Time to Listen; Time to Act

Holding Mental Health Services to Account

4 NEWS DERRY POST TUESDAY

Public Health Agency 'failing' people living in rural areas

By Caoimhe Hegarty

Sister's campaigning secures services for 'suicide' families

A year after her brother's death Julie Magee says her demand for help for bereaved families hasn't been in vain

Campaigners take fight to Stormont

Gerard McCartan

Mum of man disabled after suicide attempt says system still failing

GEMMA BURNS

Suicide campaigner hits out

Mental Health Rights Campaign

March 2014

Participation and the Practice of Rights

THE RIGHT TO HEALTH

Accountability. Equality. Participation.

About the Mental Health Rights Campaign...

For the last eighteen months, groups and individuals from across Northern Ireland have been gathering extensive evidence about people's experiences of accessing mental health services at both GP and A&E settings, the type of support they are offered and the problems they encounter with follow up care. The contribution of so many groups and individuals to the research clearly shows that people want to be heard and have plenty to say about what is and isn't working in mental health service provision.

The evidence documents the continued frustration people are experiencing with government decision making processes which exclude them.

The evidence overwhelmingly suggests that despite the ever increasing references to 'participation' and the many government policies which are supposed to promote this; people's right to be involved in decisions made about mental health services is not being made real on the ground.

This needs to change.

The Mental Health Rights Campaign brings together many individuals from across Northern Ireland who know from their own experience what needs to change. People involved in the Mental Health Rights Campaign are using human rights in an approach cited by the United Nations as best practice, to collect evidence to campaign to hold government to account.

This is the way participation should be, those who are affected by decisions around mental health services leading the way on identifying the issues, highlighting solutions and using their evidence to hold government to account. People have spoken out about their experience and what needs to change; it's time for government to not only listen, but take action.

Focussing on issues that matter to us that need to change…

etting the help you need at the GP and at A&E when you need it

Getting the right type of care for you from your GP

Staying linked into services after attending A&E

Knowing where to go when you need help and having enough information to make the best choices for you

Being part of important decisions government makes about mental health services

Getting the help you need at the GP and at A&E hen you need it

“ When I rang for an appointment I was told there was nothing. It was only after i told them how much of a crisis i was in that i was going to take an overdose that i got seen”

“ It doesn't help you if you are in the waiting room and you see people you know and they want to talk to you...you are maybe very emotional and distressed”

How people access help when they are in mental health crisis or distress was a huge issue for the people we spoke to. Many told us about problems with getting an appointment with their GP or long waiting times to be seen at A&E. It was clear that the issue of waiting times means more to people than a simple calculation of how many hours you waited at A&E or days passed before you were seen by the GP. Often people face barriers with the process for getting a GP appointment itself; as one service users commented “the problem is trying to get past reception” or as another made the point, *“unless you stand at 8.40am, it’s impossible to get through on the phone”.*Others noted the inappropriateness of the waiting areas at both GP surgeries and at A&E with people calling for “*somewhere separate to wait - quiet”. A* quiet room is also required at the GP where *“there’s no confidentiality, everyone can hear”.*

Under International Human Rights Law - we have a right to timely and appropriate treatment at the GP and A&E;

> *“The Committee interprets the right to health, as defined in article 12.1, as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health”*

UNCttESCR General Comment 14, para. 11

Under Government’s own policy;

> *“Mental health services should be provided in an age appropriate environment that ensures the safety, privacy and dignity of those who use the services and their families and carers.”* - Standard 13
>
> *“A person experiencing a significant mental health crisis should have timely access to age appropriate health and social care services 24 hours a day and 7 days per week.”* - Standard 18

(2011) DHSSPS Service Framework for Mental Health and Wellbeing Standard 13

> " A&E is that last place on this earth I would go, sure you would be sitting in A&E for 3 or 4 hours, just crying and there's people sitting in there may be covered in blood, and they're not even being seen - the system's too slow"

