



Your Experience Matters
Sensemaker Re-audit
December 2015



Foreword

'Your Experience Matters' - Sensemaker re-audit 2015

Historically, there has been a lack of good quality information about mental health services, particularly from a service user and carer point of view. In 2012, the Public Health Agency and the Health and Social Care Board surveyed people across N.Ireland to assess their experience of services. The survey was based upon *nine questions* developed by service users and carers from each Trust area. In addition, through providing additional 'free text', individual respondents could *tell their story* and describe their personal experience of using mental health services.

Over 700 people responded to the 2012 survey - the findings are summarised in the report: '*Your Story Can Change Lives*' report (GAIN, 2013).

www.gain-ni.org/images/GAIN-Mental-Health-Audit-Experiences-of-Users-Carers-June-2013.PDF

The issues and concerns highlighted in the 2012 `survey, such as the need for 'good communication', 'shared care', and 'timely information' were viewed as amenable to action and improvement. Each Trust subsequently engaged in service improvement activities to help address these issues/concerns. A key part of this process has been the 'Implementing Recovery through Organisational Change' programme (ImROC: www.imroc.org/). This is based upon staff and service users working together to ensure mental health services become more recovery-focused.

To assess progress from 2012, a '2nd Edition' of the regional survey was undertaken between Oct-Dec 2015: 665 people responded. This report therefore represents the updated views of service users and cares. The original nine questions from the 2012 survey were largely retained in their original format (question four was amended to improve clarity and understanding). Three *additional questions* were added to encompass the emergent themes of: Recovery and Physical health.

Overall, it is pleasing to report that the findings of the 2015 survey demonstrate a general improvement from 2012. Most key indicators suggest that service users (& carers) perceive their experience of mental health services has improved.

With the development of Recovery Colleges in each Trusts area, along with other service improvement initiatives, we hope that service user experience of mental health services will continue to improve.

On behalf of the regional project group, which led the survey process, I would like to thank all those who assisted with the data collection and responded to the 'Your Experience Matters' survey. Your contribution and the important information you have provided will help us to continue the process of improving mental health services in N.Ireland. Lastly, I would like to thank Mrs Briege Quinn PHA who has been instrumental in taking forward the survey and the preparation of this report assisted by Amanda Lennon, DHSSPSNI.

Dr Stephen Bergin - Consultant in Public Health, Public Health Agency

Executive summary

This report presents analysis of regional survey data collected during 2015 including a comparison with (where applicable) data from the 2012 survey. In total, 665 and 720 narratives and self-signification data were collected in 2015 and 2012 respectively from users of mental health care services, informal carers, and other respondents from the 5 Health Trusts.

There is a comparable data distribution across both data capture periods, with 82% of data collected from health care services users, 13% from carers, 1% from informal carers, and 4% from other respondents.

Overall, the data suggests that there was a positive dynamic in how people perceive mental health care services and related issues.

However, there is an observable variation between the responses given by service users and carers. For example, in both the 2012 and 2015 surveys, service users reported that they felt 'stronger' more so than their carers; while carers tended to report users as feeling frustrated and stressed more so than service users themselves. Also, out of those respondents who said that their journeys were 'confusing and/or bumpy', the proportion of service users reporting confusing journeys increased.

In summary, in 2015, compared to 2012:

- There was an increase in the respondents who said that they received the right service at the right time.
- More service users suggest that the information provided by staff in mental health services was useful and relevant.
- There is no difference in the proportion of respondents who said they received no information in both periods.
- The proportion of people reporting that staff in mental services communicated in a respectful and considerate manner has increased.
- Fewer respondents felt that they were ignored when their treatment was being planned.
- There was an increase in respondents who said there were fully involved and respected in both treatment processes respectively.
- More respondents reported that mental health services left them feeling stronger.
- Fewer respondents reported that everyday living, social, and leisure facilities were impacted most.
- More people reported that relationships with family and friends, everyday living, or both were impacted most.

- More respondents reported that they made positive progress.
- Fewer people said that there was no change after using mental health services, that they were struggling to cope, or both.
- More respondents suggested that practical support would have made the biggest difference to them.
- Slightly fewer respondents reported receiving useful information and being treated with compassion and sensitivity would have made the biggest difference to them.
- More respondents (and more users) in the current period said that their journey within mental health services was smooth running.
- The overall number of people reporting that their journeys within mental health services was confusing, bumpy or both decreased.

Also, in 2015:

- Approximately one third of all respondents say that they are hopeful for the future and a little less than one third are still working with others to plan their future.
- For the majority, recovery has been an important part of their treatment.
- More than two-thirds said that their physical health care needs were discussed in detail by their mental health team/practitioners.

How to read this document

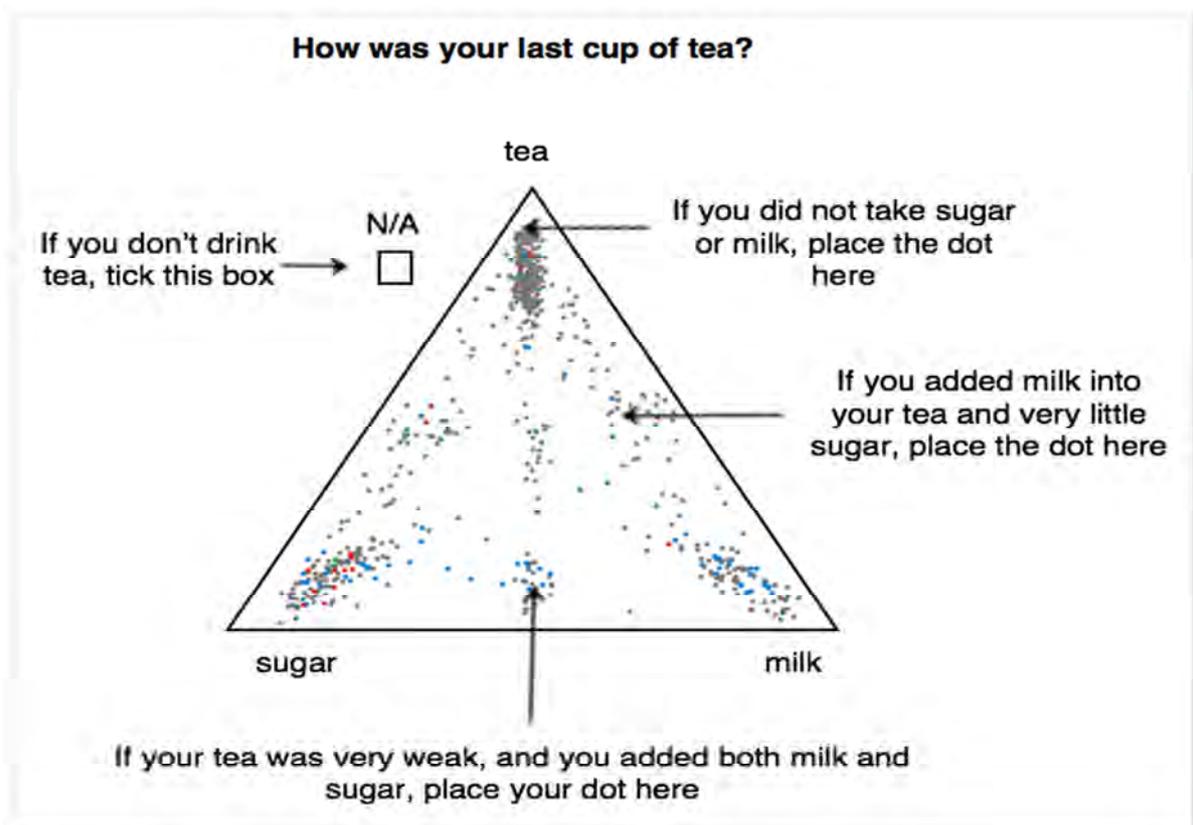
When completing the survey, respondents were first asked to describe a real experience that happened to them or someone they took care of; and then complete the questions about that experience.

The following pages display a series of triangles, or 'triads', which contain clusters of responses to these questions. Respondents placed a mark in each triad in the position that best described their experience in relation to three pre-specified responses. The closer their mark to any one statement, the stronger that statement relates to their experience. If a question did not relate to their experience, the N/A box was checked.

A high concentration of dots in a specific area indicates that many people, in choosing that specific position, indicated they agreed with the pre-indicated response in that part of the triad.

Each dot within a triad represents an individual experience of a service user/care regarding which they were asked to share at the start of the survey.

On the following pages, under each survey question, there are three triads. These relate to (1) the 2012 survey, (2) the 2015 survey, and (3) the 2015 survey, and with examples of service user/carer stories (ie. their experience) appended to each corner of the triad.

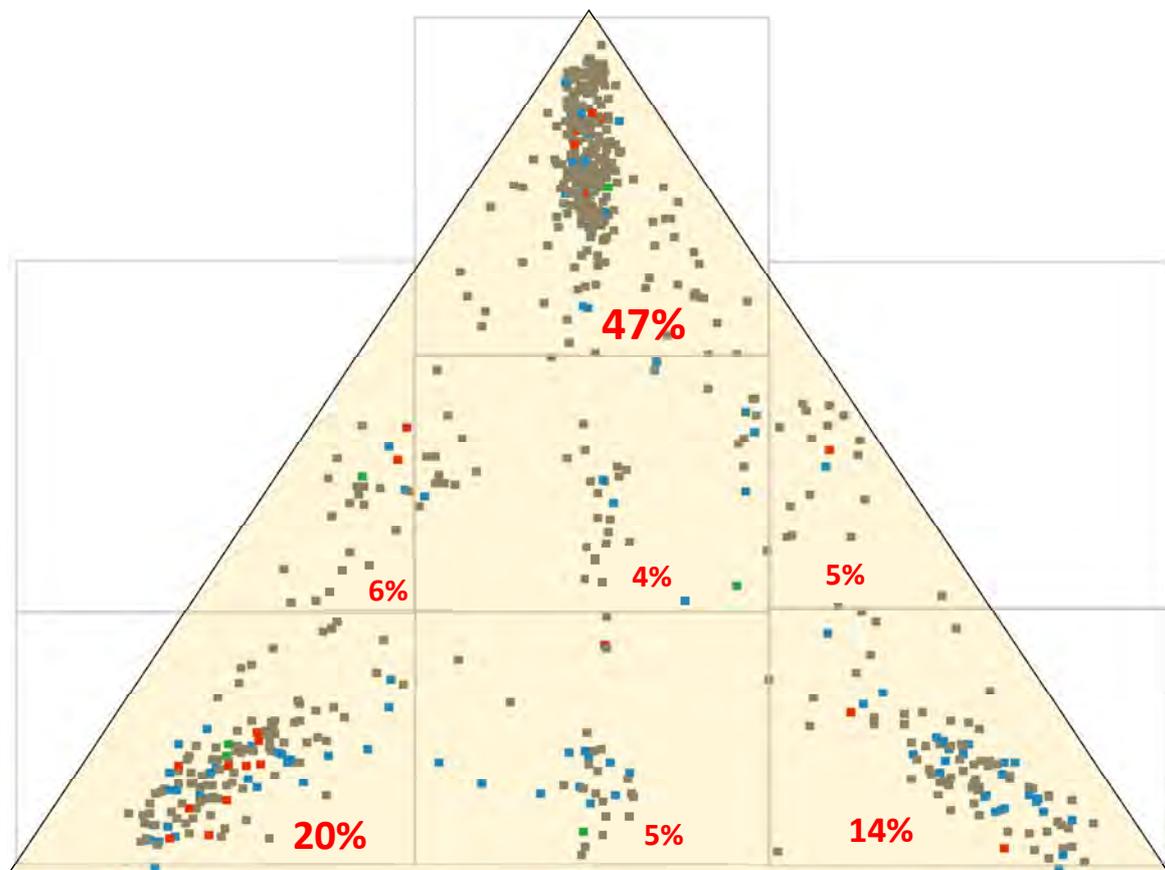


Question 1: Were you able to access the services when you needed them?

2012

Total respondents: 720
Responses to this question: 664
Total % of respondents: 92%

I received the right services at the right time



I was unable to access the services I needed

I did not know what services were available

- Service user
- Carers
- Informal carers
- Other

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

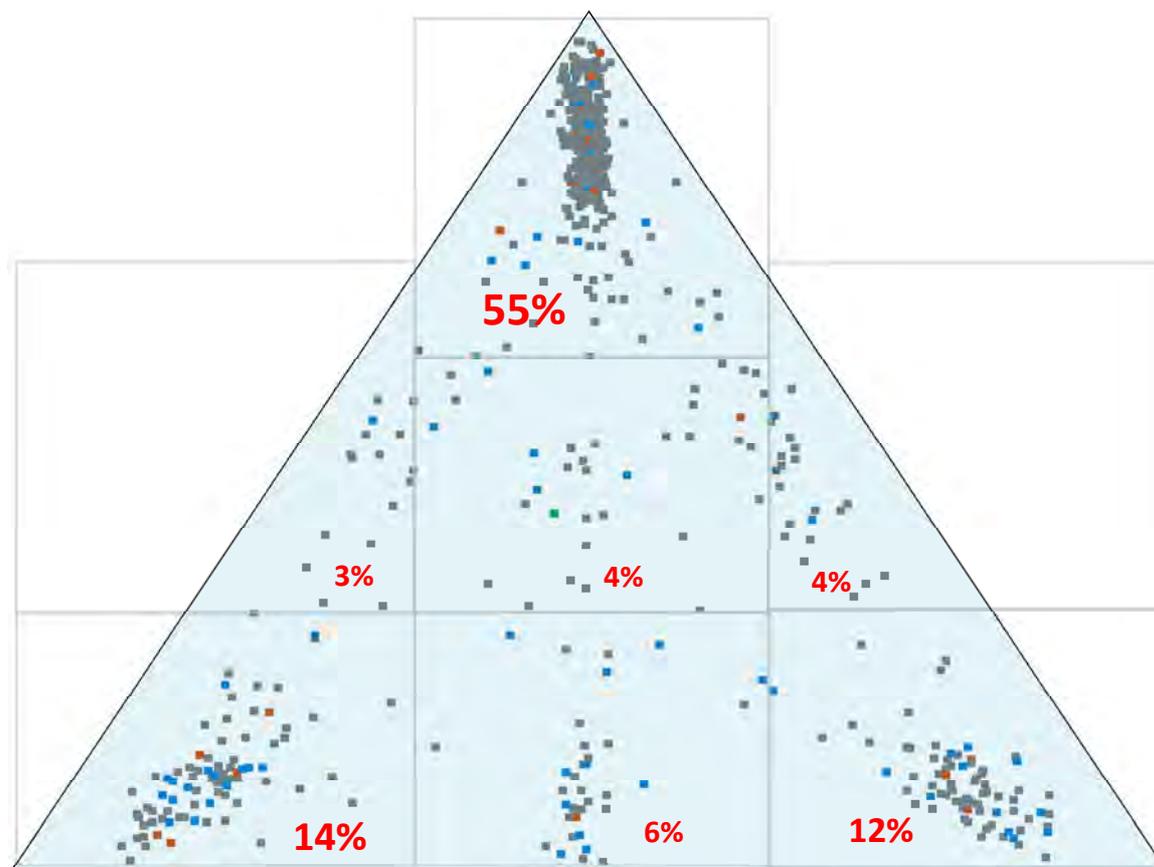
2015

Total respondents: 665

Responses to this question: 605

Total % of respondents: 91%

I received the right services at the right time



I was unable to access the services I needed

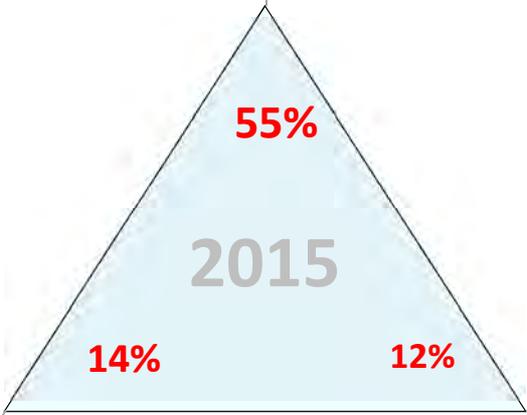
I did not know what services were available

- A greater proportion of respondents in the 2015 survey (55%) reported they had **received the right services at the right time** compared to 2012 (47%)
- The proportion of respondents who reported they were **unable to access the services needed** decreased from 20% in 2012 to 14% in 2015
- There was a slight drop in the proportion of respondents who **did not know what services were available**, from 14% in 2012 to 12% in 2015

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

***“Turning point:**I have been very fortunate my treatment here was literally what is recommended and stated in your booklets. A care plan was drawn up with me. Outcome – I am now enjoying much better mental health. I have made huge lifestyle changes and am very positive about future. I am also very interested in getting involved in programs @ recovery centre.”*

I received the right service at the right time



I was unable to access the services I needed

***“Help without judgement:** It’s complicated. I’d tried a few places/people for help but no one took me seriously until I spoke to her. She listened and never interrupted to tell me how stupid I’d been. I know that already. We started fresh. We talked about the future. She helped me fix what could be fixed and helped me to make plans for the future. I never wanted people to do for me I just wanted help to do it myself. She was the only one who got that.”*

I did not know what services were available

***“I do think depressed people need more help:** I have been on medication for years. I used to see a psychiatrist but that was axed years ago. I have kept fairly well on medication but no-one ever worries e.g. Doctor etc. I wonder sometimes if I had had some kind of therapy could I have stopped medication.”*

Additional stories

Many stories noted an improved ability to access the right services at the right time and the role of community care teams and home treatment was often commended. However, some stories indicated there are still some problems accessing certain services, in particular, service users perceive that appointments with consultants, psychiatrists, GPs, are often too infrequent:

“ On discharge from Hospital, I was introduced to the Mental Health Community Team. The CPN and myself worked together on a weekly basis. I was very anxious about going out in public due to my appearance and disability. We built up a very good relationship over time and I began to feel confident about going out again. .”

