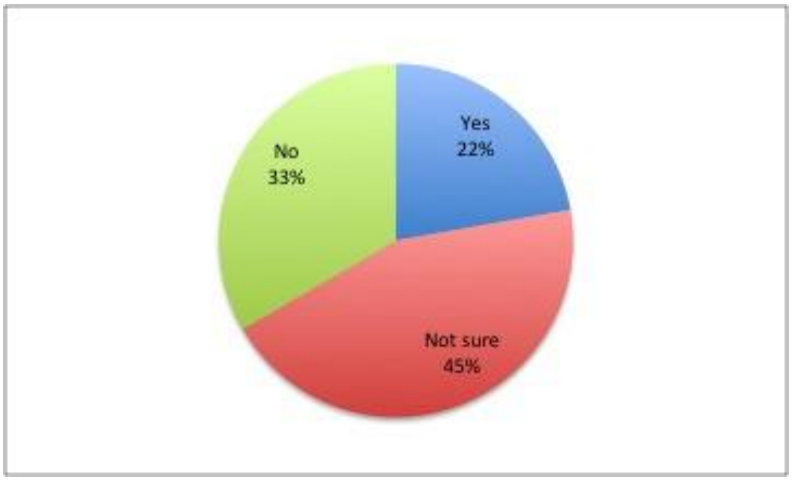
Service User comment (2013)*:*

"People should be given notes immediately, the day of the meeting. Someone should be taking notes in meeting. This will instill more trust in the system and relationship. And things don't get lost in the post."

"Immediate recording is important, straight away, as things are fresh in the mind and information is captured in the truest form."

"Notes should be written and read out and agreed with patient"

9. If you are not on CPA, do you feel you need to be?



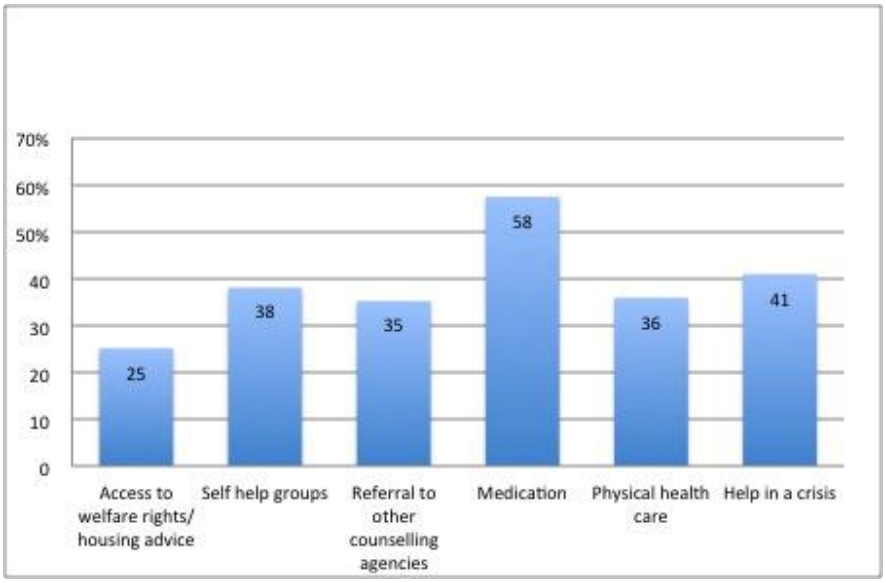
Graph Interpretation
For this question the results were taken from a total of 55 responses (N.B. those that answered No to question 1 or Maybe and did not fill in the subsequent CPA questions were not included). Out of these responses, 45% were not sure if they should be on one, 44% were sure they should not be on one and 22% thought they should be on one.

Service User comment (2013):
"I am always worried that I might become ill again but because I seem "sorted" the team took me off my C.P.A. some months ago. I still feel isolated and worry if, in doing so, they were premature!"

Section 2: Enhanced Mental Health Care in Primary Care

In total 139 responses were collated from this section.

10. How can you best be supported by your GP after you have been discharged from your psychiatrist?

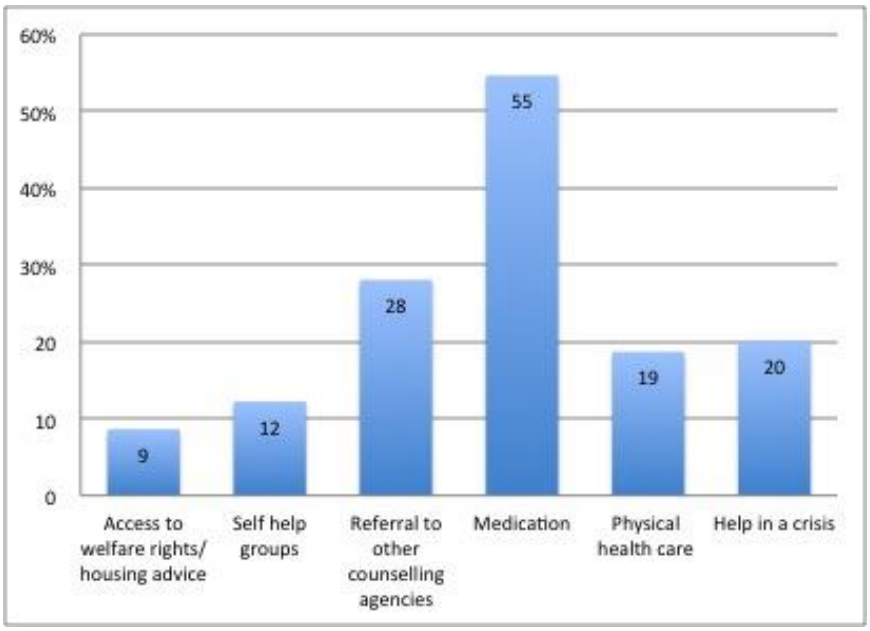


Graph Interpretation
The results indicate that the best way to be supported by a G.P. following discharge from primary care is with medication (58%). The second most popular response was help in a crisis (41%). The third most popular response was with self help groups (38%).

Service User comment (2013):
"More centres like Wiseworks and The Bridge to help mental health patients to gradually come out of their state and be more useful to themselves and society. This would provide more meaning to those affected by stigma."

"My main needs at the moment are affordable (free?) Psychotherapy, group psychotherapy. A support group, at least somewhere and something to do during the day."

