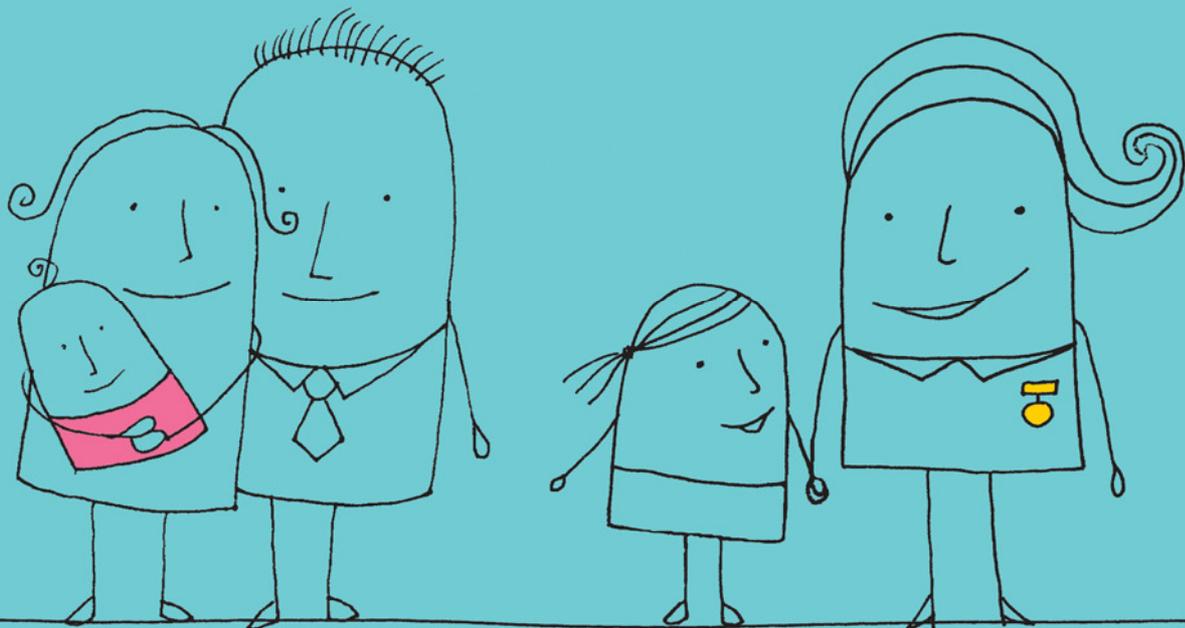www.patientclientcouncil.hscni.net

Patient and Client Council

A report on the workshop 'Shaping Information, Knowledge and Access to Mental health Services'

Held on 4th October 2010, City Hotel, Derry/Londonderry

This was a World Mental Health Day event jointly hosted by Western Health and Social Care Trust and the Bamford Monitoring Group of the Patient and Client Council.

Your voice in health and social care

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Executive Summary

On 4th October 2010, people with mental health needs, families, carers and individuals from voluntary and community organisations met with members of the Bamford Monitoring Group and the Western Health and Social Care Trust to discuss 'shaping information, knowledge and access to mental health services' in the Western Trust area.

This report provides an outline of group discussions. While the opinions of participants were varied, there are a number of key messages which should be acted upon.

The purpose of this report is to help ensure that the process for developing information and advice about accessing mental health services in the Western area reflects the views and opinions of people with mental health needs, families and carers.

Some of the opinions expressed during group discussions include:

- The importance of the GP as the first point of contact, and the need for GPs to be properly trained and aware of support services available for people with mental health needs;
- The need for a single point of access for information and advice;
- The need to have the right information, at the right time;
- The importance of involving people and carers in the development of information and advice about accessing mental health services; and
- The fundamental role of the Community Psychiatric Nurse.

The feedback clearly shows that there is a wide variety of information currently available, much of it in leaflet form. However, people questioned the effectiveness of many of these.

1. The Patient and Client Council

The Patient and Client Council provides a powerful, independent voice for people on health and social care issues. The Patient and Client Council has four main duties; they are to:

- Listen and act on people's views;
- Encourage people to get involved;
- Help people make a complaint; and
- Promote advice and information.

2. Western Health and Social Care Trust

The Western Health and Social Care Trust was established on 1st April 2007 under the Review of Public Administration.