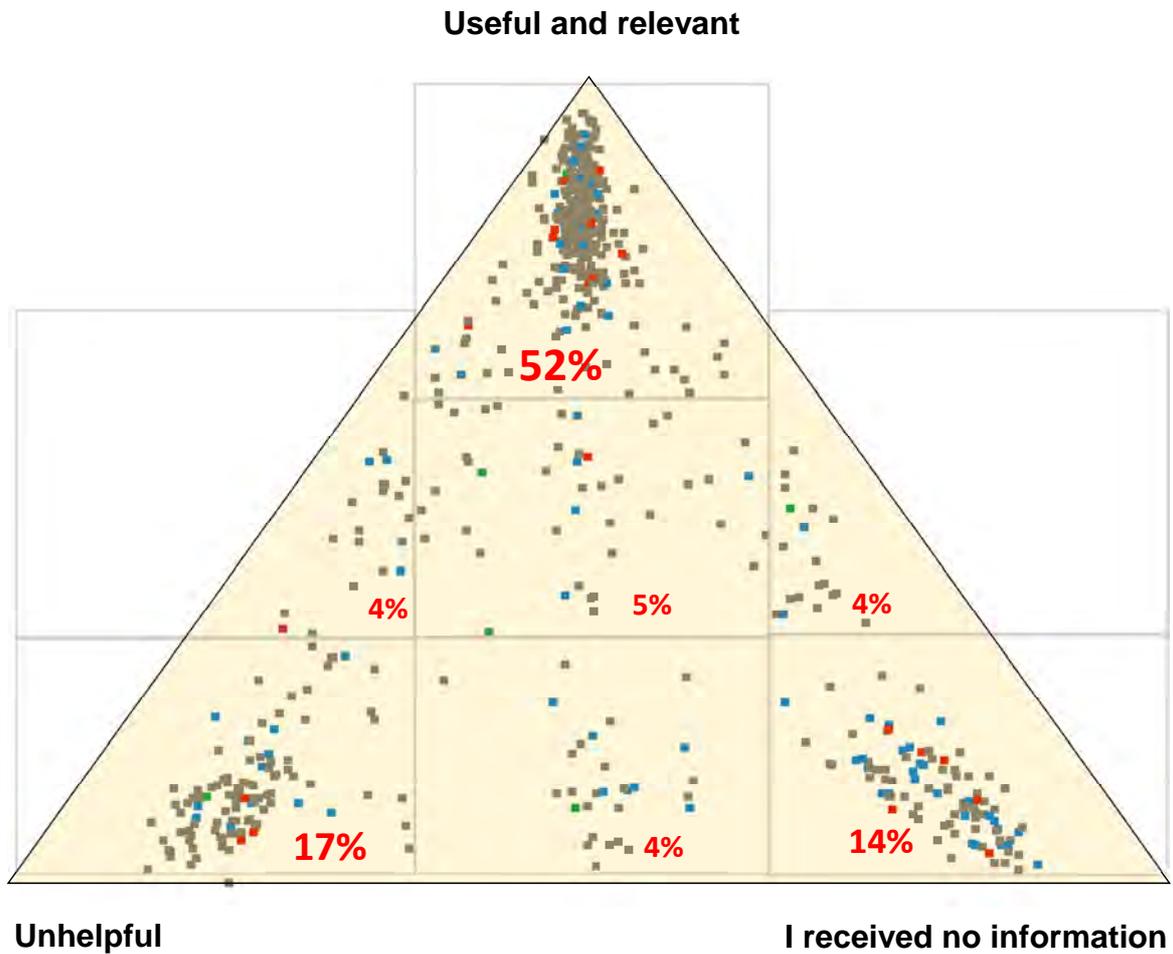
The Bubble of Chaos

The place of confusion and chaos. The place of fear and danger. The racing of the mind, what now, where is the solution to be found. Knocking on closed doors and not getting answers. Crisis day! What will be the outcome! Enlightenment. The Golden Number Mental Health Team. P.S.N.I – answers at last, a unit to go to, - chaos and tragedy averted. Treatment, recovery. Independence, life recaptured. Why was it so difficult to access!

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

2012

Total respondents: 720
 Responses to this question: 665
 Total % of respondents: 92%



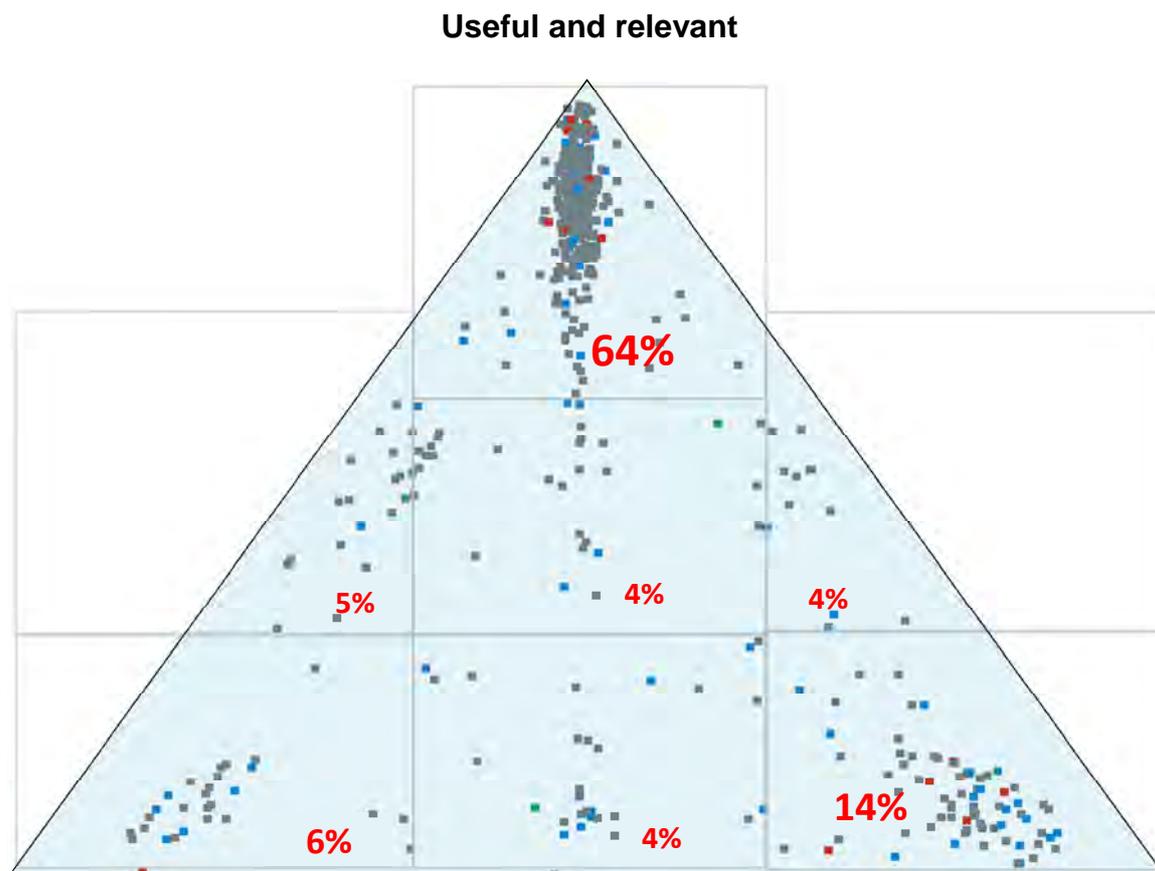
Question 2: How useful was the information provided to you by staff in mental health services?

2015

Total respondents: 665

Responses to this question: 556

Total % of respondents: 84%



Unhelpful

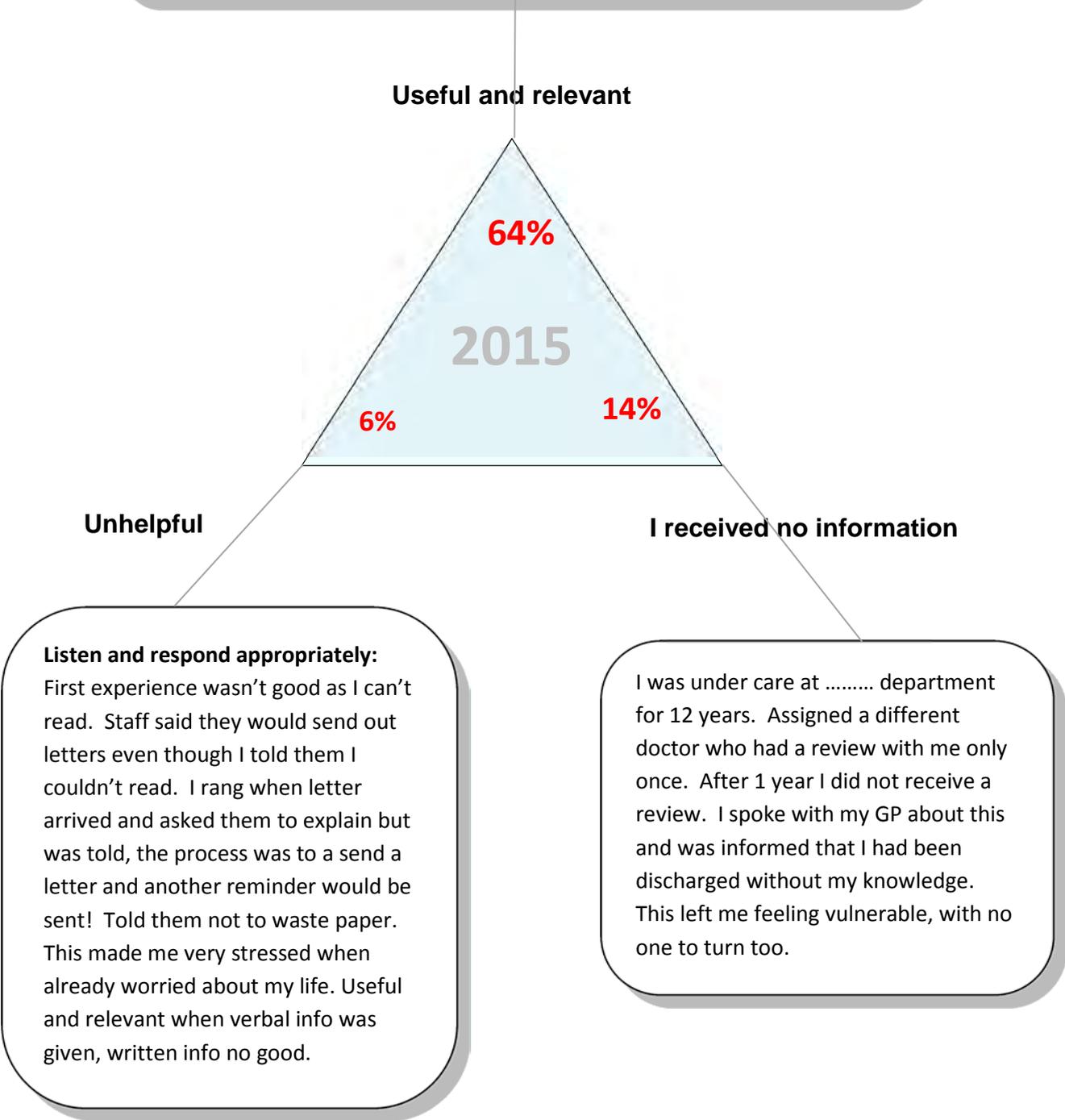
I received no information

- A greater proportion of respondents in the 2015 survey (64%) reported that they found information **useful and relevant** compared with the previous survey (52%)
- The proportion of respondents that found information **unhelpful** decreased from 17% in 2012 to 6% in 2015 ¹
- The proportion of respondents who reported they **received no information** remained similar at 14% in both the 2012 and 2015 surveys

¹ Due to a printing error in some copies of the survey, a small number of responses were removed for this question; it is not anticipated that this will have any significant bearing on the conclusions drawn

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

Things can change if you want them to.... Mental health assessment team – They talked to me about all of my problems in a way that was friendly. – They gave me options on what I wanted to do next and what I felt comfortable with. – They referred me on quickly which was good. – Now I am in a place which I feel is helping me with my issues.



Additional stories

More health service users in the 2015 survey indicated that the information provided by staff in mental health services was useful and relevant.

There is no difference in how many respondents said they received no information in both periods.