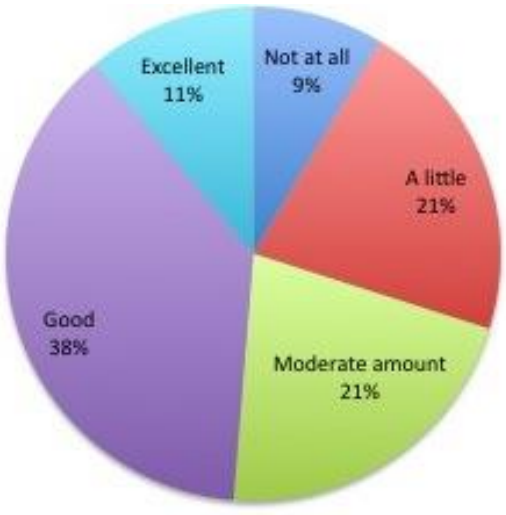
11. When you have been to your G.P to ask for support for your mental health, what has been offered?



Graph Interpretation

Matching expectations from the responses to the previous question, G.P's met service users need with medication (47%). The results indicate more of a disparity with the other areas such as help with a crisis and access to self help groups.

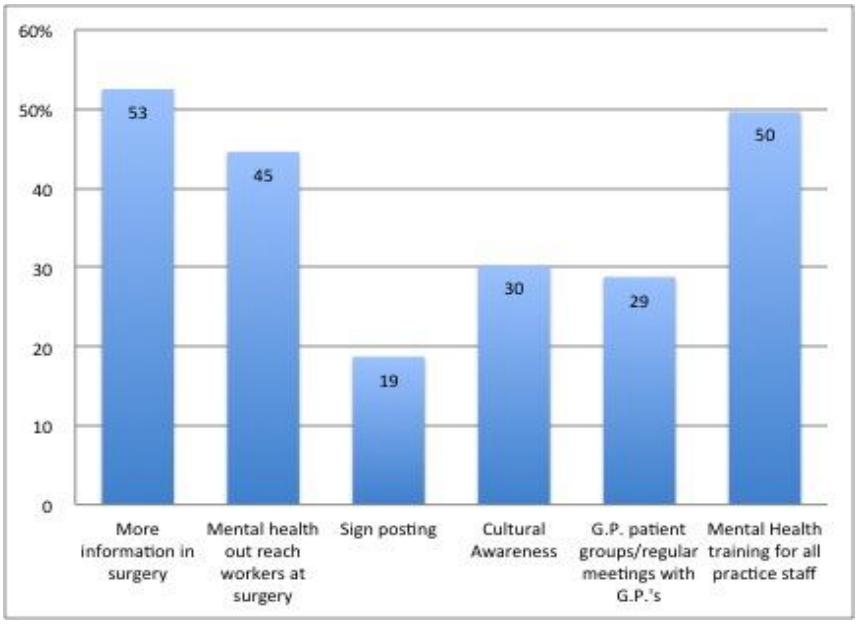
12. In Harrow, rate how much your G.P. is aware of mental health support services available?



Graph Interpretation

The results indicate that 49% of participants believe that their G.P. has good or excellent knowledge of mental health support services available, a comparable 42% have only a little or moderate knowledge of services available, and 9% are reported to have no knowledge at all.

13. How would you like to see you G.P's knowledge of local mental health improved?



Graph Interpretation

The results indicate that top three ways service users would like to see their GP's knowledge improved included more information at the surgeries (53%), mental health training for practice staff (50%) and mental outreach workers at surgeries (45%). Cultural awareness and involvement in regular patient groups all scored above 25%.

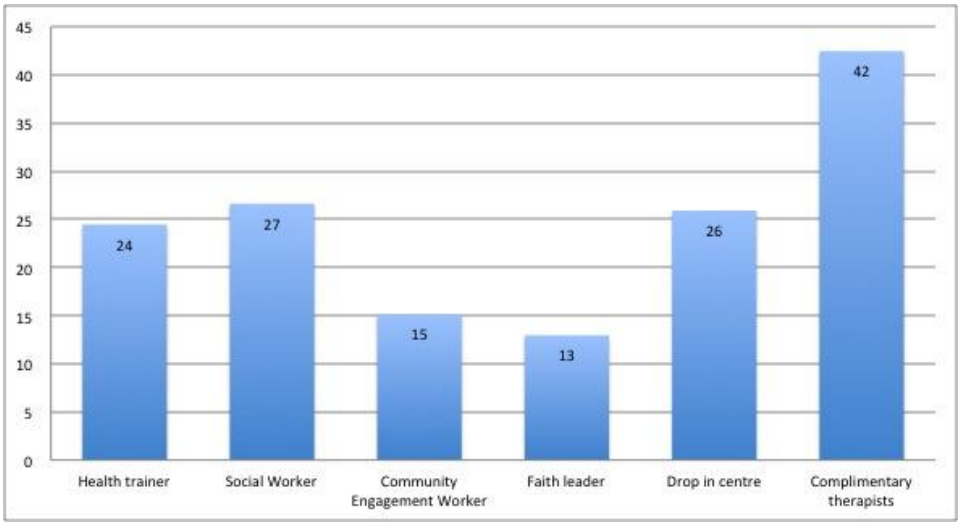
Service User comment (2013)*:*

"At my G.P. receptionists don't even talk to the patients properly. They really need to learn that."

'There is stigma against mental health users. One practice nurse who administers monthly injections referred to them as 'nutters'!"

'G.P.'s need a lot more training on mental health and there needs to be a mental health liaison nurse.'

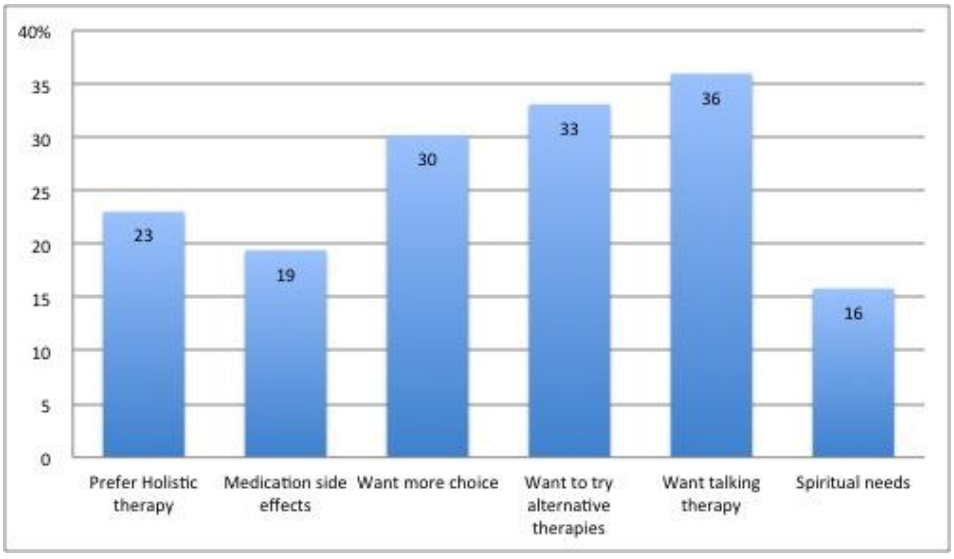
14. Would you prefer to see another health professional other than your G.P.? If so, who?