The Trust provides services across five Council areas Limavady, Derry/Londonderry, Strabane, Omagh and Fermanagh) and covers 4,842square kilometres of landmass. Services are provided to approximately 300,000 people.

The Trust employs almost 12,500 staff and invests approximately £422 million in the delivery of a comprehensive range of Health and Social Care services. The vast majority of services are provided in community based settings with access to specialist inpatient services available from a number of hospitals such as Altnagelvin, Erne, Gransha, Lakeview, Tyrone County, Tyrone and Fermanagh and Waterside.

3. Purpose of this report

The purpose of this report is to present the views of people with mental health needs, carers, voluntary organisations and community groups about their needs in relation to information, knowledge and access to mental health services.

This includes how to access mental health services, and building knowledge about mental illness and the various ways it impacts upon people's lives.

On 4th October 2010, people with mental health needs, families, carers and individuals from voluntary and community organisations met with members of the Bamford Monitoring Group and the Western Health and Social Care Trust to discuss 'shaping information, knowledge and access to mental health services' in the Western area.

This report provides an outline of the group discussions. While the opinions of participants were varied, there are a number of key messages which should be acted upon.

4. The Bamford Review

In 2002 the Department of Health, Social Services and Public Safety (DHSSPS) carried out an independent review of mental health and learning disability law, policy and service provision. It was called the Bamford Review of Mental Health and Learning Disability, now simply known as the 'Bamford Review'.

The review produced a series of 10 reports between June 2005 and August 2007 which made over 700 recommendations to improve mental health and learning disability services. It represented a vision for reform and modernisation of mental health and learning disability services in Northern Ireland.

The DHSSPS published its response to the Bamford Review, entitled *'Delivering the Bamford Vision'[1]*, in October 2009. This sets out the specific actions that Government Departments and their agencies are committed to take during the period 2009 – 2011 to improve mental health and learning disability services in line with the Bamford Review recommendations.

5. Information and Advice

The *'Delivering the Bamford Vision'* action plan tasks each Health and Social Care Trust in Northern Ireland with providing **"improved information and advice services for mental health service users and carers"**. The purpose is to give

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[1] Delivering the Bamford Vision – The Response Of Northern Ireland Executive To The Bamford Review Of Mental Health And Learning Disability. Action Plan 2009 – 2011 (October 2009)

better support for people in understanding the services that are available and making their views heard.

In order take this action forward, the Western Health and Social Care Trust (WHSCT) jointly hosted a workshop with the Bamford Monitoring Group. The theme was '**Shaping Information, Knowledge and Access to Mental Health Services'.**

In total 42 people attended the workshop, including people with mental health needs, carers as well as voluntary organisations and community groups supporting people with mental health needs. It was held on 4th October 2010, shortly before World Mental Health Day.

World Mental Health Day is observed on 10th October each year to raise public awareness about mental health issues and to promote more open discussion of mental health.

6. The Bamford Monitoring Group

The 'Shaping Information, Knowledge and Access to Mental Health Services' workshop was independently facilitated by the Bamford Monitoring Group with support from staff at the Patient and Client Council.

The Bamford Monitoring Group was established by the Minister for Health, Social Services and Public Safety. It is made up of people with mental health needs and/or learning disabilities, families and carers as well as representatives of the Patient and Client Council.

The purpose of the Bamford Monitoring Group is to capture the **views** and **experiences** of people with mental health needs and/or learning disabilities, families and carers about the changes being made to mental health and learning disability services in line with the Bamford Review. Our role is to ask people whether the changes are making a positive difference to their lives.

We aim to make sure that the voice of people who have mental health needs and/or learning disabilities, families and carers is heard and acted upon.

Details about the group, members and our annual report **'The Bamford Monitoring Group… Our journey so far'** (August 2010) can be found at the Patient and Client Council website www.patientclientcouncil.hscni.net

7. Shaping Information, Knowledge and Access to Mental Health Services Workshop

The aim of the 'Shaping Information, Knowledge and Access to Mental Health Services' workshop was to provide people who use mental health services, and carers with the opportunity to **shape**, **develop** and **improve access** to mental health services in the Western Health and Social Care Trust area.