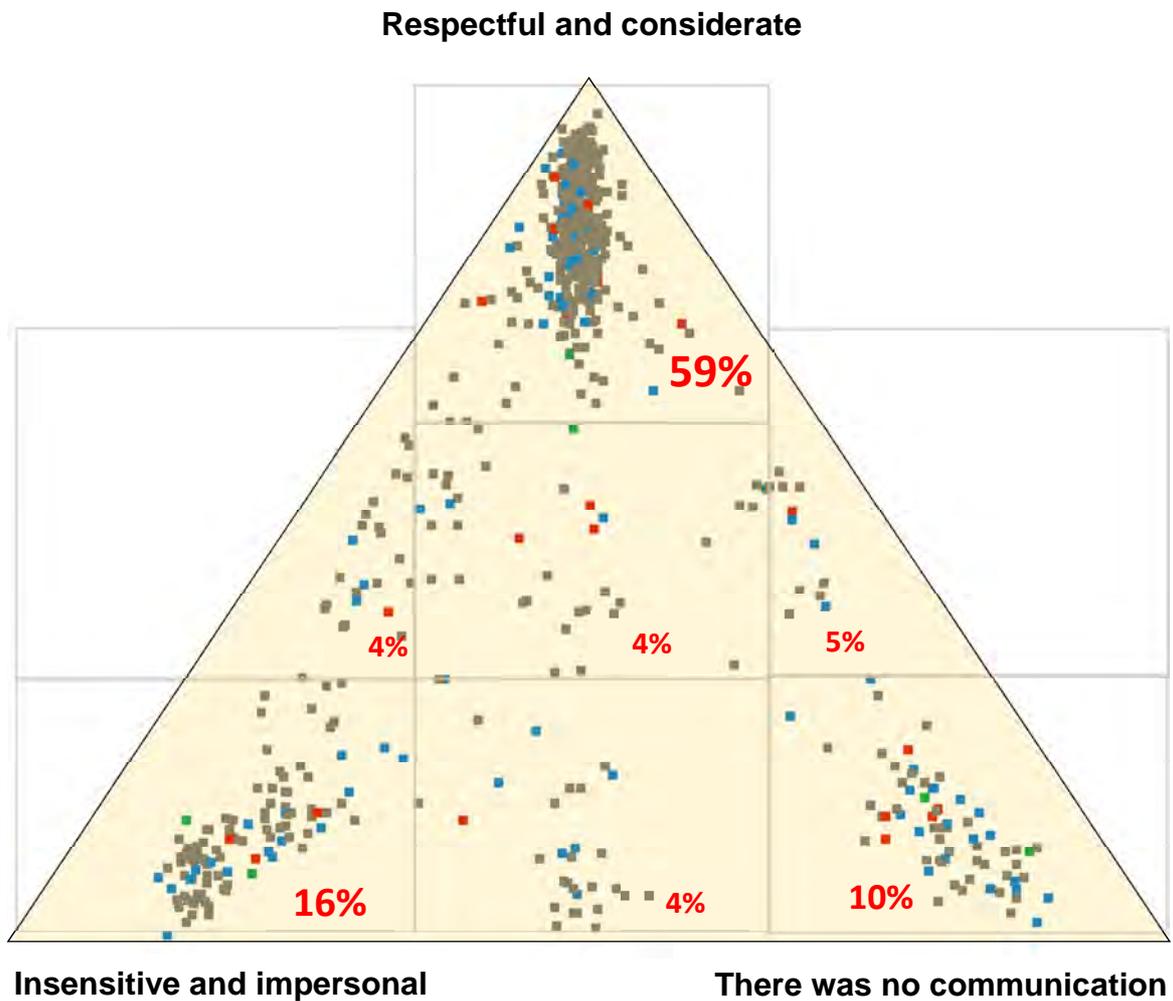
" After 1 year I did not receive a review. I spoke with my GP about this and was informed that I had been discharged without my knowledge. This left me feeling vulnerable, with no one to turn too.

"**Left to drift** ...I've been brought up to trust that the doctor will be my advocate but I have not found this to be so. I am just met with "I don't know" as an answer to any question and there are no positive suggestions."

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

2012

Total respondents: 720
 Responses to this question: 679
 Total % of respondents: 94%



- Service user
- Carers
- Informal carers
- Other

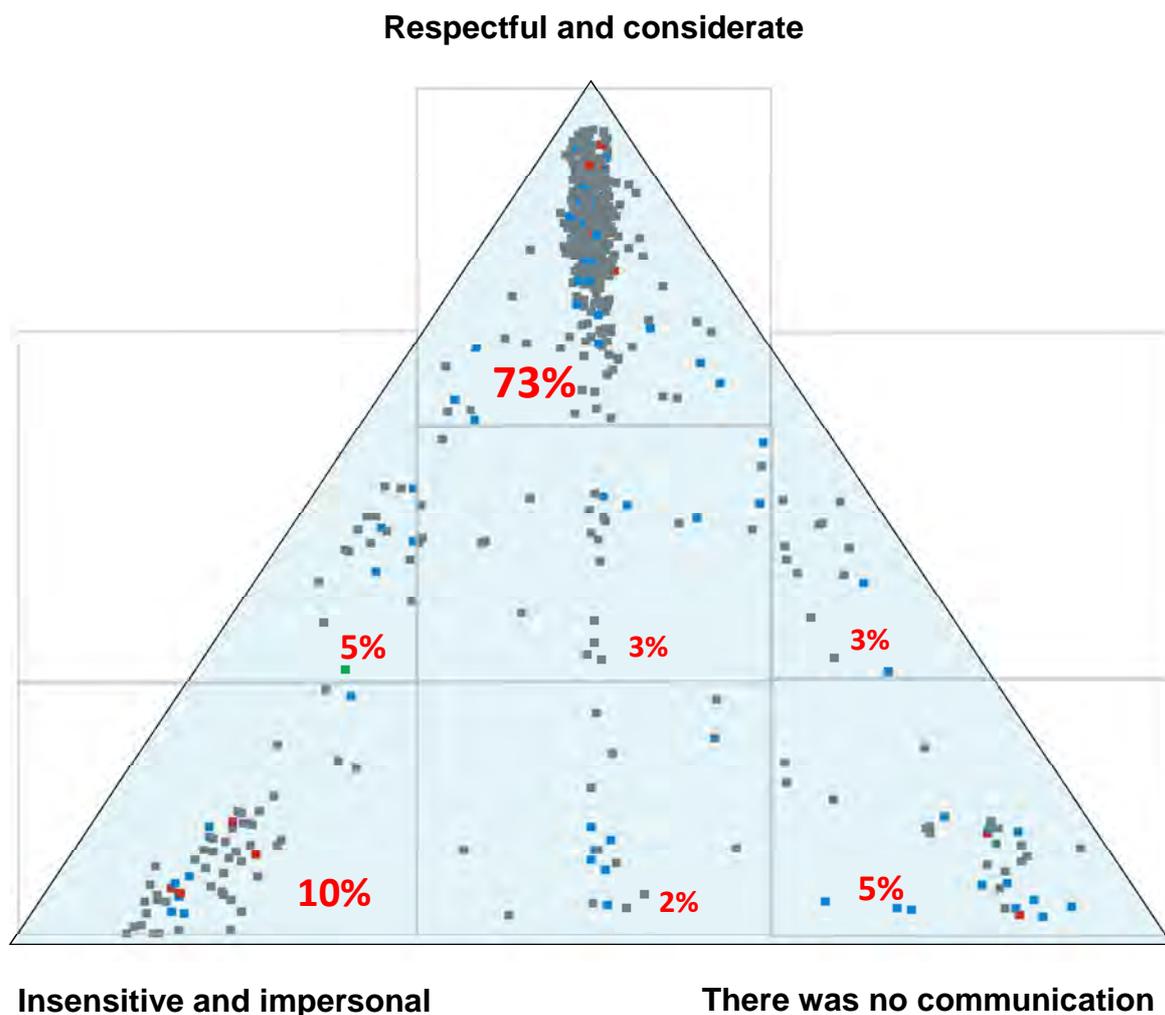
Question 3: How did the staff in mental health services communicate with you?

2015

Total respondents: 665

Responses to this question: 636

Total % of respondents: 96%

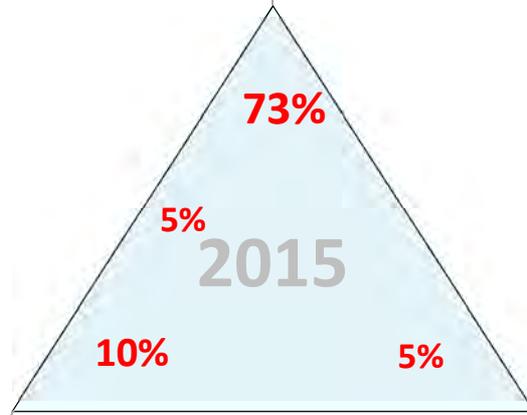


- The proportion of users that considered staff to be **respectful and considerate**, increased from 59% in the 2012 survey to 73% in 2015
- The proportion of respondents that considered staff to be **insensitive and impersonal** decreased from 16% in 2012 to 10% in 2015
- The proportion of respondents who felt **there was no communication** halved, ie. from 10% in 2012 to 5% in 2015

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

Treated with respect + dignity, a good experience: I was seen in Omagh for the first time. I had depression A CPN helped me, gave me information, kept an eye on my medication, informed my family and a plan put in place in case my health fails again.

Respectful and considerate



Insensitive and impersonal

One of my darkest days....She said before I was leaving the appointment 'promise me you won't do anything stupid now'. She knew at the time I was feeling terrible, I could not even promise myself that so how could I promise her that.

There was no communication

"Left to drift"I've been brought up to trust that the doctor will be my advocate but I have not found this to be so. I am just met with "I don't know" as an answer to any question and there are no positive suggestions.

Additional stories

Compared to the 2012 survey, the findings of the 2015 survey indicate that the proportion of people reporting that staff in mental services communicated in a respectful and considerate manner has increased.

I am very grateful to the team I work with who treat me with respect and dignity and as an equal person with a voice and a mind of my own which is so important. They do not focus on my disabilities yet deliver a service tailored to improving my quality of life and supporting me as a vulnerable person in the community. My psychiatrist is a very sympathetic and respectful gentleman who renewed my faith in the services when he corrected the misdiagnosis several years ago. He helped me understand how such a serious error was capable of being made and focusses on my abilities not my disabilities.

“ On discharge from Hospital, I was introduced to the Mental Health Community Team. The CPN and myself worked together on a weekly basis. I was very anxious about going out in public due to my appearance and disability. We built up a very good relationship over time and I began to feel confident about going out again. .”

Not being listened to by new Doctor

I went in to the appointment and told him I was depressed and he disregarded this and said I wasn't. He told me that I needed to get out more and mix with others. I felt he didn't look even at my file/notes.

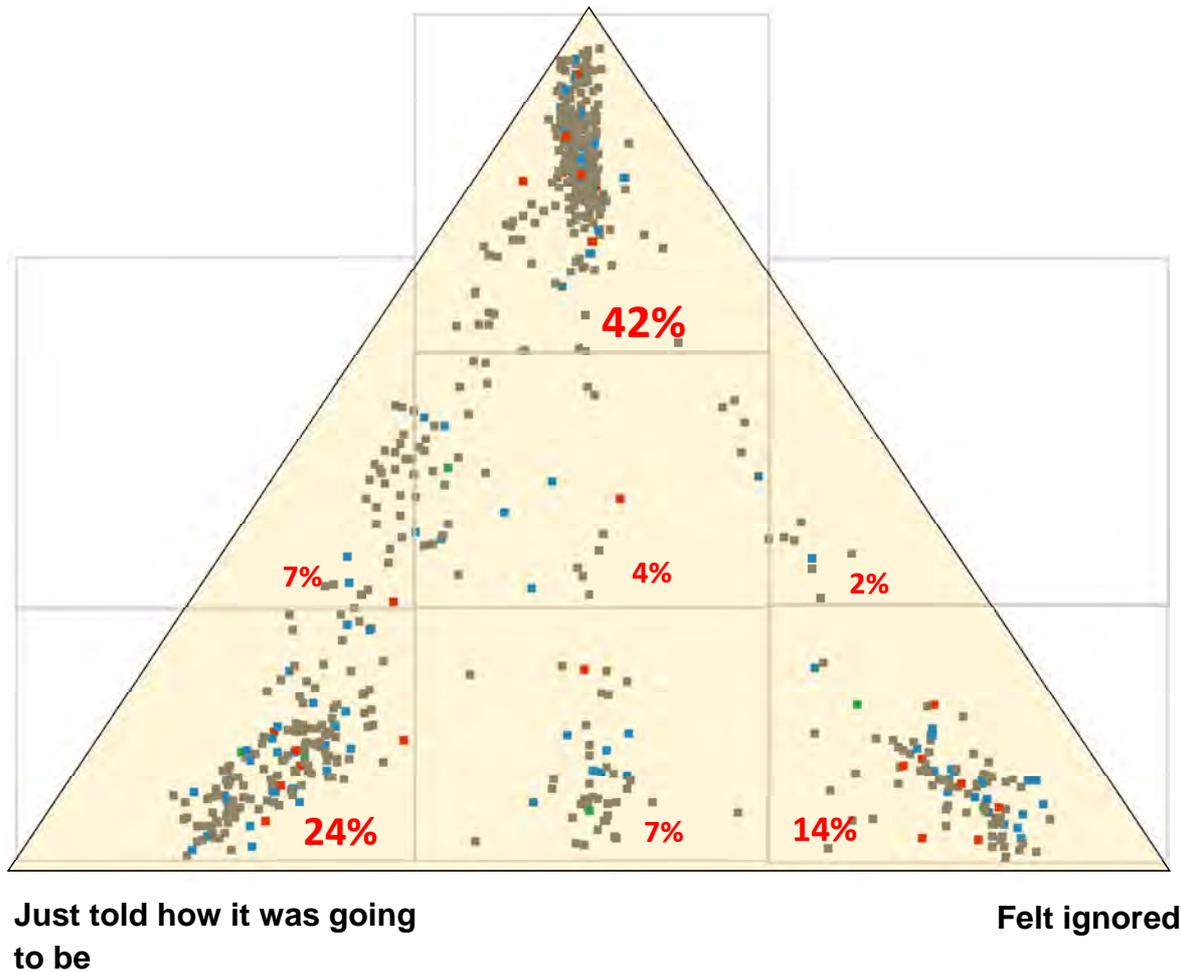
I was in another ward and one of the student nurses was working with me. I was asked to fill out a form about her. She talked to me and was very friendly and caring. She made me feel comfortable.

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

2012

Total respondents: 720
 Responses to this question: 670
 Total % of respondents: 93%

Fully involved and respected



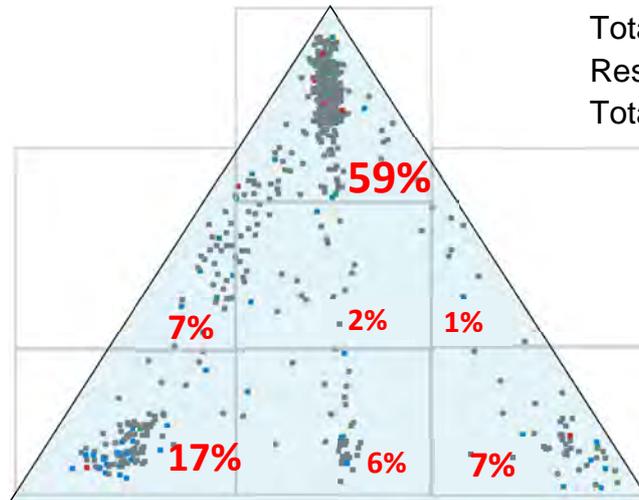
- Service user
- Informal carers
- Carers
- Other

Please note: the original 2012 question was separated into two parts in 2015. It is therefore not possible to make direct comparisons between the two survey periods, although some broad conclusions can be drawn.

Question 4a: How involved were you in planning your care?

2015

Fully involved and respected



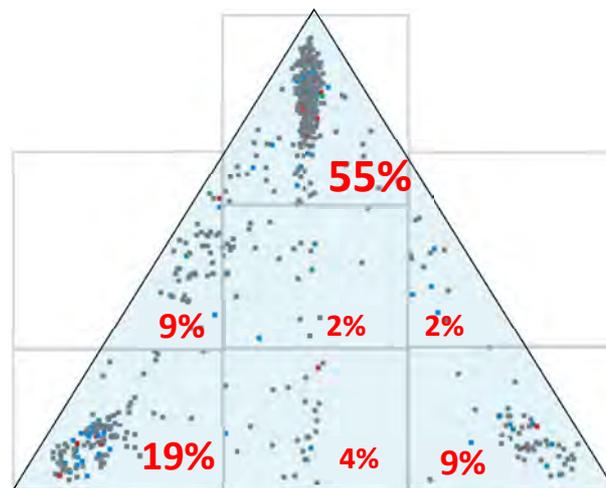
Total respondents: 665
 Responses to this question: 620
 Total % of respondents: 93%

Just told how it was going to be

Felt ignored

Question 4b: How involved were you in planning your treatment?

Fully involved and respected



Total respondents: 665
 Responses to this question: 620
 Total % of respondents: 93%

Just told how it was going to be

Felt ignored

The 2015 survey indicates that more people feel **fully involved and respected** in terms of planning their care and treatment. As shown above, 59% and 55 % felt **fully involved and respected** in planning their care and treatment, compared to 42% who felt fully involved in 2012. In 2015, 17% and 19% were **just told how it was going to be** compared with 24% in 2012.