Graph Interpretation

The results indicate a strong desire to seek complementary therapies (42%). The second most popular response was Social Workers (27%)

15. If you would prefer to see another health professional other than your G.P, why is that?



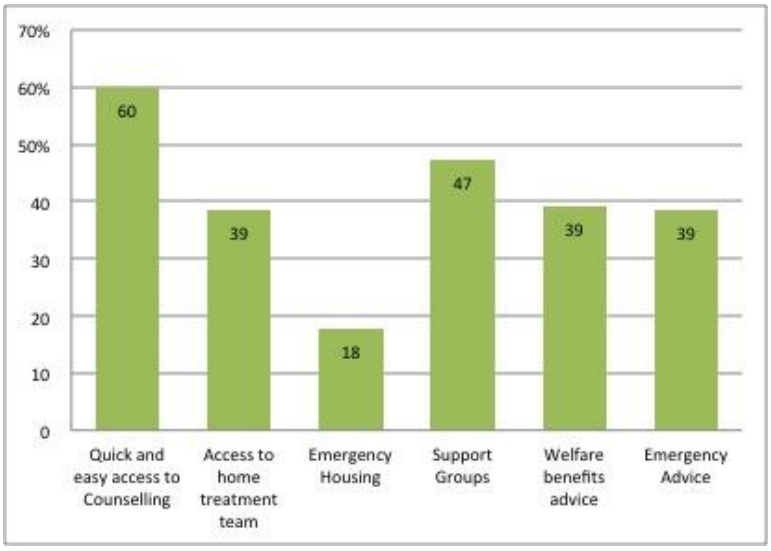
Graph Interpretation

The results show that 56% wanted holistic therapies or alternative therapies and 36% of respondents want talking therapies.

Section 3: Recovery and Rehabilitation

In total 122 responses were collated from this section.

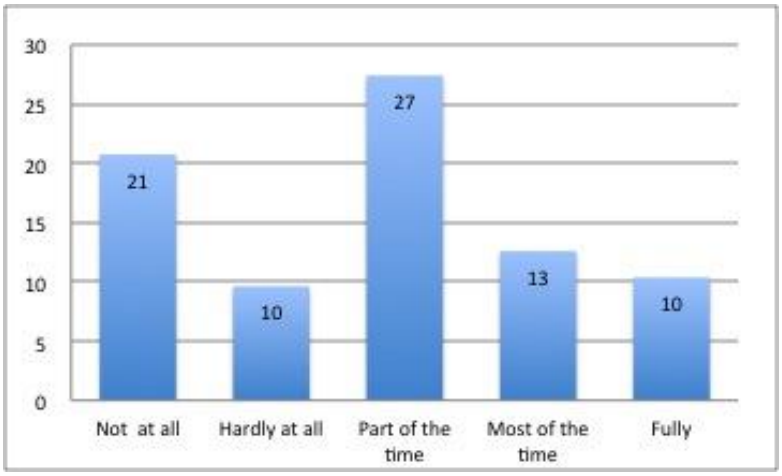
16. What type of support do you feel is helpful to prevent admission to hospital?



Graph Interpretation

60% believe quick and easy access to counselling would help prevent admission to hospital. Access to support group was the second most popular response (47%), and 39% believe access to home treatment would also help prevent readmission.

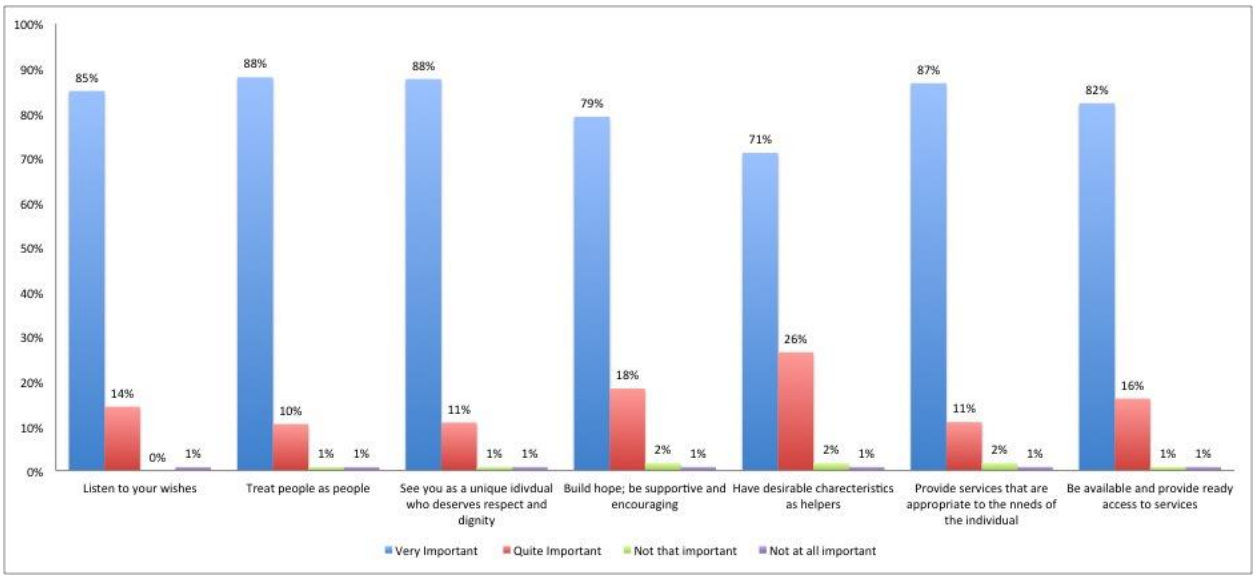
17. How much are you treatment and discharge plans discussed and agreed with you whilst in hospital and after discharge from hospital?