7.1 Overview of the event

Trevor Millar, Director of Mental Health and Disability Services, Western Health and Social Care Trust, provided opening remarks. Martha McClelland and May McCann from the Bamford Monitoring Group set the scene for the event and shared some thoughts about the importance of information for service users and carers.

Gillian McMullan from the Bamford Monitoring Group then outlined the format of the workshops and the objectives for the day.

7.2 Workshops

The day comprised of two separate group discussion workshops. The first looked at **information and knowledge**, and the second discussed **access** to mental health services. Questions were used to prompt discussion and Patient and Client Council facilitators recorded key points on flip charts.

8. What People Said

8.1 Workshop 1: Information and knowledge

A summary of feedback from the first workshop is provided below under the relevant questions:

8.1.1 What information do you need to have about mental health and support services available?

People said that it was extremely important to know what services are available to help. Some felt that there was "no clear path to help".

It was thought that the General Practitioner (GP) plays a key role in signposting people. Longer appointment times with GPs were considered necessary to gain more support and information. However, one group questioned "is there anyone other than the GP that you can go to?"

People thought that direct access to a Community Psychiatric Nurse (CPN) rather than having to go via the GP would be helpful. The CPN was considered a key contact for information about mental health services and support.

It was suggested that a comprehensive list of all mental health services should be made available via a 'one stop shop'. In this way information about services would be clear rather than fragmented.

People thought that better signposting of information should be made available. It was thought that, currently, there was no information available without 'outing' yourself as having mental health problems. In other words people would like to seek help confidentially and anonymously, and wanted information that they could access directly themselves. People also said that information available should be "non-judgemental".

People said that the most suitable way to provide information is via human contact. This allows advice and information to be given based on the needs of the individual, as opposed to the

individual "fitting into a service". People also wanted enhanced involvement for families.

It was thought that information was available but that at times this was not being passed on by professionals. For example, one individual said that they did not know about 'New Horizons' until recently, because their CPN was not aware of it.

Information based on people's previous experience and that of community and voluntary organisations was requested. Importance was also placed on making information relevant, timely and accessible. It was suggested that information should be targeted at smaller groups in the community.

Some people said that they needed more information on the following issues:

- Family-orientated services;
- Young people's services;
- Care pathways;
- Children's rights;
- Welfare;
- Parental support;
- Sexual abuse.

Some people commented on the "disjointed" service for children and adolescents. Connected to this was the suggestion that raising the awareness of mental health services should start from an early age on (for example age 13) when young people are 'changing'.

People expressed a desire for one clear document for patients, carers and professionals outlining their rights regarding confidentiality. Best practice guidelines need to be adhered to regarding the sharing of information.

People wanted more information regarding local support groups, particularly those with medical professional support.

One of the groups made particular comments about information on medication, that is how to take medications, why medication is required and its side effects. It was thought that this

information needs to be more effectively and sensitively communicated to individuals and carers.

Linked to this point was the discussion about the role of the community pharmacy in improving medication compliance. People thought that education and working collaboratively with individuals and carers as equals was important, particularly in relation to their rights to information and respect for their experience of taking different medications. This is relevant to the government focus on issues such as 'patient's experience' and 'choice' as well as medication compliance.

There was a warning, though, not to "overload" people with information. The emphasis was on having access to the right information at the right time.

8.1.2 Where do you go to get information about mental health and support services available?

The GP was the primary point of contact for people. However, it was noted by many people that the information is not always readily available, and it was suggested that training for GPs is required to raise their awareness of available help.

It was thought that statutory and voluntary organisations need to come together, and a map or directory of services of what help is available in each area was suggested.

Some of the key sources of information for people include the following:

- CPN / Social Worker;
- CAMHS (Child and Adolescent Mental Health Services);
- Voluntary Organisations (but they do not always have enough resources);
- Hospital 'crisis' teams;
- Primary Care teams;
- Peers (friends);
- "Word of mouth";
- Leaflets in public places;
- Schools.

People expressed the view that a CPN has more time to spend with you, and as a result you are more relaxed, and in your comfort zone to talk to them.

People also suggested the following types of media and technology as sources of information:

- Internet;
- Television;
- Radio;
- Social Networking sites, for example Facebook;
- Magazines;
- Newsletters;
- Texting.

The internet and websites such as 'Mind Your Head' were considered important sources of support and information. However, the dangers around 'self-diagnosing' were highlighted as a caution.