Question 4a: How involved were you in planning your care?

Light at the end of the tunnel: On discharge from Hospital, I was introduced to the Mental Health Community Team. The CPN and myself worked together on a weekly basis. I was very anxious about going out in public due to my appearance and disability. We built up a very good relationship over time and I began to feel confident about going out again. I was introduced to the Recovery College which gave me much inspiration and Hope. I have completed the WRAP course and now speak only to others about my lived experience.

Fully involved and respected

59%

7%

2015

17%

7%

Just told how it was going to be

Felt ignored

Take time to understand me better...

Outpatient appt with consultant psychiatrist,

- He was under pressure as other Doctor didn't turn up to clinic. Appointment lasted 10 minutes, – Discharged back to GP after making medication changes
- Feel he didn't listen to me, cried when I came home
- He didn't take time to ask questions to get appropriate information

A night in AE....

I was treated very badly by A+E as the doctor or nurses just looked pass me as it was a mental health problem. They didn't explain anything and kept me lying all night until I seen a C.P.N in the morning

Additional stories

Compared to the 2012 survey, fewer respondents felt that they were ignored when their treatment was being planned.

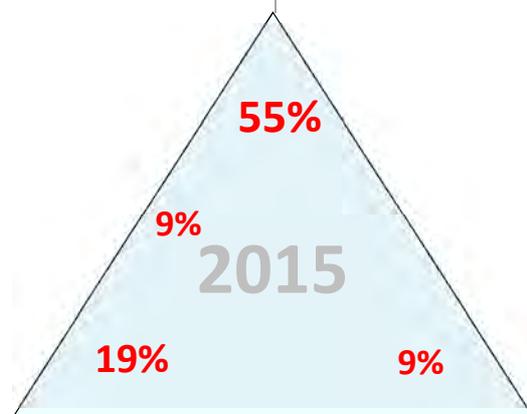
November 2014 my nurse at mental health team identified problems with blood cells due to my medication which put me at risk of seizure. I received intensive support – Home visit every week, review + monitoring whilst the medication clozapine was reduced. I experienced a further onset of psychosis – felt paranoid, and thought I might need inpatient care. My family shared this concern with my nurse as they had the same concern. My nurse arranged an emergency review from psychiatrists and I was asked my views at the meeting. I valued being asked and I felt the psychiatrist took on board my worries and my families. I was prescribed sleeping tablets + the dose of clozapine was no further reduced. My Mental health Improved almost immediately. The mental health team have helped me to develop insight to my illness and confidence to talk about it.

Ward [x] are outstanding – went above and beyond. Describe some of the staff as ‘maternal’ in their approach to caring for my son – who remembered their names and smiled at them. I treasure these staff. Under-valued at not being involved in care planning specifically in regards to his medication – no explanation given.

Question 4b: How involved were you in planning your treatment?

Over thinking leads to a sheltered life:
Unable to cope with physical problem which led to worry, isolation and fear of dying. I met [X] he discussed my problem, set goals and tried to encourage me to rethink my thoughts. I am now starting to feel like me again and am so glad I met him and he helped me get my life back on track.

Fully involved and respected



Just told how it was going to be

...Oh and yet again no offer of talking therapies, counselling etc. This is only a reflection of primary services, I was never given a chance to experience the community psychiatric team or other services that I so sorely needed... I have never been back to get help since

Felt ignored

Explaining to parents what going on and being able to contact social services...
My experience was bad my grandson was put into a hospital and no doctors came to tell us what was happening they just let him out and never came to talk to us about anything what was happening. We can never get in contact with social workers when we need them.

Additional stories

The 2015 survey demonstrates an increase in the proportion of respondents who said they were fully involved and respected in both planning their care and treatment.

When my nurse comes to see me he gives me my injection. I could tell you before he comes the three questions he will ask me. Are you eating, sleeping, and have I been out. I just say yes to them. He always says he will make time for us to talk. I have been waiting a year.

Getting out helps me a lot...

Being taken to the local Indian restaurant. Getting out and back into the community has had the most impact on me. When taken out I felt more relaxed and the staff encouraged it. The outcome, I was happy and relaxed and felt better about myself.

Stop hiding

I have recently finished CBT. It helped me own my difficulty and take away the fear of people knowing - my CBT experience has been fantastic and life changing. After 20 years I am well. Regular consult appointments of great support.

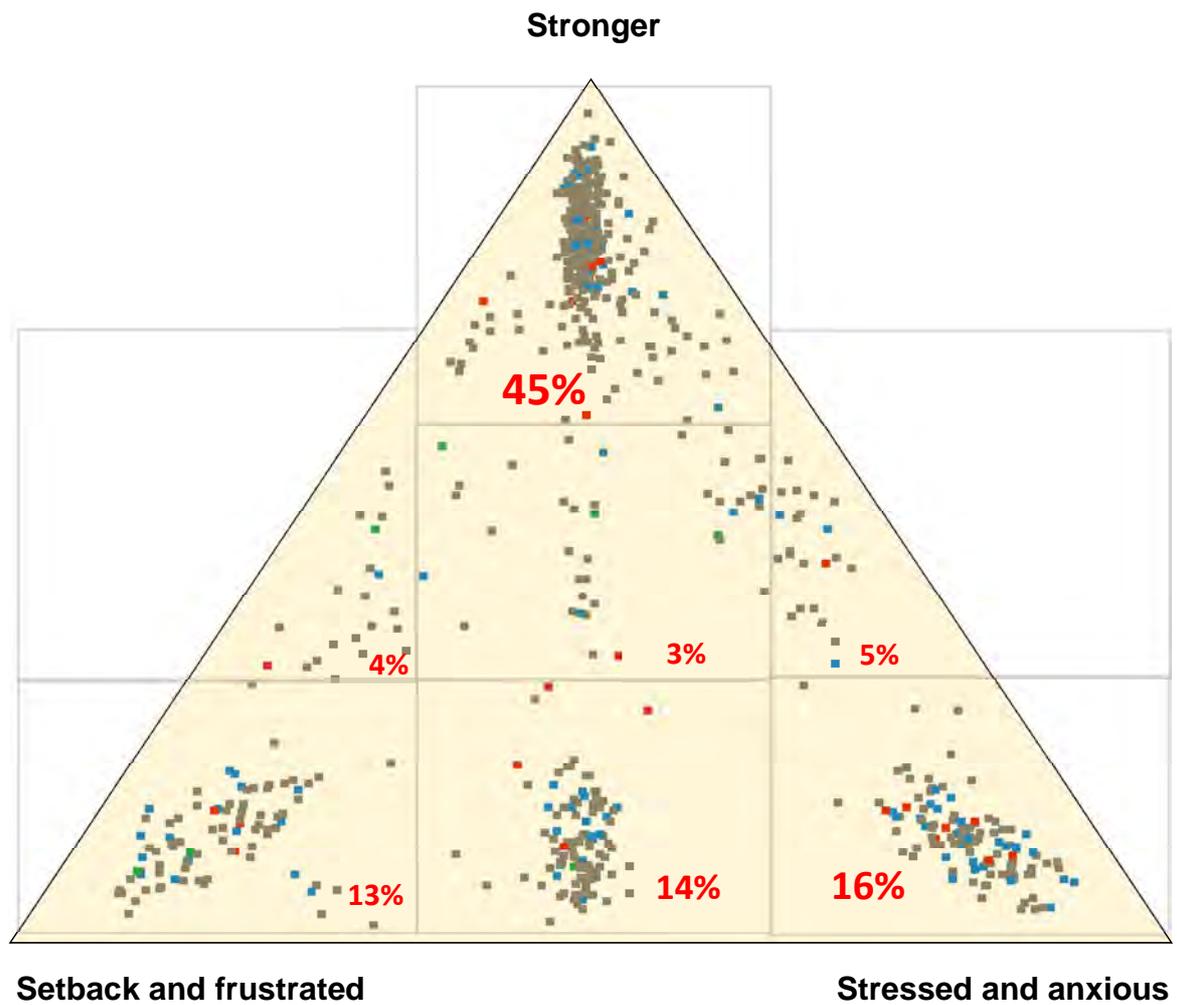
Question 5: How has this experience of mental health services left you feeling?

2012

Total respondents: 720

Responses to this question: 704

Total % of respondents: 98%



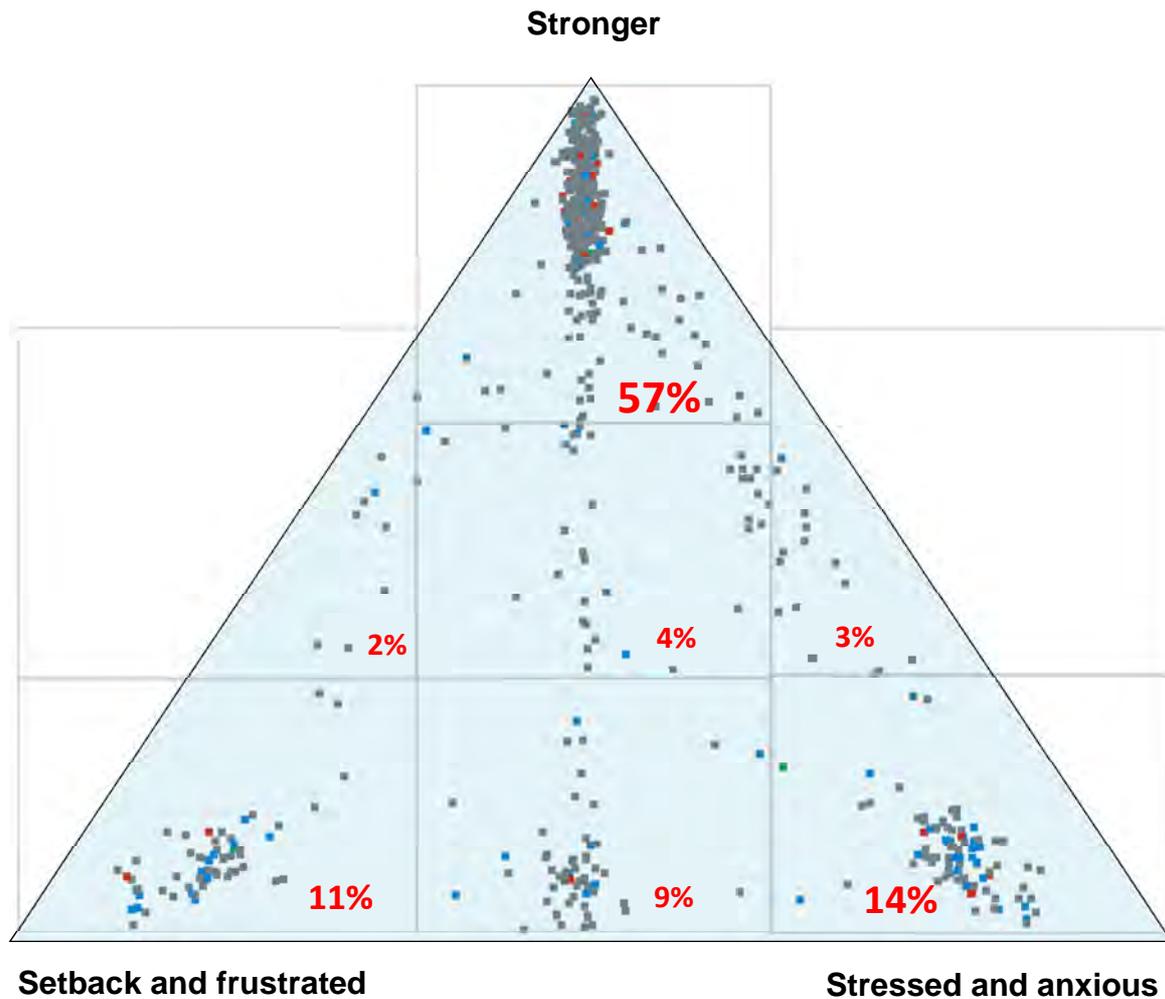
Question 5: How has this experience of mental health services left you feeling?

2015

Total respondents: 665

Responses to this question: 635

Total % of respondents: 95%

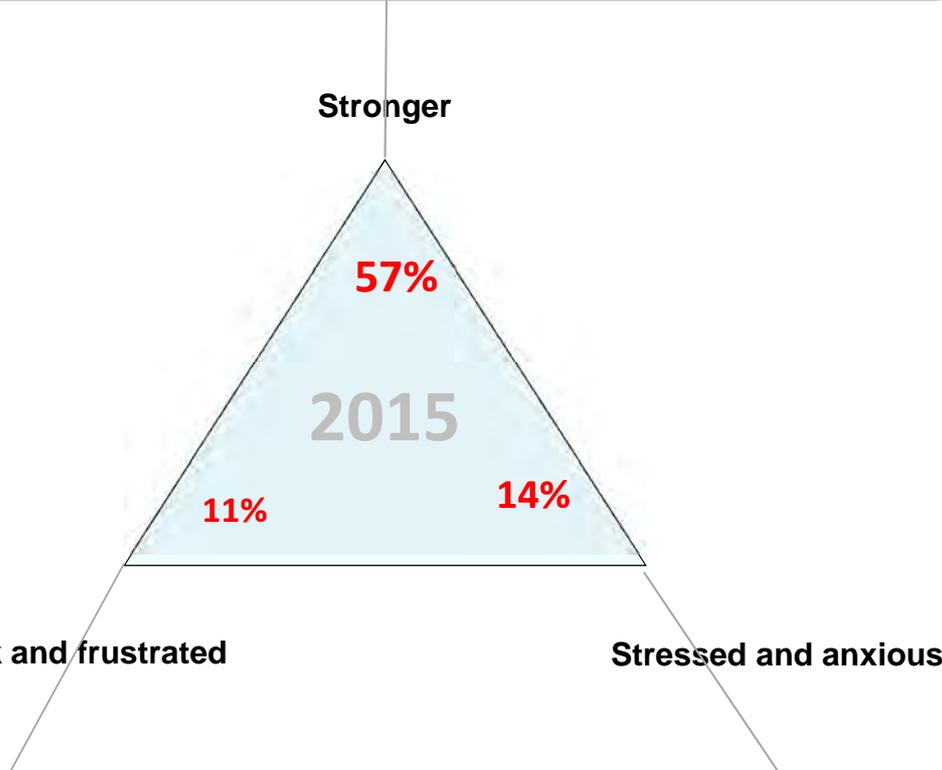


- A greater proportion of respondents (57%) reported that they felt **stronger** after their experience of mental health services compared with the previous 2012 survey (45%)
- The proportion of respondents that reported their experience left them feeling either **stressed and anxious**, **set back and frustrated** or **both**, decreased from 43% in 2012 to 34% in 2015.

Question 5: How has this experience of mental health services left you feeling?

There are people who care:

I am withdrawn & feel isolated. My Mental Health Social worker is always there for me. If I can't get her on the phone first time, she always ring back. She suggested I apply for DLA and helped me fill in the detailed form. My DLA application was successful and having the extra money is one less thing to worry about. It has been a positive in my life and she is extremely supportive and encouraging.



Staff to show compassion and interact with patients and show care...

It was a helpless feeling. A+E where unsympathetic and impersonal. I struggled to hold onto my son, he needed to stay in the waiting room, no one helped. They left him sitting until there was just us – still no one came 6+ hours

Listen to carer...

My experiences of mental health as a Carer, is getting the Doctor's to listen to me as a Carer. Every time my wife goes into hospital they change her med's or take them away. Can't thank the home treatment team enough or her CPN. But its Doctors who I don't think LISTEN.

Additional stories

The 2015 survey indicates that more people perceive that mental health services left them feeling stronger.