Graph Interpretation

From 105 responses, only 23% replied that their treatment and discharge plans were fully or mostly discussed and agreed whilst in, or after discharge and 58% responded that their treatment and discharge plans were partly, hardly or not discussed at all with them.

18. How can mental health services and staff improve their support to you in your mental health recovery?

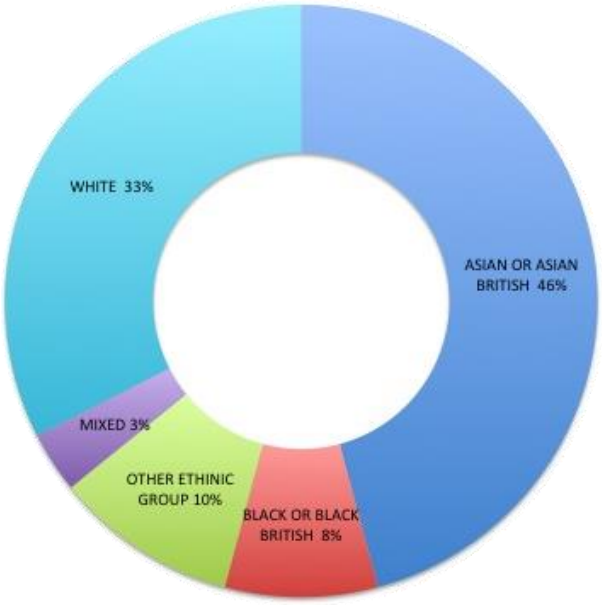


Graph Interpretation

The results indicate that service users feel that all the above-mentioned qualities are very important for mental health services and staff to have. The most significant factors being, for staff and services to treat people as people, and to respect service users as unique individuals.

Equalities monitoring data

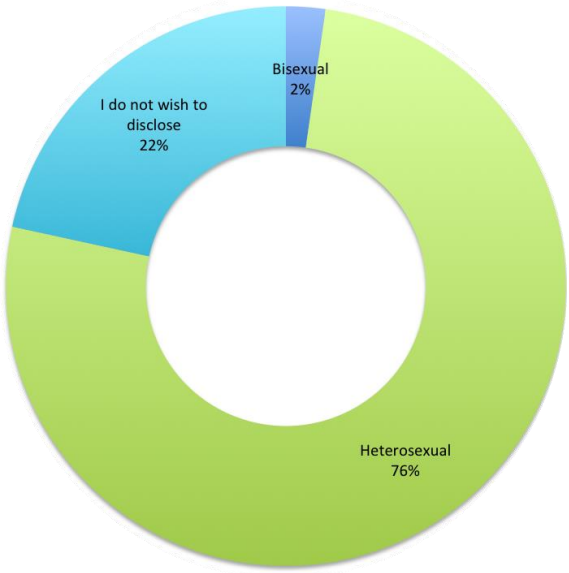
19. Ethnic Group



Graph Interpretation

The results were taken from 120 responses. The largest ethnic group was Asian or Asian British (46%), with the second largest being White British (33%).

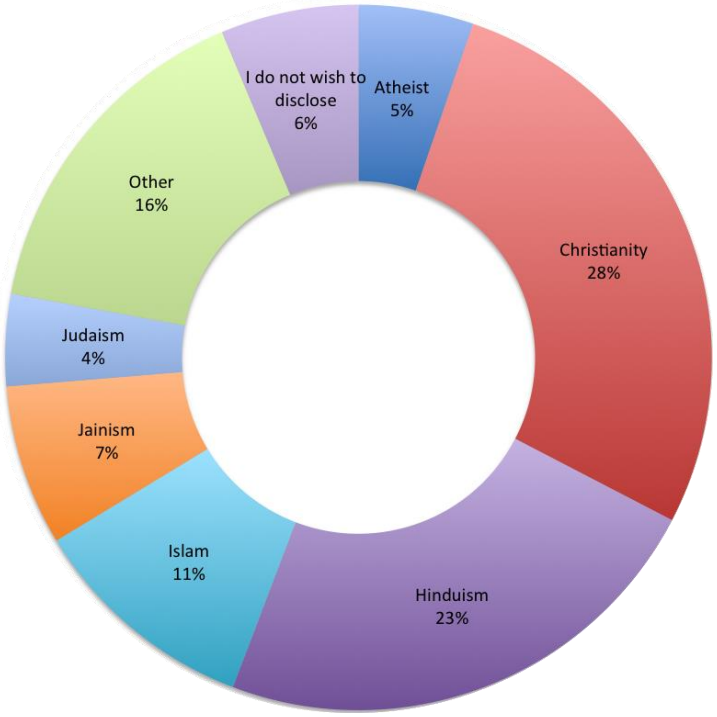
20. Sexual orientation



Graph Interpretation

The results show that the majority of respondents were heterosexual, 76%.

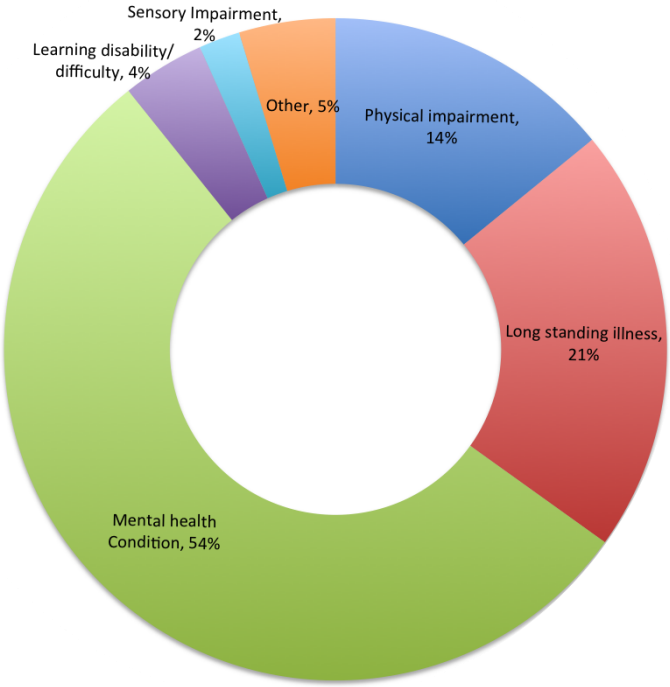
21. Religion/Belief



Graph Interpretation

The results show that the Christianity (28%) and Hinduism (23%) make up over half the religious background of respondents.