People suggested that a 'mental health hour' discussion in local areas at community level, to hear about other people's experiences would be helpful.

8.1.3 How do you prefer to hear about mental health and support services provided?

People said that they would prefer to use the following sources to find out about mental health and support services:

- One to one sit down and talk through options and what is going to happen;
- A central helpline to advise people would be useful;
- Interactive website;
- Other professional;
- Personal recommendations;
- Internet;
- Leaflets;
- Calendars;
- Texting;

- Social networking sites.

Many people emphasised the value of 'face to face' communication to talk through the situation and discuss the options available.

Many people also suggested the value of a central helpline to advise patients on a 24/7 basis. People said that there is an issue that directories go out of date too quickly.

8.1.4 Examples of information provided by Western Health and Social Care Trust

The Western Health and Social Care Trust provided the Bamford Monitoring Group with some examples of available information about mental health services. The information was circulated amongst groups for comment and feedback.

The information provided included the following Trust developed information[2]:

- 'Adult Mental Health Services' information available via the Trust website;
- 'Supporting Carers' information available via the Trust website;
- 'Carers Database', WHSCT leaflet;
- Family Liaison Service, WHSCT leaflet;
- Autism Spectrum Disorder 'links', WHSCT leaflet;
- 'Autism Specific Services', information sheet;
- 'Autism Spectrum Disorder Service – The journey Through the Assessment Process', WHSCT leaflet;
- 'Information for relatives/ carers of problem drinkers', Addiction Treatment Unit, Tyrone and Fermanagh Hospital;
- Addiction Treatment Unit, Tyrone and Fermanagh Hospital leaflet;
- 'CAMHS in Brief', WHSCT leaflet.

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[2] While autism and drug use were referred to by people attending the workshop and in the leaflets provided by the Western Trust for the event, neither of these issues come under the remit of the Northern Ireland Mental Health Order. They are however highlighted in the Bamford Review of Mental Health and Learning Disability.

Further information for the Western area included the following:

- 'Caring for Carers'; Western Health Action Zone booklet;
- 'Managing Stress @ Work', Western Investing for Health booklet;
- 'Don't let depression get you down', Western Investing for Health leaflet;
- 'Bereaved by suicide – a guide to the feelings and services', Westcare booklet;
- Mental Health West, website.

Regional information regarding mental health included the following:

- Looking after your mental health, Health Promotion Agency, Minding Your Head and DHSSPS leaflet;
- 'Everybody Hurts Sometimes', Lifeline leaflet;
- 'r u ok?' information card;
- Lifeline information card;
- 'The pocket guide to good mental health, Health Promotion Agency, Minding Your Head leaflet.

Feedback and comments people gave about this information is summarised below:

There was concern that the information was too "bland" and the format was too "paper based". One person said "everything is about paper".

There was also concern that the leaflets were packed with too much information and the colours and the fonts were 'too grey and depressing'. However, it is important to note that some of the information leaflets provided were photocopies so it is unclear if the originals were colour or black and white.

The issue of talking to people and explaining information contained in leaflets was considered important.

It was commented that the website mentalhealthwest.com was "not very useful" and that the site was "disappointing", with no links to other services.

Some people mentioned the negative implications of the location of Child and Adolescent Mental Health Services, commenting that a community-based setting would be preferable. Also, people felt that the leaflets did not focus on the communication needs of young people.

A few people also mentioned that they "didn't know to go to the Western Trust site for services for carers", and were "not aware of the carers database".

The number of different leaflets and how quickly information goes out of date was highlighted as something that could be improved.

People questioned how many leaflets the Trust produced and where they are distributed.

Positive feedback was made regarding the 'carry cards' which were described as excellent as they "stood out". The lifeline leaflet was described as "very well laid out" and the telephone number was widely known and available to people.

There was positive feedback on the 'Looking after you mental health' leaflet as it was colourful, with good photographs and a diverse mix of people on the front cover.

Some people suggested that perhaps the Trust could consider colour coding information for services, for example green for mental health, blue for learning disability services and red for suicide awareness.

8.1.5 How can we improve information about mental health and support services available?

Many people stressed the importance of talking to people to explain leaflets, and the importance of using the appropriate language with the appropriate audience to ensure that the information is passed on effectively. Provision of information in "non-leaflet" form is important as well.