- *On admission, I felt very low, overwhelmed and depressed. I have been on the ward for 8 weeks.*
- *Generally speaking, I have been happy with my overall care, (nursing, medical, and OT staff)*
- *The environment does not always support recovery, (noisy, privacy, resources, garden)*

I have recently finished CBT. It helped me own my difficulty and take away the fear of people knowing. My CBT experience has been fantastic and life changing. After 20 years I am well. Regular consult appoints of great support.

My support worker is a great fella. He picks me up and we go out to different places. Ha always makes my day and we have a good laugh. For a little while I leave my dark world behind. I feel I can talk to him and we can be straight with each other. He can see when things aren't good, I don't even have to say to him. Last year he told me that I needed to go and see my consultant. He got me a quick appointment and phoned me nearly every day in between the days we usually met. When I want to see the doctor he came with me and we had a long talk. He changed my medicine and things got better. To be honest I didn't even know they were bad. It was my worker who saw it.

Question 6: Which area of your life was impacted most by this experience?

2012

Total respondents: 720
 Responses to this question: 680
 Total % of respondents: 94%

Relationships with family and friends



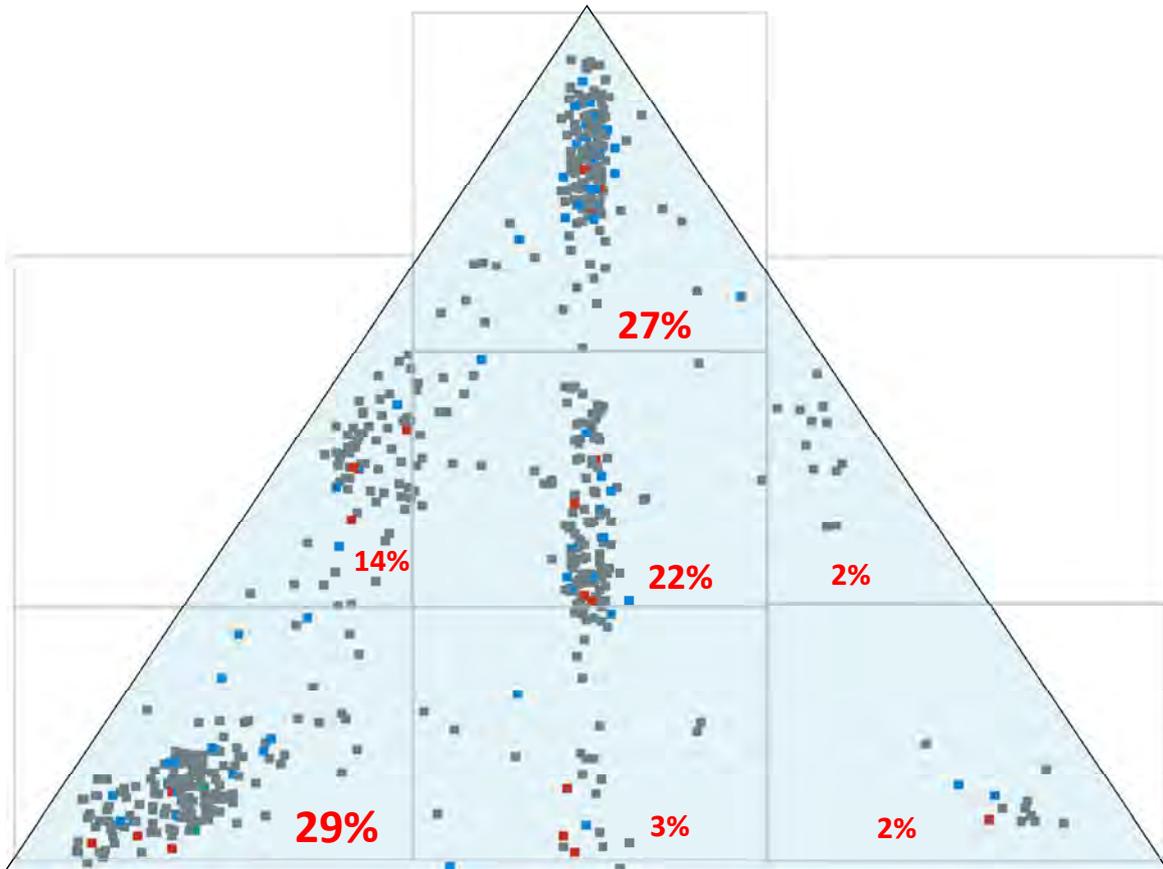
- Service user
- Carers
- Informal carers
- Other

Question 6: Which area of your life was impacted most by this experience?

2015

Total respondents: 665
 Responses to this question: 626
 Total % of respondents: 94%

Relationships with family and friends



Everyday living, social and leisure activities

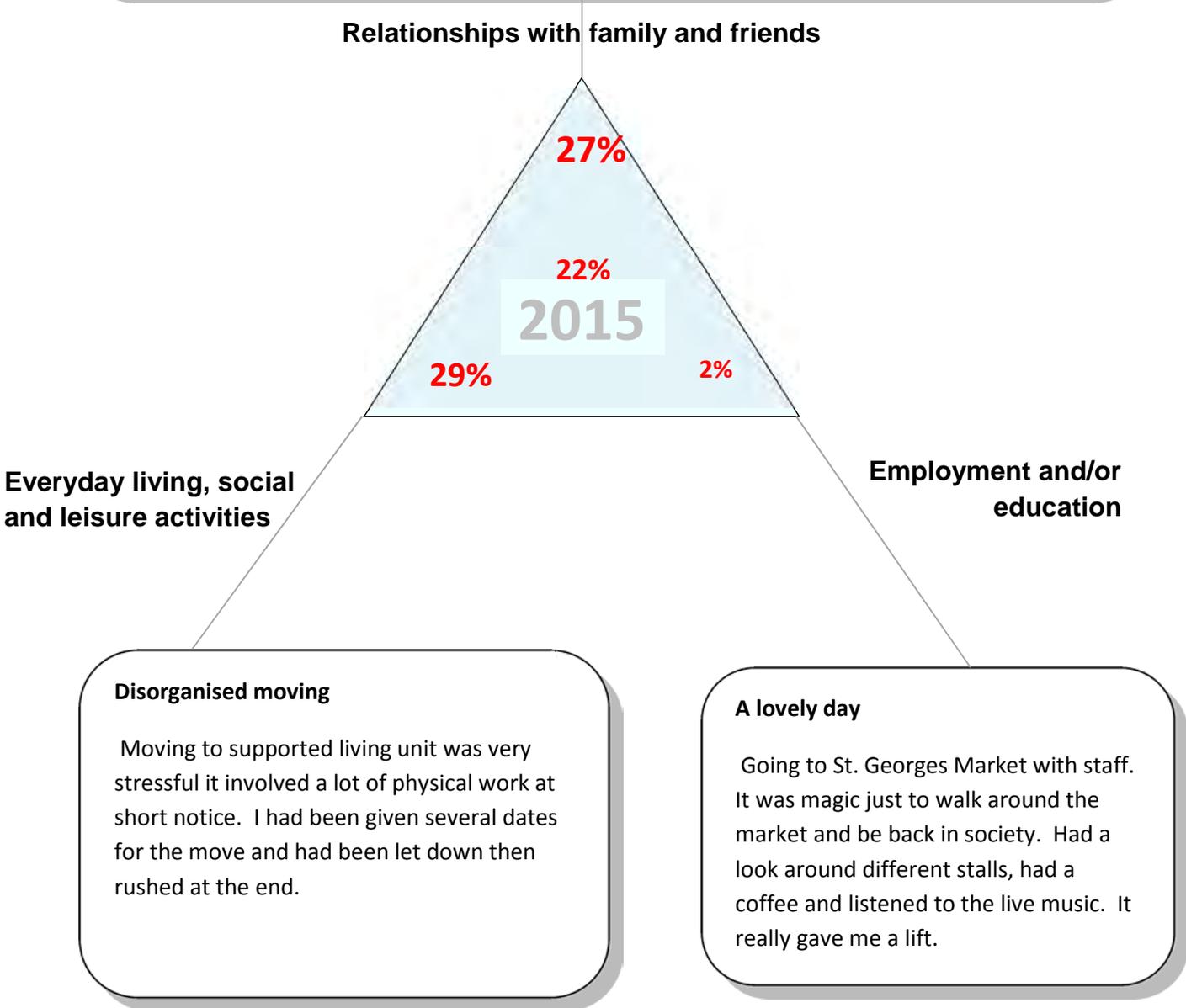
Employment and/or education

- There was little overall change in the areas of their lives respondents reported had been most impacted by their experience between the 2012 and 2015 surveys
- The proportion of respondents that reported impacts on **everyday living, social and leisure activities, relationships with family or friends** or a combination of **both**, remained similar, at 74% in 2012 compared to 70% in 2015
- As with the previous 2012 survey, few respondents considered their
- **employment and/or education** to be the most impacted area of their lives

Question 6: Which area of your life was impacted most by this experience?

Mental illness can destroy families:

I had a breakdown. I was suicidal and self-harming. I was admitted to Ward.....via my CPN. My marriage broke down because of this. I was in hospital for approximately 3 weeks. I got my medication changed whilst in hospital. Peer support workers and OTs were particularly helpful. It also helped speaking to patients in same position as me. A week after, I received court orders for me to get out of my home and lost custody of my children. This is the worst time of my life. I am still fighting through the court to get them back. My CPN and AMH New Horizons are being a great support to me. This has been so hard on my whole family.



Additional stories

Compared to the 2012, fewer respondents reported in the 2015 survey that everyday living, social, and leisure facilities were impacted most. More people reported that relationships with family and friends, everyday living, or both were impacted most.

As well as providing me with excellent training opportunities and the chance to learn new skills. A voluntary organisation xxx has assisted me in developing my self-confidence and also has greatly increased my self-esteem. I am gaining recognised qualifications which will hopefully assist me in entering the labour market.

I gave up employment to care for my son. I do miss my job. I would have appreciated being more involved in son's care. However, the other experiences of mental health services have helped me support my son more.

It has been the centre of my life attending the day centre.

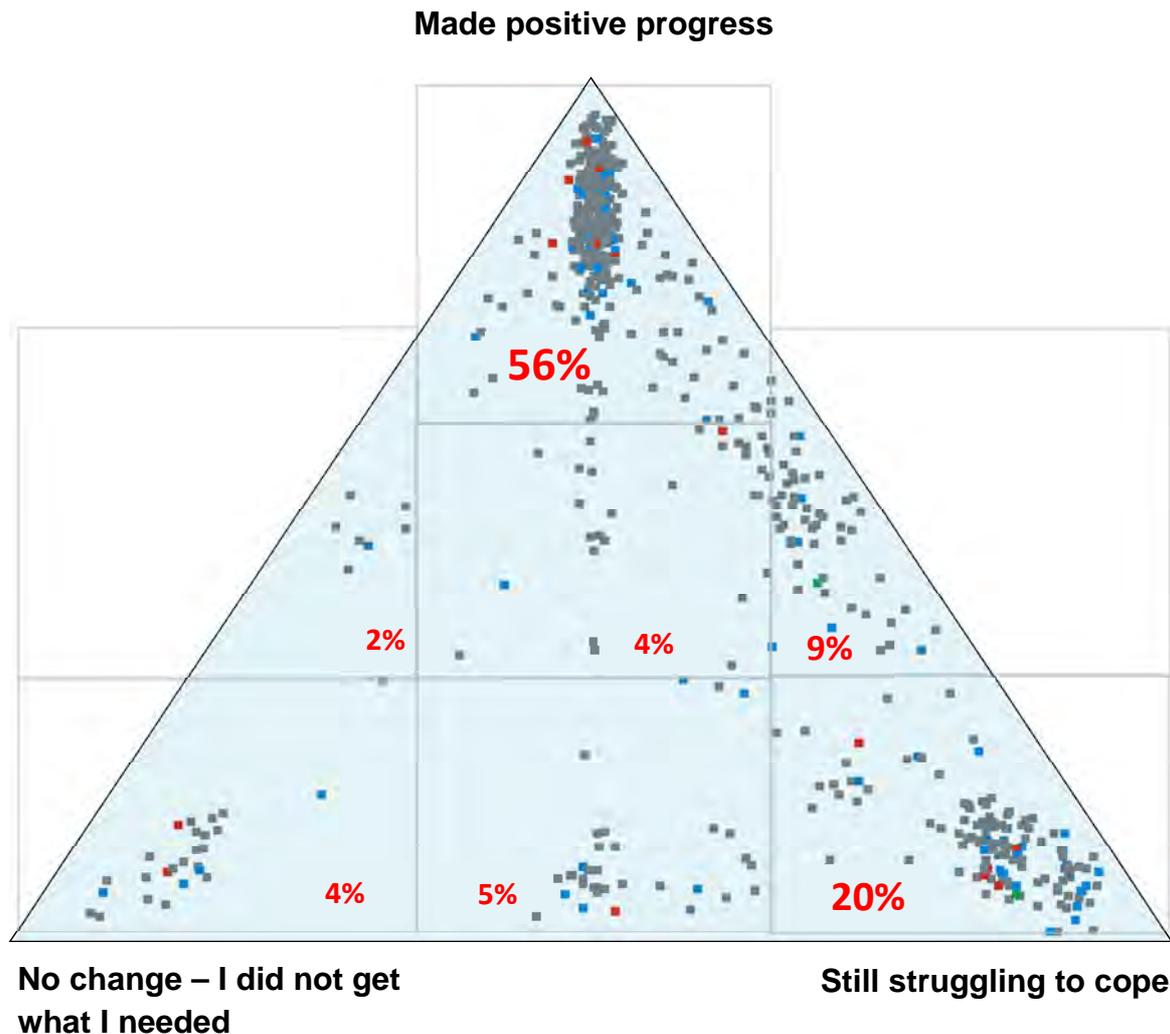
Question 7: What was the outcome / impact of using mental health services?

2015

Total respondents: 665

Responses to this question: 629

Total % of respondents: 95%

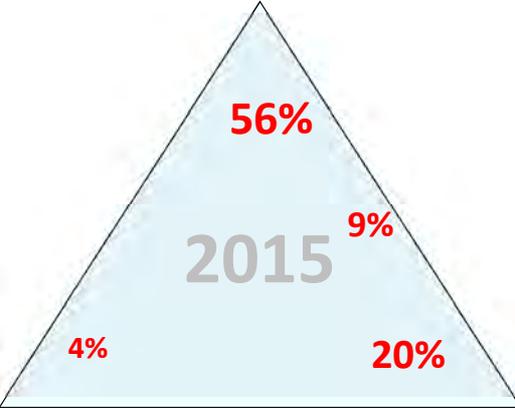


- A greater proportion of respondents (56%) reported that they had **made positive progress** compared with the previous survey in 2012 (47%)
- The proportion of respondents that reported that they were **still struggling to cope** dropped by 7%, from 27% in 2012 to 20% in 2015; approximately 9% of respondents reported making some progress while still struggling to cope
- The proportion of respondents that reported seeing **no change (and did not get what they needed)** halved from 8% in 2012 to 4% in 2015

Question 7: What was the outcome / impact of using mental health services?

Experience doing it
Made myself well, staff helped really well. Couldn't wait felt excited.

Made positive progress



No change – I did not get what I needed

Where do I turn next?
I have been to everywhere I can think of but my son doesn't need to visit someone to 'talk' every week – he needs detoxed dedrugged + practical help?!! I have not great experience with the services.

Still struggling to cope

Another crisis
Depressed, – Moody – Self harms – anxiety – fear – wants forgiveness

Additional stories

More respondents reported in the 2015 survey that they made positive progress compared to 2012. Fewer people said that there was no change after using mental health services, that they were struggling to cope, or both.

I can do, I will do, because I choose to do

Have been to GP to have my medication reviewed and it was agreed that I should be put back on previous with lowered dosage. No hassle. Have had very positive experience with recovery college both as a student and a trainer + participant in committees.

I feel that the classes, groups & visits that I receive are very much supportive, they make me feel at ease and uplifts my spirit and self-esteem.