22. Disabilities



Graph Interpretation

35% of the respondents indicated that they long term illness or physical impairment.

Appendix 1: Comments from Questionnaires:

Section 1: Hospital and Inpatient Care - Care Programme Approach (CPA)

If you are not on CPA, do you feel that you need t o be? If yes, why?

- The medical team should be aware of our condition, situation and to keep up to date as our health differs day to day
- Help in mood. I am feeling isolated. Drugs do not help without this service.
- Don't know what CPA is all about
- No one has ever explained what C.P.A. is.
- My psychotherapist between 2010-2012 said I would need a CPA, but I do not know if it was ever implemented. I may have one, but am not sure.
- Need more support from care team
- I'm with St. Luke's
- Involved in ESOL, CONVAS, User led support group (Friday), voluntary jobs
- So that I can sign post my ability and learn more about my health
- I want that somebody to care for me
- Need to know about changes
- I have severe leg pain (somatic) and PTSD which requires a proper care plan
- I am always worried that I might become ill again but because I seem "sorted" the team took me off my C.P.A. some months ago. I still feel isolated and worry if, in doing so, they were premature!
- C.P.A. really meets my needs

Section 2: Enhanced Mental Health Care in Primary Care

Ways you were offered help and support by your G.P for support for your mental health?

- Initially not encouraged to talk regarding my depression. Then told was OK. Referrals - seen as expertise who knows nothing about
- Nothing
- None. I wanted referral to other agencies - no help was given to me.
- Went to Harrow association for disabled people (HAD) but G.P. did not tell me about this
- Longer appointments to listen to me
- Listening with a caring attitude
- Referral to Atkins House
- Told there were lots of cutbacks and if they want to attend a cross borough day centre, the G.P. cannot help. They have to find their own help.
- For ailments other than mental health, the person was referred quickly. Specialist appointment received in weeks, but not for mental health.
- Al Anon (families of Alcoholics)
- I don't feel I was given any support or understanding from my G.P.

- Not much support offered
- Having a chat with the practice nurse
- More meetings with the care team
- Help with a cancer patient
- Physiotherapy. G.P. help Sent for E.C.G. Urine problem. Exercise
- Understanding the unfortunate system of bookings.
- Ring team at Atkins house
- No help from G.P.
- None
- G.P. listened to my problems
- More on exercise programmes
- Not helpful
- By continuous monitoring of my mental health with regular appointments with the 'recovery team' at Atkins's House.
- The social worker helps me a lot - she comes every two weeks
- No apparent help
- Never been to G.P. for mental health
- Referral to CMHT

In Harrow, how much your GP is aware of mental heath support services available. Comments section.

- Initially old that the eating disorders service was at Royal free. My google'ing told me it was closed. Spent whole appointment where she didn't know where to refer me. Practice manager then found Vincent Square - which I'd already worked out!
- No idea
- My G.P. seems to learn from me about the different groups available
- If he is aware, he has not told me so I do not know how to answer this question!!
- One thing I would complain about - I don't always see the same doctor at the surgery.
- I am very pleased
- G.P.'s need a lot more training on mental health and there needs to be a mental health liaison nurse.
- Never asked him

How would you like your G.P.'s knowledge of local mental health improved?

- There needs to be at least one G.P. comfortable in talking about MH issues who can be referred to - or encouragement that nurse is available for example.
- My G.P. is rude
- Must have mental health training - or how can you deal with patient
- Specialist training for G.P.'s
- 24 hour access to someone trained in mental health
- Do not think mental health training is realistic for all staff as there is not enough time
- Particularly the receptionists
- Receptionists do not need to ask what is wrong with you

- More information on day care and local religious programmes
- At my G.P. receptionists don't even talk to the patients properly. They really need to learn that.
- The stigma just aggravates the suffering that mental health users are experiencing. Too often, medication is prescribed as an easy and quick option.
- My G.P. certainly needs to be more aware and more approachable for people who are depressed.
- A sympathetic approach to mental health information, for the normal public, through G.P.'s
- Health trainers on site to see mental health patients
- Although training is welcome, it won't take the place of trained psychiatrists
- My G.P. is very good at understanding my mental health problems
- Better communication at reception. Nicer waiting room.
- A professional at the G.P. clinic who is well trained to look after mental health needs, would be comforting for service users.
- I like to learn English
- Compulsory regular training or medical students, surgery staff and G.P.'s
- I think a lot more could be done to improve "the Cinderella" service i.e. mental health
- Good communication
- A lot more sensitivity and understanding at G.P. surgeries.
- I have had no real need for my G.P. to get anxious about me.
- Training is the most thorough way to increase knowledge

Would you prefer to see another health professional other than you GP? Who?

- I am in private therapy
- Mind in Harrow worker
- Psychiatrist
- G.P. has own role but others sometimes help
- A trained CPN to whom you can ask questions without repercussions.
- Support worker
- A counsellor
- Would like more information about medication taken
- Especially pyscho and hypno therapists. I have a private therapist but this is expensive!
- Support worker
- Care coordinator
- Counsellors
-
- Not really. My G.P. is excellent
- An arts and crafts and natural therapy offered to mental health patients to get eventually involved with the general public.
- On site
- A psychologist
- I want more support from my G.P. about my health problem
- A catholic priest

- Counsellor/talking therapist
- Alternative therapy e.g. Chinese Herbal remedies, massage
- Would prefer to go to a faith leader
- Referral could be from G.P.
- Maybe a dietician
- Yes
- For a second opinion
- Nutritionist

If you would prefer to see another health professional other than you GP, why is that? Other reasons?