Better use of 'cool' promotional items such as key-rings, pens, and something similar to the lifeline 'torches' were recommended as a more effective way of communicating information.

The use of posters and leaflets in tandem was suggested. In particular, the provision of the option of a box to "self refer" confidentially to services was requested.

It was suggested that the location of leaflets could be improved- with better distribution in GP surgeries, schools, dentists, hospitals, phone boxes, taxi ranks, pubs, shops, Citizens Advice Bureaus and churches. It was also suggested that better use could be made of television, radio and internet resources.

Many people thought one telephone number to contact services would be effective. This should provide a 'one stop shop' to signpost and direct people appropriately.

It was also suggested that many improvements could be made to existing facilities which offer information and support, for example provide information and advice sessions in tandem with alternative therapies or offer leisure or social activities in tandem with information sessions to younger people.

People also advised to use language that children will understand.

8.1.6 General comments

In more general terms, the participants would like to see an improvement in access criteria for services and a reduction in stigma surrounding mental health issues.

It was suggested to establish one regulatory body for all statutory and voluntary organisations. Also, it was proposed to have one central database that was regularly kept up to date and which could be easily accessed.

8.2 Workshop 2: Access to services

A summary of feedback from the second workshop is provided below under the relevant questions:

8.2.1 How do you 'access' mental health services and support? That is how do you go about getting help when you need it?

Many people stated that they did not know where to go to get help because the services were not advertised, and they asked for information about who the "key contacts" were.

When asked the question on how to 'access' mental health services and support, one person said simply "with difficulty".

People said that their GP was the normal starting point. When accessing services, people also mentioned they would approach the following for getting help:

- Voluntary and community groups;
- New Horizons;
- Help-lines;
- Lifeline;
- Social worker / CPN;
- Internet;
- Hospitalisation.

'Word of mouth' was important in accessing information, and the internet was suggested as a good source of information.

It was thought that there were no hospital services/psychiatrists for children, and it was particularly difficult for young people to get into hospital.

People also thought that there was not enough support for addiction and they said that there was no detox service for women.

8.2.2 Can you identify any barriers to accessing services? If so, can you suggest solutions?

(1)   Stigma
Stigma and fear were mentioned as a major barrier for people coming forward to seek help.

(2)   Service availability
The 9am – 5pm availability of services was seen to be a barrier to accessing help as and when it was needed. People felt that there was "nowhere to go after 5pm". Further, it was felt that there should be more flexible hours for the phone systems.

(3)   Involvement
Listening to and involving family and carers was considered highly important. It was thought that there was generally a lack of feedback to family members and carers. During multidisciplinary team meetings to review a person's progress, families are often asked to leave.

One person asked why it was so different to involve family and carers in supporting someone with mental health needs than with medical concerns.

More professional support for carers was requested. It is important to ensure that their needs as a carer are being met.

People with mental health needs said they were afraid to "challenge the system" regarding their care, for fear of being "struck off" the list. Further, people said that they had difficulties in speaking with professionals, and that they needed help with confidence matters and speaking up.

(4)   Missed appointments
The nature of mental illness itself was described as a major barrier, for example when causing people to miss their appointments.

One person commented that "you are usually the last person to know that you have a mental health problem, you don't listen to family and friends".

There was an appeal that there should be reminder phone calls or texts or whatever is appropriate for the person concerned to help them keep their appointments.

People also suggested that there should be a **stop** to the practice of taking people "off the books" due to missed appointments. Missing appointments should be treated as a need for help, follow-up and efforts to bring that person into the system again.

(5) Discharge process

The discharge process from hospitals was described as a barrier within services, as there was not enough information about it. The 'Report of the Independent Inquiry Panel to the Western and Eastern Health and Social Services Boards' (May 2007) was cited as evidence of informing families and involving them in discharge arrangements. The importance of involving individuals and carers in Care Planning was emphasised as part of this discussion.

Both people with mental health needs and carers emphasised that they want a way to contact back into the inpatient ward for advice after discharge.

Information about "re-accessing" the system when it is needed and the ongoing opportunity for communication was considered important.

(6) Knowledge about mental illness

Education was mentioned as a major barrier to accessing services. Some people thought that GPs' lack of knowledge and understanding about mental health could result in a lack of necessary referrals being made.