Saved me the distress of a hospital admission

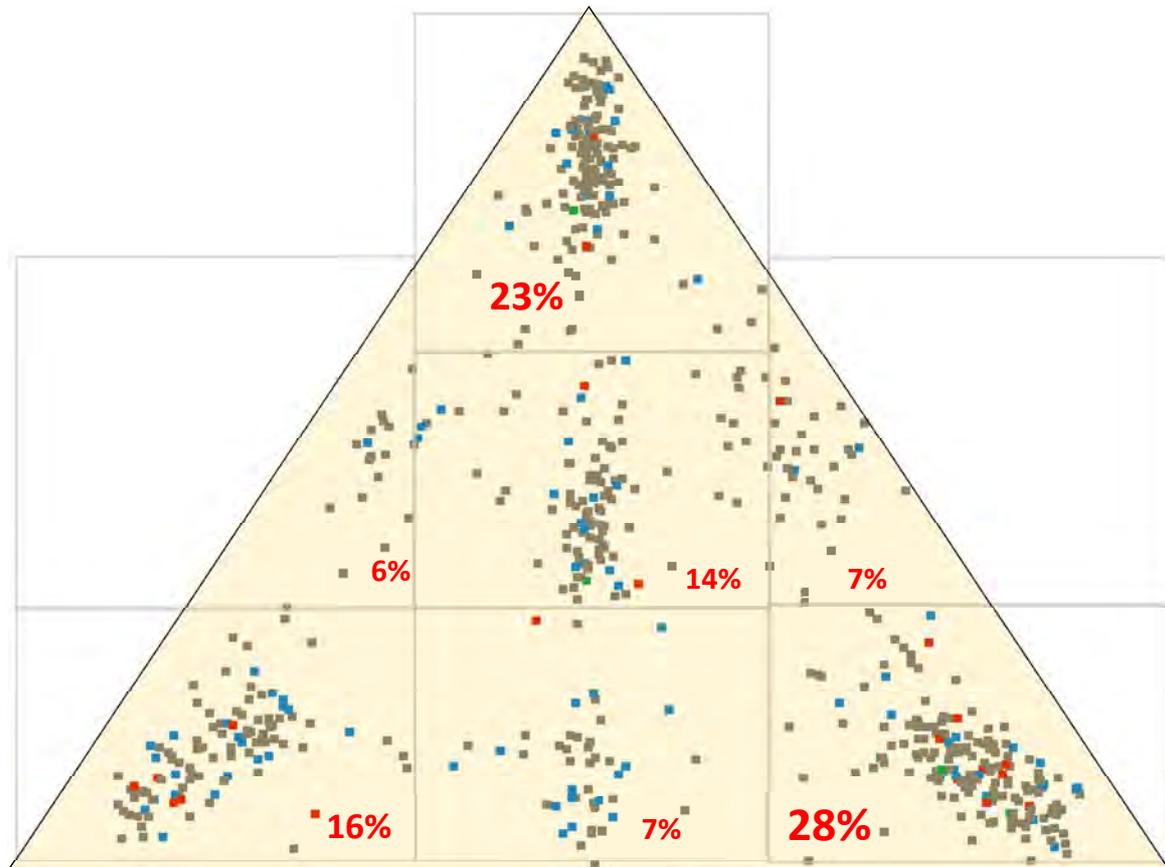
I had a very positive experience with home treatment and it saved me the distress of having a hospital admission which would have always been the case in the past. Because I have been a service user for so long I think the Home Treatment is a vital service for the patient with being able to get treated in their own environment.

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

2012

Total respondents: 720
 Responses to this question: 641
 Total % of respondents: 89%

Practical support with day to day living



Receiving useful information about my situation

Being treated with compassion and sensitivity

- Service user
- Carers
- Informal carers
- Other

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

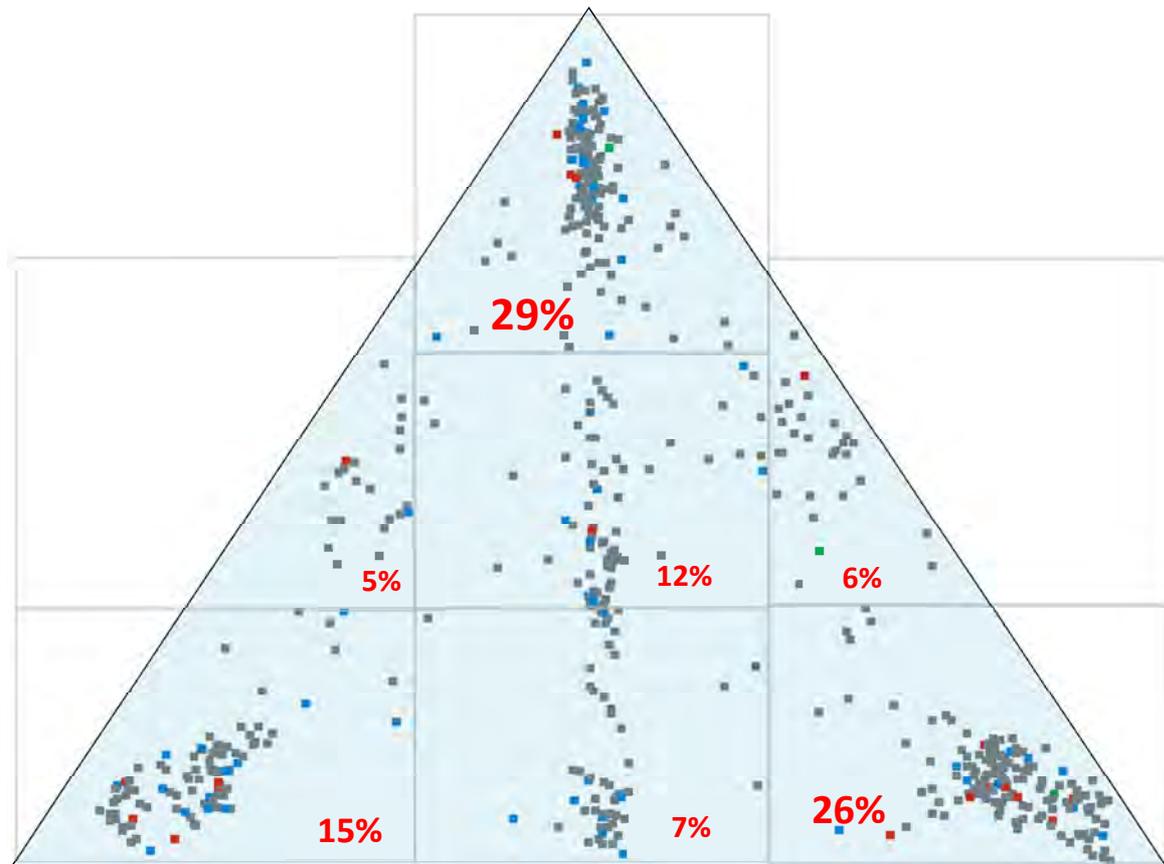
2015

Total respondents: 665

Responses to this question: 582

Total % of respondents: 87%

Practical support with day to day living



Receiving useful information about my situation

Being treated with compassion and sensitivity

- There was little overall change between the 2012 and 2015 surveys in the aspects respondents thought would have made the biggest difference to their experience
- The proportion of respondents that considered that **practical support with day to day living** would have made the biggest difference to their experience increased from 23% in 2012 to 29% in 2015
- There was a slight decrease (2%) in the proportion of respondents that considered that being treated with compassion and sensitivity would have made the biggest difference to their experience, from 28% in 2012 to 26% in 2015

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

Ongoing support by ADT:

(B86) After receiving treatment with Home Treatment Team + House I started classes at ADT. I find them very helpful and useful both socially to build up confidence again, meeting new people but being in a supportive caring environment. Very helpful, classes could be ½ hr longer as I enjoy them.

Practical support with day to day living

29%

2015

15%

26%

Receiving useful information about my

Being treated with compassion and sensitivity

Better explanations about what is happening...

Was attending outpatients and I told the nurse all that was happening to me but no-one give me any diagnosis. The nurse was going to refer me to the psychiatrist but I was admitted to hospital in between times via the out of hrs as I was suicidal and overdosed. Had to go tofirst because there was no beds in Nurses are wonderful in the ward but still feel not getting enough information. Had a brain scan but no one told me results

Importance of self-love...

Interaction with OT i.e. cooking + art + music groups. Makes me feel more confident. The staff were supportive + the outcome was that I found a real passion for art. The art really helped me get through a hard time.

Additional stories

Compared to 2012, a greater proportion of respondents in the 2015 survey suggested that practical support would have made the biggest difference to them. Marginally fewer respondents reported that receiving useful information and being treated with compassion and sensitivity would have made the biggest difference to them.

If everyone in my life treated me or had treated me as well as the mental health practitioners I probably would never had needed psychiatric intervention in the first place. The quality and consistency of service has enabled me to live at home bring up my daughter on my own without recurrent admissions into hospital which can be upsetting and a setback of sorts.

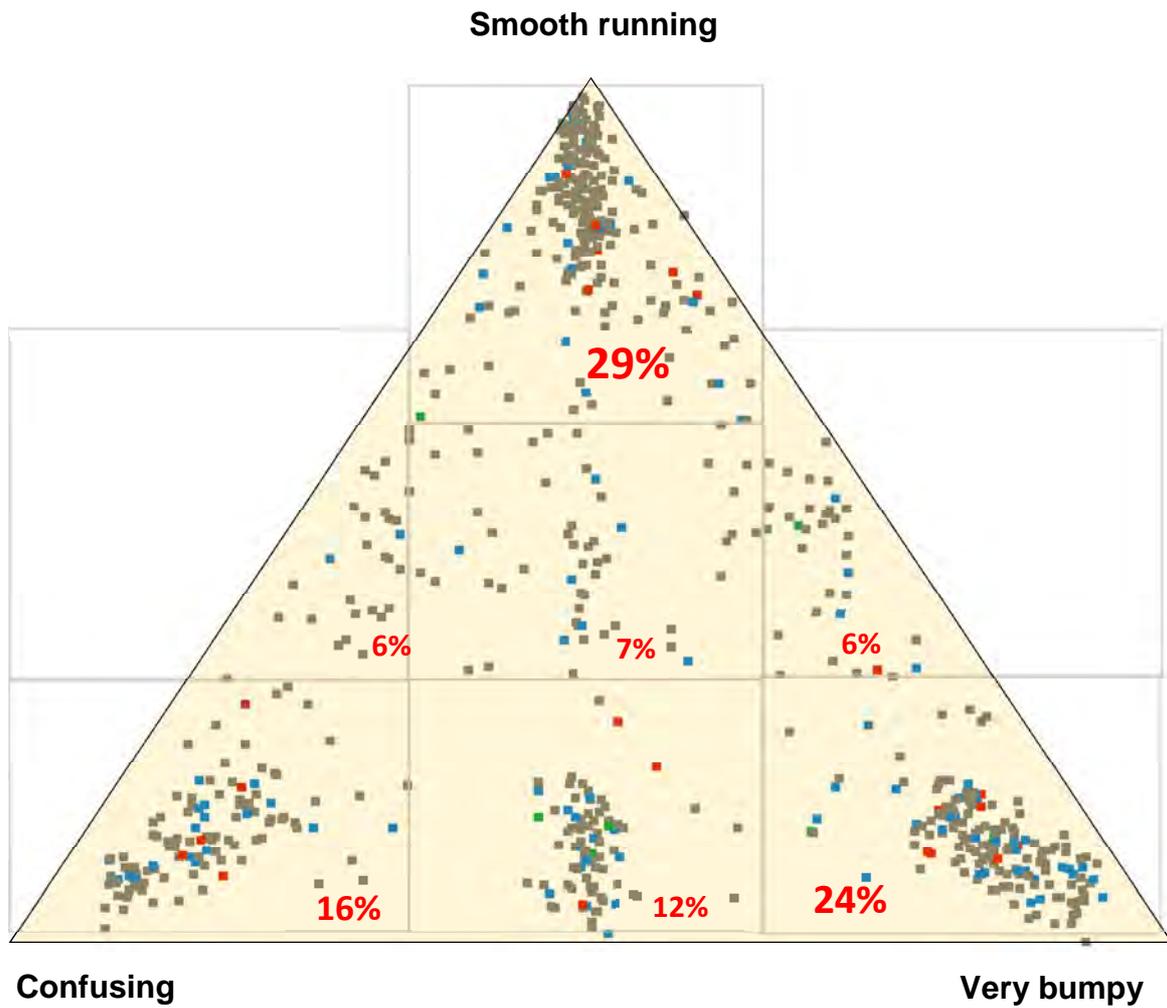
*Wards need rebuilt with single ensuite rooms
– Should have gyms + visitors cafe areas.*

....I got help for my addiction. That 6 week period helped regarding the addiction bit I still needed treatment for the mental problems. Which are still ongoing. I suffer from anxiety and depression. Going to xxx vol /comm organisation does help me. To be honest if I hadn't got this place to go to I would not be as far on as I have good days and bad days.

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

2012

Total respondents: 720
 Responses to this question: 700
 Total % of respondents: 97%



- Service user
- Carers
- Informal carers
- Other

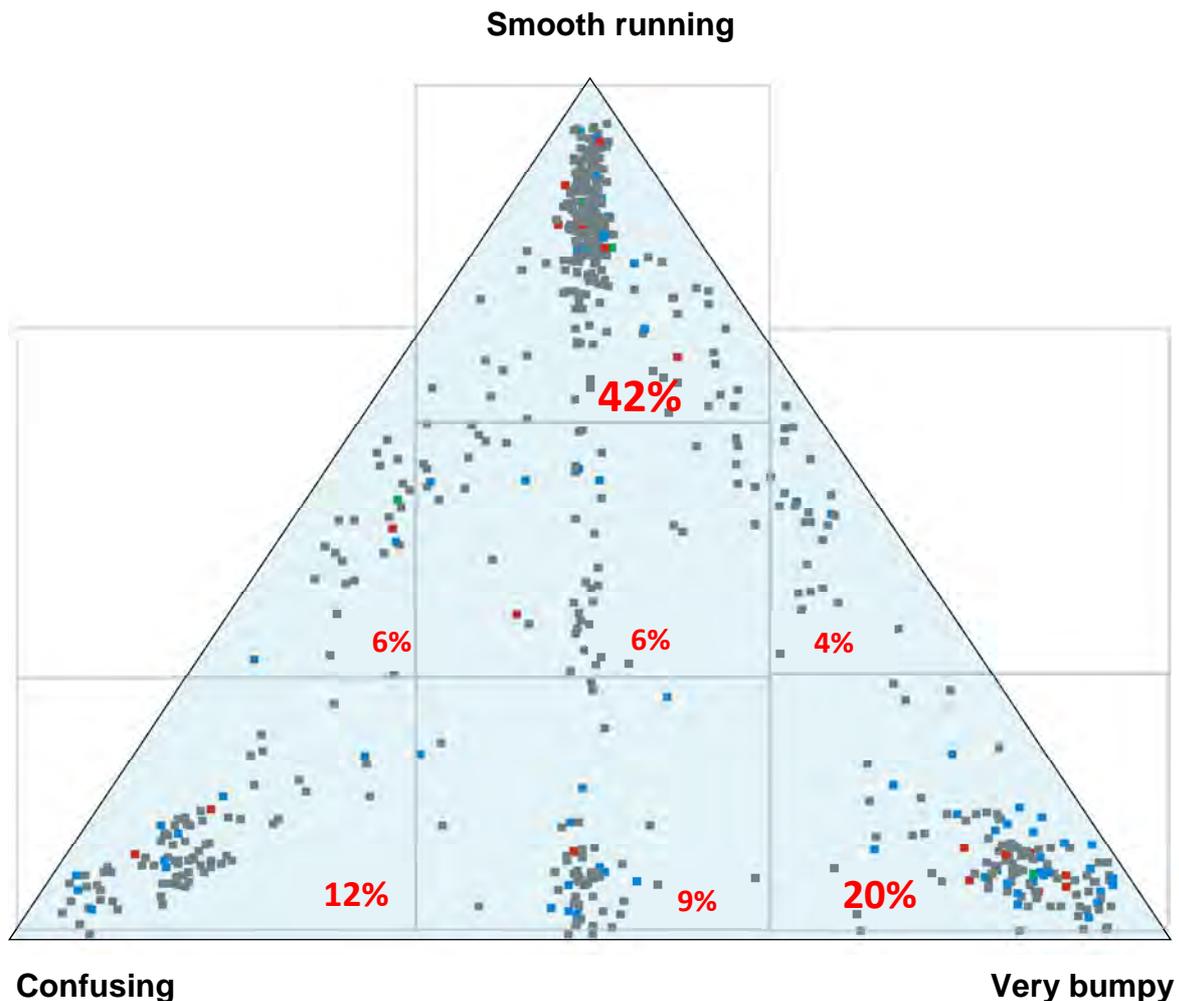
Question 9: Thinking about this experience how would you describe your journey within mental health services?