- No idea what is available
- Should know about person as a whole
- Social worker to discuss benefits and housing
- Massage, acupuncture
- I found complementary therapy very relaxing and relieved the mental pain I was having such as the Indian head massage at the local summer school.
- I feel my G.P. is not very understanding of mental health and only has limited time to talk to them
- Need more information of what is available for mental health patients. To improve health and outlook
- More time with my G.P. to explain the side effects of my medication and lengthen the time it should last for. Too many years on the same meds.
- Want to exercise twice a week
- Talking therapy can help get to the root of the problem
- I have impossible side effects. Mainly 24/7 giddiness
- No particular preference

Section 3: Recovery and Rehabilitation

What type of support do you feel is helpful to prevent admission to hospital? Other types of support

- Support groups outside of working hours. A G.P. who helps me feel better and doesn't increase my stress and who can urgently review/change my medication if necessary.
- Regular help and check up
- This really depends on individuals coping strategies
- Out of hours transfer to crisis lines from The Bridge or any other service being used
- None, because my psychosis comes on suddenly
- More centres like Wireworks and The Bridge to help mental health patients to gradually come out of their state and be more useful to themselves and society. This would provide more meaning to those affected by stigma.
- An identified key worker for an emergency
- Wireworks
- More social groups
- Exercise, self responsibility, non misuse of substances of particular

properties
- Educate the community about the triggers and symptoms of mental health problems and inform them where to look for help once symptoms have been recognised.
- Holistic therapies. Support from charities like Mind and Day Care
- I would have ticked all of them but I own my own house and it is a refuge for me
- Crisis team visits once a week. I have a very kind social worker. Talking when mentally ill again, to a duty officer
- The hospital helps me to take medication and feel helpful

Other general comments

- Reception staff not helpful
- Excessive violence used. Staff don't treat you like people. Keep to their word of supportive activities.
- I think to my best knowledge most professionals do not understand mental health and this results in the community not engaging with the services.
- I have found the psych service given to me is very disjointed or not much help!
- Insufficient information given in hospital about the illness and focussed on my psychosis, not on depression
- More explanation and discussion before being admitted to hospital.
- They used to help but now they say they don't have the money to help with the gardening. The partner is old and cannot manage herself.
- My main needs at the moment are affordable (free?) psychotherapy, group psychotherapy. A support group, at least Somewhere and something to do during the day.
- They don't support much. Reasons given: lots of cut backs
- Counsellors who are always available and not judgemental. Easy access, not having to approach G.P. or long waiting. Counsellors who understand religious and cultural backgrounds.
- Too long to wait for blood test appointments and results
- So far, I have slowly managed to come out of the depression I was in, some time ago. Supported by the dedicated staff at The Bridge, Wireworks and staff members at the hospital. I would like to thank them all for the excellent help.
- More frequent positive contact. Care coordinators should engage more fully with service users
- Could have more frequent contact
- G.P. by their very definition cannot have the in-depth knowledge of a psychiatrist who has specialised in mental health for years, hence the need for good communication G.P. and psychiatrist departments.
- The services are very good at the moment. Having more funds for activities will help me. Before, there were more trips and things to do. For example, we went on a trip to see X factor. Having more trips for the mentally ill will help us!!
- More time with the doctor's and to be more supportive.
- When I was living in Kenton Road, I wanted to move. The environment wasn't suitable. People were taking drugs and I was trying to give up.

Nobody listened to me at the time.

- Hospital staff at Fernley and Eastlake need to be trained to be sympathetic to patients needs. Please no more Nigerian staff in the hospitals. No Bank nurses. No more unsympathetic staff.
- Lack of this type of thing for me, outside stepping stones project
- I feel services have improved from where they used t be 10 years ago. But I feel the service providers have gathered a lot of service user opinions on how to improve services but not much has been done.
- I am Sri Lankan
- I have mental health. My thought I can't think. "I have asked for talking therapies".
- Need home visits
- Definitely being 'available'. In the past, when I have tried to make contact with mental health professionals, they have all been unavailable - I had to make do with any help.
- I think I have all the support I need (both when ill and when well and stable).
- NHS mental health services are barbaric and archaic. They need to be urgently reformed into a holistic service where the person is looked at in terms of mind, body and spirit in the 21st century.
- I feel that the treatment to my needs is and can be adequate, but definitely can be improved.
- More awareness of self help groups to users of services

Appendix 2: Feedback from Mental Health Strategy Focus Groups

Questions:

Hospital and Inpatient Care – Care Programme Approach (CPA)

- How soon would you like to receive copies of your care plan & how would you like to receive copies of them?
- Who do you feel should be involved in a CPA meeting (how and why?)
- How would you like your social needs to be considered and discussed as part of a Care Plan?

Two additional questions were asked in the second focus group due to the responses received in the session.

- Would you like GP's to be involved in CPA meetings in other ways if they can't attend meetings?
- How would you want CPA to be more holistic?

Enhanced Mental Health Care in Primary Care

- How would you want GPs/practice staff to provide support/info in their surgery for their patients affected by mental health care?
- What type of mental health training would you like practice staff at GP surgeries to have?
- What type of cultural/faith issues would you like practice staff at GP surgeries to be aware of?

Rehabilitation and Recovery

- What services do you feel need to be in place to prevent emergency admission to hospital?
- What issues do you feel should be discussed in a treatment and discharge plan to support recovery?
- What has helped you on your journey to recovery?

Session One: 04/07/13

Discussion write-up:

Hospital and Inpatient Care – Care Programme Approach (CPA)

How soon would you like to receive copies of your care plan & how would you like to receive copies of them?

- Care Plans often altered and no copy given
- Written notes on day are not always legible
- Patients have no pre-CPA meeting beforehand
- Would like hard copy – in person (to be able to discuss changes) or posted
- Highlight changes to care plan
- Information sent to GP – often details are incorrect

Who do you feel should be involved in a CPA meeting (how and why?)

- Would like service user choice as to who is there and need to discuss why
- Would like an advocate – provide support and are independent witness (CPA hard copy often has mistakes – advocate can help to clarify)

- Notes should be written and read out and agreed with patient
- Patient wants family member, friend and independent person e.g. Mind worker/charity worker (someone you trust)
- CPA is challenging, intimidating and overwhelming
- CPA should not be tick-box exercise

How would you like your social needs to be considered and discussed as part of a Care Plan?

- Social needs have been addressed, should be holistic approach, we want person-centred approach:
- community, family, spirituality, healthy living, employment, education, socialising, voluntary opportunities
- Help integrating into the community and rebuilding your life (prepare for real world)
- Hospital institutionalised and needs structure

<u>Enhanced Mental Health Care in Primary Care</u>

How would you want GPs/practice staff to provide support/info in their surgery for their patients affected by mental health care?

- Need mental health awareness training for all practice staff
- Fast track for mental health patients and an allocated walk-in time
- GP should be able to fast-track straight to a ward
- Two way – need to indicate needs for patient – want mental health to be a priority for GPs
- GPs need signposting for respite care e.g. seaside, retreats
- Double appointment time for mental health patients
- Mind HUG away day

What type of mental health training would you like practice staff at GP surgeries to have?