One group said that there is a need to provide education for people with mental health problems about mental illness and how best to cope with it – not just 'information'.

> Training for GPs and health care professionals regarding mental health services that are available in their area is required.
>
> It was thought that the job of educating, communicating and providing information to people with mental health needs and carers should be mainstreamed into staff job descriptions. This should be supported by a designated person taking overall responsibility for this aspect of work.

(7)   Information leaflets

Some of the language used in the leaflets was seen to be 'inaccessible', and they also needed to be clearer as to what services are offered.

Further, problems of communication for people who cannot read or for ethnic minorities who speak English as a second language were identified.

> Create more accessible 'user-friendly' information, taking into account the communication needs of different groups.

(8)   Collaborative working

Access to mental health services and support is not just a 'health' issue. There needs to be integrated working across Government departments around public health and mental health promotion.

(9)   General comments

'Risk assessments' were seen to focus too much on bureaucracy and not on the needs of the patient.

The lack of resources was identified as a problem as well as their location, for example in hospital settings. It was suggested that there should be counsellors available in every health centre.

The rule that you have to be drug/alcohol free for three days before you can access the addiction services was seen as a barrier[3].

Not having the option to speak with someone of the same sex as well as having a lack of confidence in 'speaking up' were mentioned as significant barriers.

8.2.3 How can we make sure the right information about accessing services reaches people?

Better networks would ensure better communication between service users and professionals; a critical point was the clarification of who the right person would be right from the start. A 'pack' with full information about support on discharge was suggested. The role of advocacy to support and inform people about services and accessing help was emphasised.

It was considered important to make information available locally with more 'trendy' formats such as beer mats, pens, torches etc., and with advertisement of services in public places such as bars and nightclubs. Creative communication with younger people is required.

> It is important to work in partnership with the people who use the services in order to bridge the gap between the help people ask for and the services that they are offered.

It was suggested that visiting people on an individual and group basis to gather views about accessing services would ensure that individual needs are indentified and qualitative research is carried out. Using feedback from organisations, workshops and events should be used to guide service development.

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[3] While autism and drug use were referred to by people attending the workshop and in the leaflets provided by the Western Trust for the event, neither of these issues come under the remit of the Northern Ireland Mental Health Order. They are however highlighted in the Bamford Review of Mental Health and Learning Disability.

People also said that the Western Trust should not be scared of complaints; these are important to identify and highlight areas for improvement.

It was suggested that a yearly mail drop to houses in the Western Trust area would ensure widespread distribution of leaflets. Further training for GPs and information about services available in the Western Trust area that they can refer to would result in the right information being passed on at the right time.

One group suggested a different approach by training taxi drivers to provide information as they are an excellent resource used by many people.

8.2.4 What can we do to make sure people are involved and can share their views and experiences of mental health services?

"**Make it easier for people to participate**" was a key message. Speaking directly to people is important when seeking their views and experiences. People at the workshop said "go to where the people are". It was thought that the statutory sector needs to work closely with voluntary and community groups to keep participation going.

More public events are needed where organisations can promote their services so people do not always have to go to a GP or health care professional. People said it was important to have better advertisement and more advanced notice of public events and group meetings.

Patient and client forums, regular patient experience feedback surveys and evaluations are good ways of seeking participation.

It was thought to be important to place a greater focus on fun, social and leisure activities to attract young people to come forward and share their views. Better use could be made of social networking sites and interactive website formats to encourage involvement.

It was suggested that the Western Trust could promote mental health more in the community, for example with a 'mental health' bus travelling around.

Using positive language to describe mental health groups would reduce stigmatisation, and a focus on leisure and social activities would attract more young people to seek support.

9. Final thoughts

The Bamford Monitoring Group and the Patient and Client Council would like to take this opportunity to thank all of the people who gave of their time and attended the 'Shaping Information, Knowledge and Access to Services' workshop.

The increasing focus on collaborative healthcare involving patients as 'experts' in their illness, and carers as 'partners in care' requires commitment to a change in healthcare culture involving the development of more equal relationships between service providers, service users and carers. Information and knowledge is central to this process.

The event was an important step to ensure that the voices of people with mental health needs, families, carers as well as voluntary and community groups are heard and acted upon.

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