2015

Total respondents: 665

Responses to this question: 635

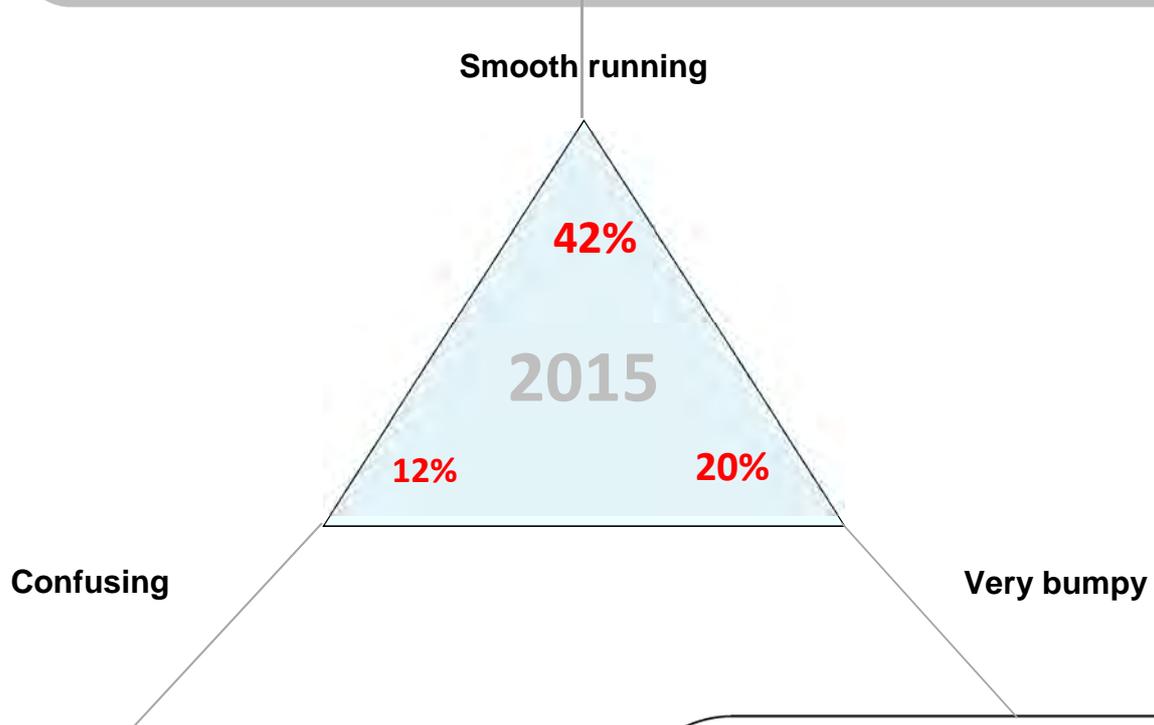
Total % of respondents: 95%



- A greater proportion of respondents (42%) in 2015 reported that their journey within mental health services had been **smooth running** compared with the previous 2012 survey (29%)
- Fewer respondents considered their journey to have been **confusing, very bumpy** or a combination of **both** compared to the previous period, from 52% in 2012 to 41% in 2015

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

Changed my life for the better
 I am glad that I am attending AMH. A family member who works in mental health referred me in the last few months. I look forward to Wed/Thurs when I come in as it breaks the week up for me + I have something to get up for. I get on with everybody and it does help me as with my illness I was mostly in the house. 5/6 years ago I could only go as far as my garden. The supervisors are great + I enjoy the classes



A holistic approach needed
 A family member suffered from depression + self medicated with alcohol. It wasn't treated as a dual diagnosis. When he went into crisis and tried to commit suicide on several occasions. I felt he was let down on several occasions because of no follow-up. A tick box exercise. If he answered it was a mistake and he didn't mean it, he was allowed to leave hospital and no follow-up. Family members who knew his story were not allowed any input.

Be consistent
 I have been unwell for 20+ yrs now – in and out of hospital etc. A few years ago I was with Home Treatment Team and they were great. I got one to one every day, almost 24 hr telephone access – good home visits + practical help. So when I became unwell recently I wasn't worried about going under the home treatment team. I have to say it wasn't a good experience! My home visits were rushed + not consistent, didn't get same people, had to start my 'story' over + over! I used services of local group + GP + CPN to get through my crisis although it took longer this time to recover.

Additional stories

More respondents in the current period said that their journey within mental health services was smooth running.

Young mum finally gets help with mental health

Young mum of two loses children over mental health issues Home treatment called due to girl being unstable. Meetings and reviews were made of her mental health state. As nervous as she was the home treatment team were very helpful and supportive of the girl. This girl was left with no help and support from other parties but home treatment lined her up with group therapies and counsellors.

Over the past three years my mental health condition has improved for the better. The reason for this being I started helping myself by cutting out alcohol and cigarettes. I have also joined my local service user group and have attended some IMROC workshops which I have got a lot out of.

At present I have moved on to part time study and I am slowly re-integrating back into society. I now feel optimistic for the future since help is finally coming my way.

I've had a v positive experience with my GP in health centre around my depression and anxiety. I was referred for CBT in June and this began in Decembe0r last year. I feel that I have been listened to. I've also attended a Mindfulness session run by xxxx and the Stress Control classes which I found useful as tools to help me.

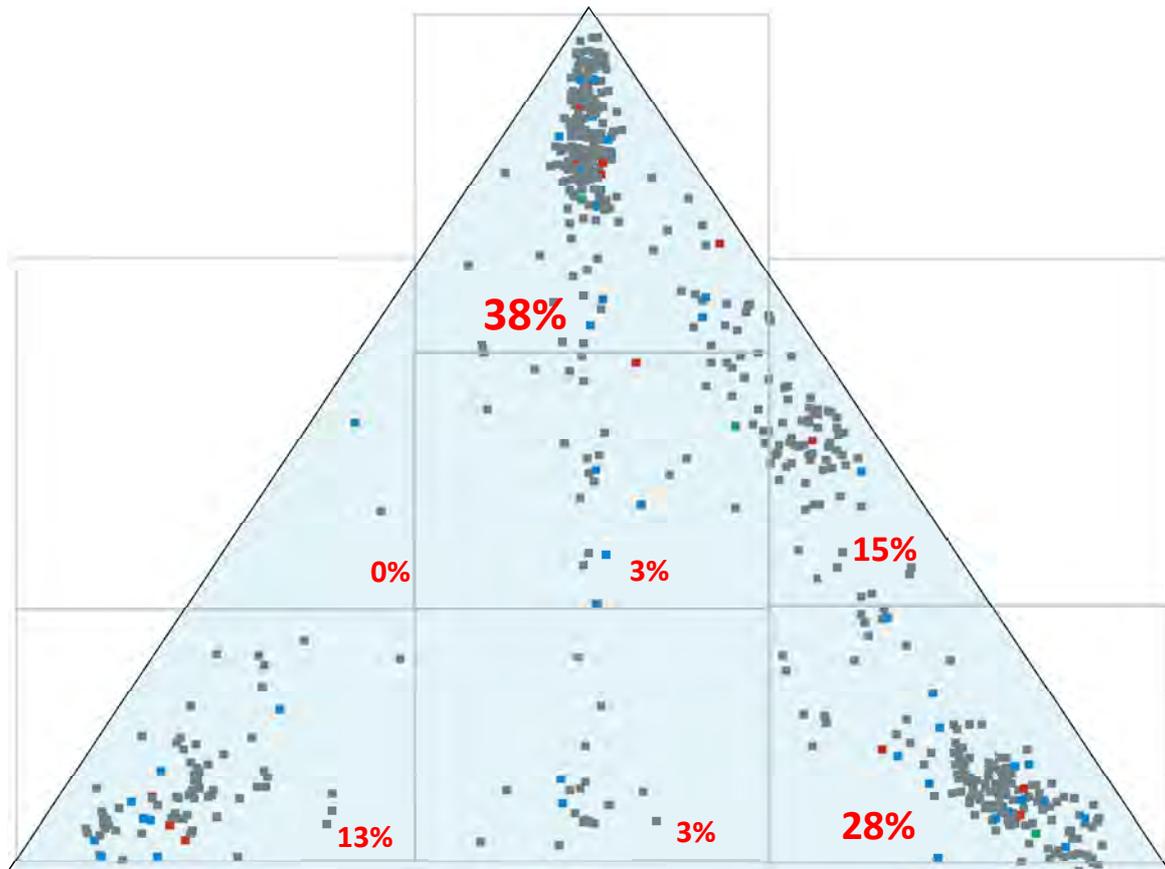
Journey: Smooth now but bumpy as hell in the past. Feel now physical health is my main worry now. Recovery discussed, I take my tablets and see my social worker.

Question 10: How do you feel now about managing your mental health?

2015

Total respondents: 665
Responses to this question: 608
Total % of respondents: 91%

I am more hopeful for the future



Don't know, feel confused

Still working with others to plan the future

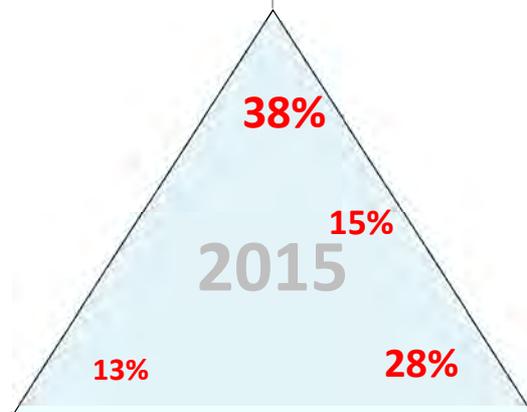
- Over a third of respondents (38%) in the 2015 survey reported that they are **more hopeful for the future** when it comes to managing their mental health
- 28% of respondents are **still working with others to plan the future**, while approximately 15% stated that they are more hopeful for the future while still acknowledging the need to do more work with others
- 13% of respondents **don't know or feel confused** about how to manage their mental health

Question 10: How do you feel now about managing your mental health?

"ME" me me me me...!!!

I was sinking further and further into depression and this was destroying my family ...and now I realise ...me..!!!..I was" rescued " by the most wonderful person who introduced me to a wider team of the loveliest people I have been privileged to meet.. During the one to one meetings I was allowed to examine "me"..understand "me"..get to know"me"..like "me"...and then BE "me"..after 60 years it was such a relief to close the lid of the box of my childhood baggage which I had been dragging with me all this time having a huge effect of my life over the years..!!!..

I am more hopeful for the future



Don't know, feel confused

Still working with others to plan the future

To free or not to free

I was recently moved from a long stay ward to supported housing even though its great to be out of the hospital life hasn't really changed much as I still don't have my freedom staff decide what I eat and cook the dinner I am only permitted out of grounds with staff there is still a lot of routine but no real freedom

A positive change to my life

I feel that the visits from the community mental health team have had a very positive impact on my health. The practical supports provided by my CPN and peer support worker in helping me move to a better flat have really improved my mental wellbeing

Additional stories

Compared to 2012, the proportion of people reporting that their journeys within mental health services were confusing, bumpy or both decreased in the 2015 survey.

I have a lovely wee nurse who comes to see me - he is a nice wee lad but what I'm scared of is that he moves. I have had 3 nurses in the last 2 yrs + every time I get used to one they move..... It's great to have someone who cares. I have told him things I have never told anyone before. He is so respectful + even offers to make me my tea in my own house. I'm so glad he is there.

I was being treated in community and eventually was hospitalized. The Home Treatment team attended me at and they were very understanding and helpful and responded very quickly when I needed them. One staff member was prepared to go that extra mile and stay with me overnight as I was so distressed and no family nearby.

.....Suicide attempt extremely depressed. Admitted and sectioned.

Diagnosis, medication. Recovery, supported by children. Community care assistant. Vol/comm – counselling. Community services CPN still attended. Today I feel peace of mind and contentment.

..... I was off work for 4 weeks – back for 2 months – off for 3 months. The second doctor said I was suffering from depression what a relief! He put me on medication but after a relapse a year later referred me to WRAP – that changed my life.

Question 11: To what extent has recovery been discussed with you by your mental health team?

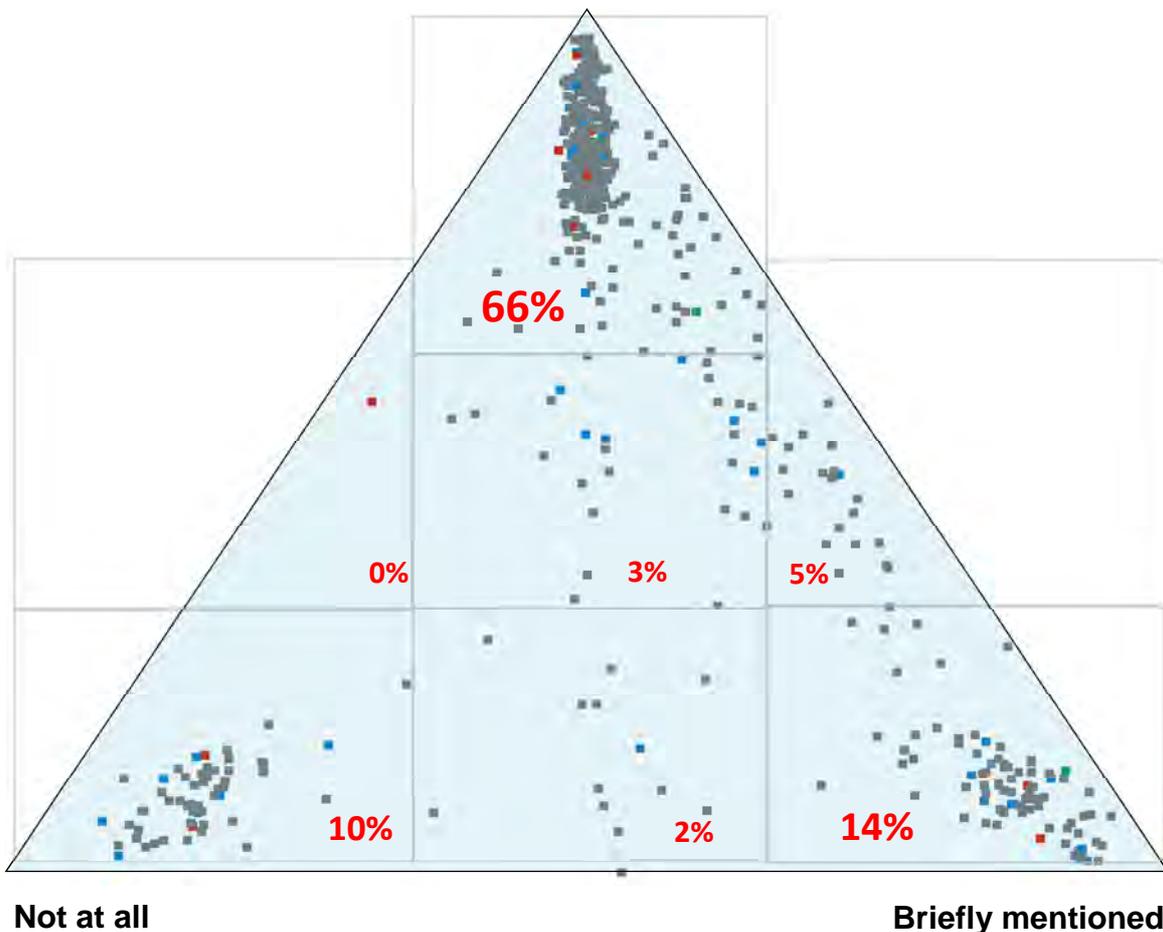
2015

Total respondents: 665

Responses to this question: 584

Total % of respondents: 88%

It has become an important part of my treatment and support



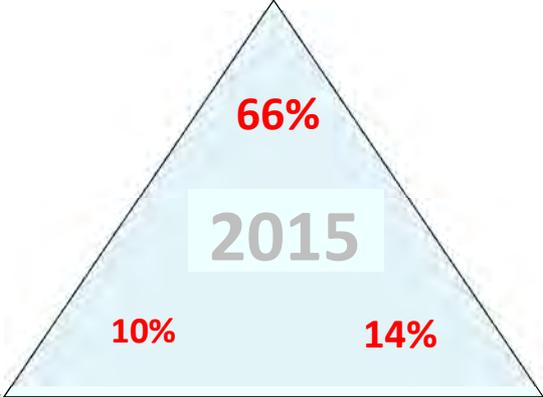
- Two-thirds of respondents (66%) in the 2015 survey reported that discussing their recovery **has become an important part of their treatment and support**
- 1 in 10 respondents (10%) reported that their recovery was **not discussed at all** with their mental health team
- For a total of 26% of respondents, their recovery was **not discussed at all** or was only **briefly mentioned**

Question 11: To what extent has recovery been discussed with you by your mental health team?