- Employ a CPN
- Employ health trainers with basic mental health awareness
- Receptionist to be more understanding
- GPs do not look at patients physical needs
- More flexibility for appointment booking times for mental health patients
- Awareness of anxiety
- Fast track mental health phone number

What type of cultural/faith issues would you like practice staff at GP surgeries to be aware of?

- lady doctor or nurses only for those females that require it
- GP should have info on cultural issues at surgery to promote community engagement
- Exercise on referral at culturally sensitive venues
- GP to be aware of faith or spiritual belief system
- Refer to spiritual but not religious place
- Prescription for complementary therapy with medication
- Holistic approach to treatment/care (Mind, Body & Soul)
- Visits from Faith Ministers

Rehabilitation and Recovery

What services do you feel need to be in place to prevent emergency admission to hospital?

- Would like day-to-day practical support e.g. social worker or key worker, to help organise to pay bills and day-to-day living
- AT present, eligibility criteria for care workers is restricted
- Need support for people who are not in the system; support telephone numbers should be widely distributed at GP surgeries and information about mental health conditions and at libraries
- Training to recognise and manage illness and symptoms for patients
- Counselling and talking therapies – very hard to access and get appointments – why can't we have peer educators and active listeners?
- People are scared to leave their homes – need home visits and telephone counselling.

What issues do you feel should be discussed in a treatment and discharge plan to support recovery?

- If the person is very ill, they should not be discharged. Person should not be left in limbo
- CNWL should distribute crisis packs
- There should be one-to-one interview before the patient is discharged
- There should be more of a holistic approach – housing needs, language, look at all the circumstances, cultural needs etc
- Person is discharged but not given enough information about access to services
- Helpful if after discharge they are linked with a befriender/link worker as people are very vulnerable
- If patient wants family to be involved, they should be and in some cases patients don't want family to be involved, in which case they should be given a link worker.
- Access to drop-in centres and activities to help them develop skills
- Skills based opportunities e.g. Recovery College
- Consider complementary therapies and social care needs and transport
- Make an involved plan
- Easy access to talking therapies

What has helped you on your journey to recovery?

- Talking therapies (psychotherapy more helpful than CBT/psychology)
- Solution-focussed therapy
- Faith and spirituality
- Community involvement – activities, engagement
- Creative writing/art therapy, pottery
- Drama, dancing
- Medication and on-going psychiatric support
- Good Care Coordinator
- Freedom Pass
- Welfare benefit help and mental health service users need help to fill out forms. HAD is overstretched.
- Free venue for welfare rights and mental health rights e.g. surgery
- Translation service
- Friends

General points:

- GPs are overstretched and it is better to have a CPN or psychiatrist to advise GP
- GPs and psychiatrists should work more closely together
- Involve patients in life-changing decisions
- Recovery important when discharged from hospital
- GP should have more mental health information on websites
- Do not feel included in full process e.g. care plan or making outpatient appointments
- See different doctor each time = no continuity
- GPs should see patients' physical and mental health needs holistically and give time and suggestions to patients – more choice of treatments; patient very often too ill to have treatment
- Should have choice of family or carer included
- Some GPs only get 4 months training in mental health
- Westminster & Chelsea have liaison nurse for mental health in GP surgeries

Session Two: 15/07/13

Discussion write-up:

Hospital and Inpatient Care – Care Programme Approach (CPA)

How soon would you like to receive copies of your care plan & how would you like to receive copies of them?

- People should be given notes immediately, the day of the meeting. Someone should be taking notes in meeting. This will instill more trust in the system and relationship. And things don't get lost in the post.
- What actually happens is what has been agreed in a CPA changes, it is constantly changing and staff find it difficult to reconcile what the current state of affairs is with what is put in the CPA.
- Immediate recording is important, straight away, as things are fresh in the mind and information is captured in the truest form.

Who do you feel should be involved in a CPA meeting? (how and why?)

- No, it depends on how unwell you are deemed to be.
- Went from CPA to seeing a lead professional. This transition was not made aware to S, he was just told in passing at a meeting. He feels that no formal agreement of this transition was made
- You are very vulnerable when in a CPA meeting. It can be very intimidating, people in the meetings talk around you, which is horrible. J's CPA stopped when her social worker was sick. It was stopped because the service wasn't there anymore. This is happening again due to cuts in hospitals and people are dropped back into the G.P. world. She doesn't trust her GP with psychiatric problems. A lot of G.P.'s don't to go on the six months training because they are already over stretched with workload.
- G.P's have to know a little about everything but more in depth knowledge is needed.
- Lack of information given to patients about CPA rights. This should be more widely circulated. Maybe something written on the actual CPA form. 'You can have a copy of this'.
- Maybe a notice on the office where the CPA is happening 'Remember to get a copy of your care plan'
- Doesn't it depend on what a patient needs/wants…? Family…..for some but some people don't get on with their family. The essential people are the psychiatrist and the social worker/Community Psychiatric Nurse (CPN). Consultants should

lead the discussion with the patients, but in her experience they talk over the client…to other people in the room. You are the important person in the room, it should be about you. It's also about being timid, when you are just coming out of primary care/time of distress you are extremely vulnerable and people in CPA seem to forget that. That one needs space to be expressive.
- One's carer, would be useful to have them on board.
- A trusted friend. If a person cannot articulate things, a friend could do this for you. This could be a carer or relative too. He has a sneaky feeling carer's don't let users be free, they are solely in command, that they are trying to sponge on benefits…..GP's should be given a copy of CPA form in detail. S's GP did not have a clue about his CPA. In his case, he had to change his GP from older to younger person. He advocates that young G.P's are more enthusiastic and more in tune with new systems of administration.
- An employment link worker involved in the conversations would be useful - when deemed ready by client and main lead person. Have some sort of cross over/transition to this.

Would you like GP's to be involved in CPA meetings in other ways if they can't attend meetings?

- Yes, I think so. It would be good to have them on board in another form or platform. It is good because a G.P. can relay a patients' multitude of illness needs, such as other physical problems, to the psych team. It should be about holistic care and GP's are the link between the two worlds. J has asthma, cancer as well as MH needs.
- To have a trusted friend nominated by the client is a unanimous decision of agreement in the focus group.

How would you like your social needs to be considered & discussed as part of a care plan? Such as employment, voluntary work, social networks….