Open minded

When I was doing the spiritual recovery Itt brought my sister back together again as we hadn't spoken in 6 years so that was the outcome of it. We lost contact / fell out after our father + sister passed away. It changed my whole life for the better. I am very spiritual and during the course I had a lovely holiday and thought a lot about my sister and while away I bought her a gift and built up the confidence to make contact. The spirituality course made me more aware of my own spirituality and my situation.

It has become an important part of my treatment and support



Not at all

I have found this information is not well communicated, especially on the wards. I appreciated a flyer every month – but only given after I requested something like this. I would advise staff to have a checklist to give out to ALL service users and carers.

Briefly mentioned

I had a bad experience of not being heard. I had to get angry through frustration. And because of this was then heard. I then attended WRAP which helped me have a voice.

Additional stories

For the majority of people, recovery has been an important part of their treatment.

'I' in 'illness' whereas 'W' in 'wellness' = working together

Positive experience – Recovery College – complete contrast – the recovery college has been positive, enriching + informative both for my own mental well-being and for teaching me new skills to help support my son. Taught be to be more self-aware and I have seen changes in my capacity for insight into my son’s condition + how to best support him. The courses have helped me increase my confidence + I believe they have even had an impact on my son’s confidence too specifically in relation to his ability to communicate. I now find my son communicating more with me and expressing positive emotions. I have more hope for my son’s future + believe that one day he will also attend the recovery college. I feel that my experience of the college has helped empower my son. I feel I have more skills and resources to help my son’s recovery. Son’s language changing – more positive.

Highs+lows.

I do believe that the darkness is now behind. And things like the Recovery College have given me hope + light for my son + my future. Mindfulness helped me significantly. Spiritual belief. Support and community.

Condition Management

Completed the condition management programme (CMP) in my local job centre. This included contact from a mental health nurse and a dietician. This greatly benefited my ability to deal with and accept my problems. The anxiety and mood did not drastically change but my acceptance of the illness was better.

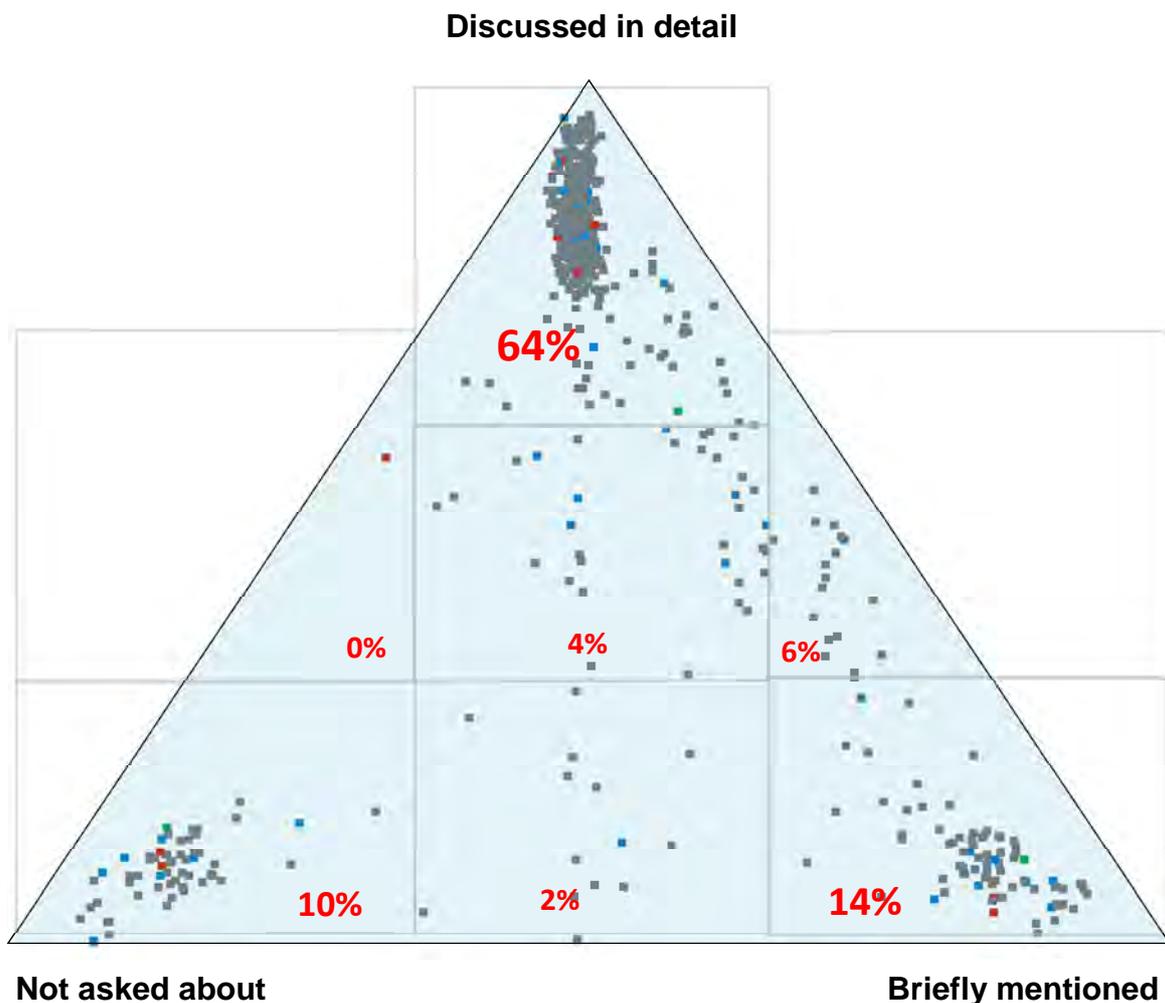
Question 12: Were your physical health care needs considered by your mental health team/practitioner?

2015

Total respondents: 665

Responses to this question: 584

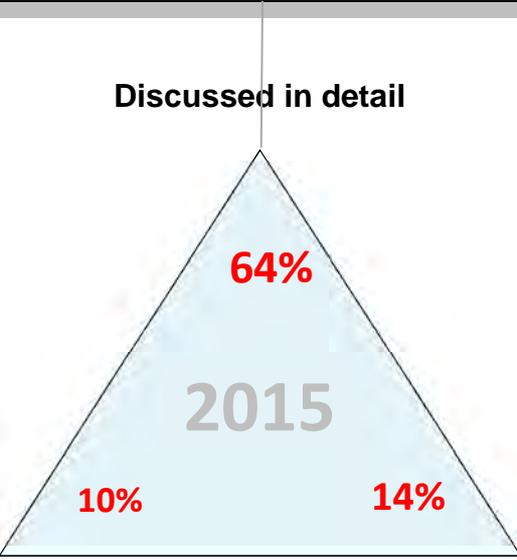
Total % of respondents: 88%



- Almost two-thirds of respondents (64%) in the 2015 survey reported that their physical health care needs were **discussed in detail**
- 1 in 10 respondents (10%) reported that their physical health care needs were **not asked about**
- For a total of 26% of respondents, their physical health care needs were **not asked about** or were only **briefly mentioned**

Question 12: Were your physical health care needs considered by your mental health team/practitioner?

Nothing but helpful
Physical needs: mentioned at every review particularly about smoking. See GP regularly.



Not asked about

...I then went to the G.P. at university for my pre-uni medical - They made such a huge deal at the fact that I had previously been on anti-depressants that I was glad I was now "managing without them".

Briefly mentioned

Wee angel
I have breathing problems + am also physically unwell. The wee nurse is really nice with me and knows when something is wrong and will ask me. The nurse before him never had time they were always in a hurry – meeting themselves on the way out as they come in!

Additional stories

Approximately one-third of all respondents in the 2015 survey said they are hopeful for the future and just under one-third are still working with others to plan their future.

More than two-thirds said that their physical health care needs were discussed in detail by their mental health team / practitioners.

From despair to Recovery

I was suffering with a problem with food. Constantly eating to confirm my low self esteem about my body issues.

I decided one day that I couldn't keep living this way. I was constantly crying and eating in secret, so I typed my symptoms into Google and binge eating disorder came up.

I felt relieve and decided I needed help. I went to my GP and explained the nature of the issue.

I was referred to an eating disorder specialist.

The work that we have done started from me trying to overcome my low self esteem and problems with food and now I speak publicly about my story, I teach about it at the recovery college and have started to acknowledge the strengths I have and use them to help others. It helps me mentally – I hope he doesn't move.

Results - (Demographic Information)

Table 1 – Age Profile of Participants

Age Range	2012 Total Responses: 720	2015 Total Responses: 665
12-19	4 (1%)	10 (2%)
20-29	84 (12%)	81 (12%)
30-39	115 (16%)	100 (15%)
40-49	189 (26%)	170 (26%)
50-59	200 (28%)	172 (26%)
60-65	76 (10%)	61 (9%)
66+	52 (7%)	48 (7%)

Table 2 – Returns by Gender

Gender	2012 Total Responses: 720	2015 Total Responses: 665
Male	322 (44%)	275 (41%)
Female	393 (54%)	370 (56%)
Transgender	2 (1%)	0 (0%)
Prefer not to Comment	3 (1%)	3 (0%)

Table 3 – Sexual Orientation

Sexual Orientation	2012 Total Responses: 720	2015 Total Responses: 665
Heterosexual	589 (82%)	540 (81%)
Gay	11 (2%)	8 (1%)
Lesbian	14 (2%)	4 (1%)
Bi-Sexual	11 (2%)	6 (1%)
Prefer not to Comment	95 (12%)	59 (9%)

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

Commonality	2012 Total Responses: 720	2015 Total Responses: 665
0 (Rare)	16 (2%)	17 (3%)
1	13 (2%)	21 (3%)
2	35 (5%)	41 (6%)
3	126 (17%)	131 (20%)
4	146 (20%)	103 (15%)
5 (Very Common)	234 (33%)	214 (32%)
Don't Know	150 (21%)	96 (14%)

Table 5 – Ethnic Group

Group	2012 Total Responses: 720	2015 Total Responses: 665
British	323 (45%)	151 (23%)
Irish	311 (43%)	155 (23%)
Any other White Background	37 (5%)	316 (47%)
Chinese	2 (0.5%)	1 (0%)
Traveller Community	3 (0.5%)	-
White and Black African	-	1 (0%)
Other Ethnic Group	6 (1%)	1 (0%)
Not Recorded	38 (5%)	38 (6%)

Table 6 – In which setting did your experience occur?

Setting	2012 Total Responses: 720	2015 Total Responses: 665
At Home	200 (27%)	177 (27%)
Local Centre in the Community	121 (17%)	88 (13%)
Hospital Ward	135 (19%)	167 (25%)
Outpatient Clinic	114 (16%)	95 (14%)
Other	150 (21%)	104 (16%)

Table 7 – In Which Health & Social Care Trust area did this experience take place? *(NB This is the HSC Trust where the respondent indicated the experience took place and may differ from the HSC Trust which collected and submitted the survey – see Table 10)*

Trust Area	2012 Total Responses: 720	2015 Total Responses: 665
Belfast	184 (25%)	116 (17%)
Northern	115 (16%)	116 (17%)
Southern	166 (23%)	164 (25%)
South Eastern	138 (19%)	132 (20%)
Western	104 (14%)	91 (14%)
Regional Service	1 (1%)	4 (1%)
Don't Know	12 (2%)	12 (2%)

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

Condition	2012 Total Responses: 720	2015 Total Responses: 665
Depression	362 (56%)	390 (59%)
Anxiety Fears Phobia	178 (28%)	231 (35%)
Schizophrenia	144 (23%)	121 (18%)
Self Harm	121 (19%)	121 (18%)
Psychotic Illness	117 (18%)	102 (15%)
Bipolar Disorder	96 (15%)	107 (16%)
Bereavement/Grief	84 (13%)	87 (13%)
Alcohol Misuse	69 (11%)	83 (12%)
Obsessive Compulsive Disorder	61 (9%)	38 (6%)
Personality Disorder	56 (9%)	67 (10%)
Eating Disorder	55 (9%)	56 (8%)
Post Traumatic Stress	53 (8%)	79 (12%)
Don’t Know	49 (8%)	23 (3%)
Other	33 (5%)	61 (9%)
Substance Misuse	31 (5%)	58 (9%)
Postal Natal Depression	16 (3%)	13 (2%)
Gambling Addiction	13 (2%)	7 (1%)
No Reply	33 (5%)	-

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

Services	2012 Total Responses: 720	2015 Total Responses: 665
Psychiatrist	433 (60%)	67 (10%)
GP	390 (54%)	372 (56%)
CPN	274 (38%)	257 (39%)
Social Worker	223 (31%)	185 (28%)
Nurse	215 (30%)	248 (37%)
Voluntary Organisation	129 (18%)	87 (13%)
Counselling	107 (15%)	121 (18%)
OT	102 (14%)	122 (18%)
Psychologist	97 (13%)	87 (13%)
Other	90 (13%)	145 (22%)
Day Hospital	86 (12%)	61 (9%)
User Support Group	56 (8%)	62 (9%)
Helpline	55 (8%)	62 (9%)
Advocacy	55 (8%)	75 (11%)
Church/Faith	49 (7%)	44 (7%)
Dietician	34 (5%)	25 (4%)
Community Group	27 (4%)	35 (5%)
Health Visitor	21 (3%)	16 (2%)
Don't Know	20 (3%)	11 (2%)

Table 10 – Number of Survey Responses Submitted by each Health and Social Care Trust

HSC Trust	2012 Total Responses: 720	2015 Total Responses: 665
Belfast	184	121
Northern	115	109
South Eastern	138	151
Southern	166	176
Western	104	105
Don't Know/Regional	13	3
Northern Ireland	720	665

Table 11 – Percentage and Number of Respondents

HSC Trust	2015 %	2015 Total Responses: 665
Users of mental health service	82%	548
Informal carer of service user	13%	5
Carer of service user	4%	84
Other	1%	28