- Before discussions begin, the CPA team should be aware of what things are available to clients so they can signpost with ease. Have knowledge of some services at hand that could be accessed by client. Personal budget things for example: what is available to people and how to use it is not widely discussed or available yet.
- Been in NHS for 20 years and all throughout have never been asked by employment. It was assumed that as she had a husband and a family, this was enough. Now she feels a huge pressure to get into work, which is unfair because she is not prepared for it. This is due to government changes: now she is being pushed into the world of work which she thinks is unfair. All about saving money than people's welfare.

How would you want CPA to be more holistic?

- Something such as employment should be discussed informally with client before being put on table 'you need to find a job'.
- They should be asking you about your existing networks, where would you like to be in next six months, should be asking open questions, draw things out of client slowly before being bombarded by requirements.
- Apprehensive about interacting with people, scared of upsetting people. This anxiety affects her ability to get back into work. This should be addressed too. CPA should know their client fully.
- Social needs should be introduced slowly and gradually into the CPA programme. First coffee mornings, pottery classes (for example) and then build up to an employment. It is a continuum of care to move at pace client deems fit. Client needs taken into account, gentle steps, and holistic care.
- CPA should be holistic from the time of release from hospital.

Enhanced Mental Health Care in Primary Care

How would you want GP's/practice staff to provide support/info in their surgery for their patient affected by mental health?

- Recovery patients could be voluntary staff at surgeries; they could be consultants. Someone who has experience of MH could be on call for expert advice. They could provide support and advice to GP staff. GP's do not seem to treat patients as individuals. They repeat treatment without studying progress of a client over time.
- MH training awareness for staff at offices so they are not treated just like 'ordinary' patients. So the staff are not frightened by the MH concerns of patients. Educating them on phone manners when a client is quiet or anxious. Receptionists are the first line of contact, need to be trained on care needs of MH patients.
- As soon as you walk in door there is a level of expectation by staff. There is a solid stigma at surgeries. Issue with blood test results. My lithium levels were high in a blood test, this was not picked by staff or GP. If a CPN was at the surgery or another member of a psych team, they might have pick up on it.
- A drop in surgery once a week for example, run by a mental health nurse. They have special diabetes nurses and clinics, why not MH ones?
- GP's should have a holistic, MOT approach to blood tests etc. rather than just prescribing antidepressants…….there could be other contributing factors.
- GP's should give more than 10 min slots to mental health patients. You can ask for double appointments but are people aware of this? Do they get it?
- MH patients who are very depressed/anxious need more rapport building time to get information across to their G.P.'s.
- If you are being discharged back to your GP from psychiatrist care will you receive your same allocated one to one time? Psychiatrists give 20 mins, will GP do this every six months too? Should have the same level of care. If psychotic, or in severe need, patients need these six monthly appointments to build up a rapport.
- Why can't there be a mobile unit of MH care, with CPN and psychiatrists involved? A mobile unit that is sent out as a rolling programme across Harrows GP surgeries. This person/people could also run the drop ins.
- A specialist GP at each surgery with MH training. This would be the optimal/best case scenario.
- One should get the same GP for duration. New GP's/locums will ask all the questions again, about your past history. This can be unsettling if in recovery.

What type of mental health training would you like staff at GP surgeries to have?

- Stigma busting and general awareness training to increase knowledge and reduce discrimination.
- Also training around how MH and physical health interact. A more holistic approach to this kind of stuff.
- Cultural awareness training too around MH.

What type of cultural/faith issues would you like to practice staff to be aware of?

- You could think someone is being psychotic but they are not, the person could be communicating using a style that is specific to their cultural background and 'normal' to them. Staff need to be aware of cultural relativity.
- I am not religious, but when I am psychotic, I am over the top religious. At one point I was hitting myself, reciting the revelations. So some knowledge of the bible would be beneficial to treatment and approach to care.
- Signposting could be important too at the surgery. A community liaison person or health trainer at the surgery for one to one support…. signposting services.

- Not just for MH but other stuff too. This person could be the 'go to' after having seen a GP, if left unsatisfied.
- Presence of a resource at hand at the GP meetings; someone who has the expertise by experience for example, or someone who has knowledge of community services, who can feed back information.
- Had no idea about the offer of alternative care services to patients at GP surgeries. Such as gym and exercise on prescription.
- Mentions that there are incentives for GP's to maintain budget surplus at end of year…..bonuses etc.?? This will undoubtedly decentivise optimal level of patient care!!
- All surgeries have patient groups that meet, maybe they could do a special mental health patient groups every quarter with the G.P.'s too? Where there could be an exchange of information between the establishment and client.

Rehabilitation and Recovery

What services do you feel need to be in place to prevent emergency admission into hospital?

- Long waiting lists. Group coordinator suggests the idea of a drop in or a holding facility at surgeries, available until the counselling comes available. Similar to a crisis team?
- Someone to talk to and assess you at surgery, GP to do this or someone else, to see if there really is a need to go to A and E.
- Access to someone maybe even on phone, a help line, manned by trained staff, Samaritans are not always trained in MH issues.
- There is already a crisis team that works pretty well. To be seen quickly when you at a surgery or at A and E. is important. A and E is not the best place to send clients with MH problems. In many cases it is the worst place to send clients. In the past, I could always see my psychiatrist in the hospital. Being able to see a consultant who knows you would be a great idea. Link this in.
- Mentions that a key worker throughout your care programme who is contactable at a stage of emergency is useful. This person will be able to decipher whether it is a real emergency or if the person needs something more palliative.
- After hospital discharge one should have access to community services where recovery can be monitored. If this if available in the first instance, it could prevent relapse or escalation to a subsequent crisis situation.

What issues do you feel should be discussed in a treatment and discharge plan to support recovery?

- Knowledge of family and support network already in place. If there is nothing, maybe they could arrange something for you. Personal care, health, social care needs….house work, shopping, and all the practical things.
- Also holistic care needs, knowledge of physical ailments e.g. asthma/diabetes.
- Housing and benefits advice, access made to things like meals on wheels. The crisis card, should be reviewed as some information is out of date and should be handed to every one upon discharge.
- Help with bills and sorting them out. Budgeting assistance. Information about local services. Information about PB's.

What has helped you on your journey to recovery?

- My husband, lots of support from my psychiatrist, medication and being compliant for years and years. In the past (circa 1999) she was allowed to stay over night, when going through a bad patch and suffering from panic attacks.
- Regular check ups and The Bridge. Being kept as an outpatient upon release before being placed back into community care full time.
- Someone to help with the transition period at initial phase of release from hospital would be good. Interim support. Someone available to explore your faith and MH issues.