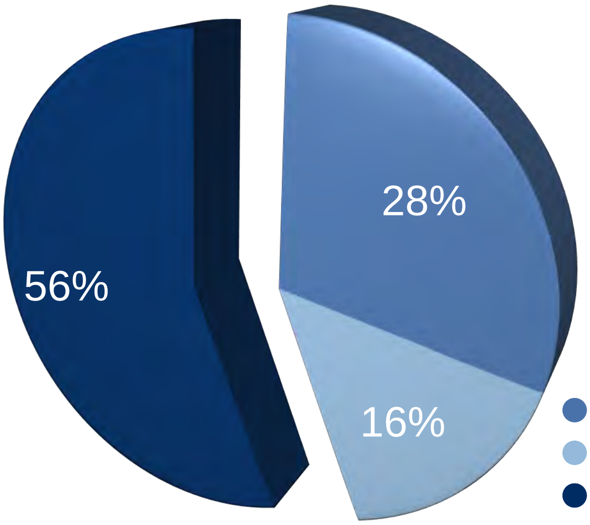
What are we measuring?

1. % of patients and carers who thought waiting times for an appointment with the GP were unsatisfactory or very unsatisfactory

2.% of patients and carers who thought waiting times at A&E were unsatisfactory or very unsatisfactory

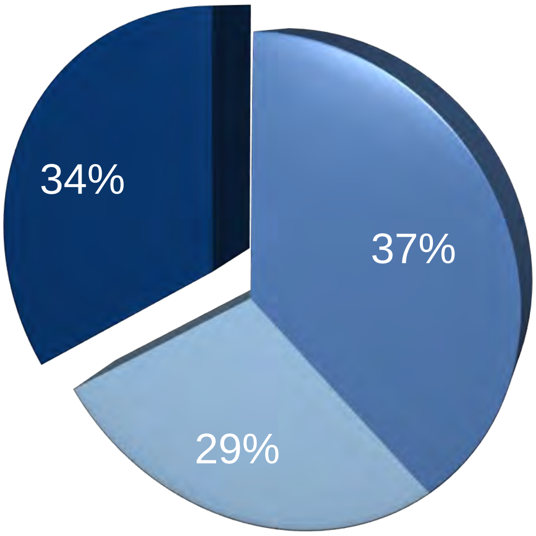
At the GP...

% of patients and carers who thought waiting times for an appointment with the GP were unsatisfactory or very unsatisfactory	44%



At A&E...

% of patients and carers who thought waiting times at A&E were unsatisfactory or very unsatisfactory	66%



What change do we want to see?

	TODAY	IN A YEAR'S TIME THIS SHOULD BE...
% of patients and carers who thought waiting times for an appointment with the GP were unsatisfactory or very unsatisfactory	44%	14%
% of patients and carers who thought waiting times at A&E were unsatisfactory or very unsatisfactory	66%	14%

> *"They need to have somewhere in the GP's you can go before and after your appointment. Something like a quiet room – not a formal waiting room."*

> *"They need to change the way urgent appointments are made at the GP. They have an automated system, could there be an option to press if you need an urgent appointment for mental health reasons? Then you could be put through to someone who has a good understanding of mental health, or straight though to a GP?"*

Getting the right type of care for you from your GP

Length of appointments, type of follow up care given and how people felt at their appointment came up over and over when we asked people how satisfied they were that their GP had given them the most appropriate type of care.

" I've asked to see a psychiatrist and the doctor says try these tablets first"

People often commented on how the short length of appointments made them feel rushed and unable to fully explain to the doctor what type of help they needed with comments such as "the *GP put a time limit on my grief" and "I was told twice – "I have another patient to see""* common.

One service user told us about her experience "I *went to the GP he was very uncomfortable talking about suicide and mental health- no information for me on support services available or other help. He offered me tablets which I didn't want to take."* A carer summed up the experience of accompanying a relative to the GP as *"Not being listened to, GP was patronising and dismissive. We weren't taken seriously, felt like they thought we didn't need to be there"*

Most people we spoke to were prescribed medication. Despite the overwhelming evidence that people wanted access to counselling, our survey revealed that only 27% of those prescribed medication by the GP were also offered counselling.

Mum of man disabled after suicide attempt says system still failing

Under International Human Rights Law - we have a right to the highest standard of mental health care:

> *"The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."*

International Convention on Economic, Social and Cultural Rights, Article 12(1) [ratified by UK 1976]

Under Government's own policy;

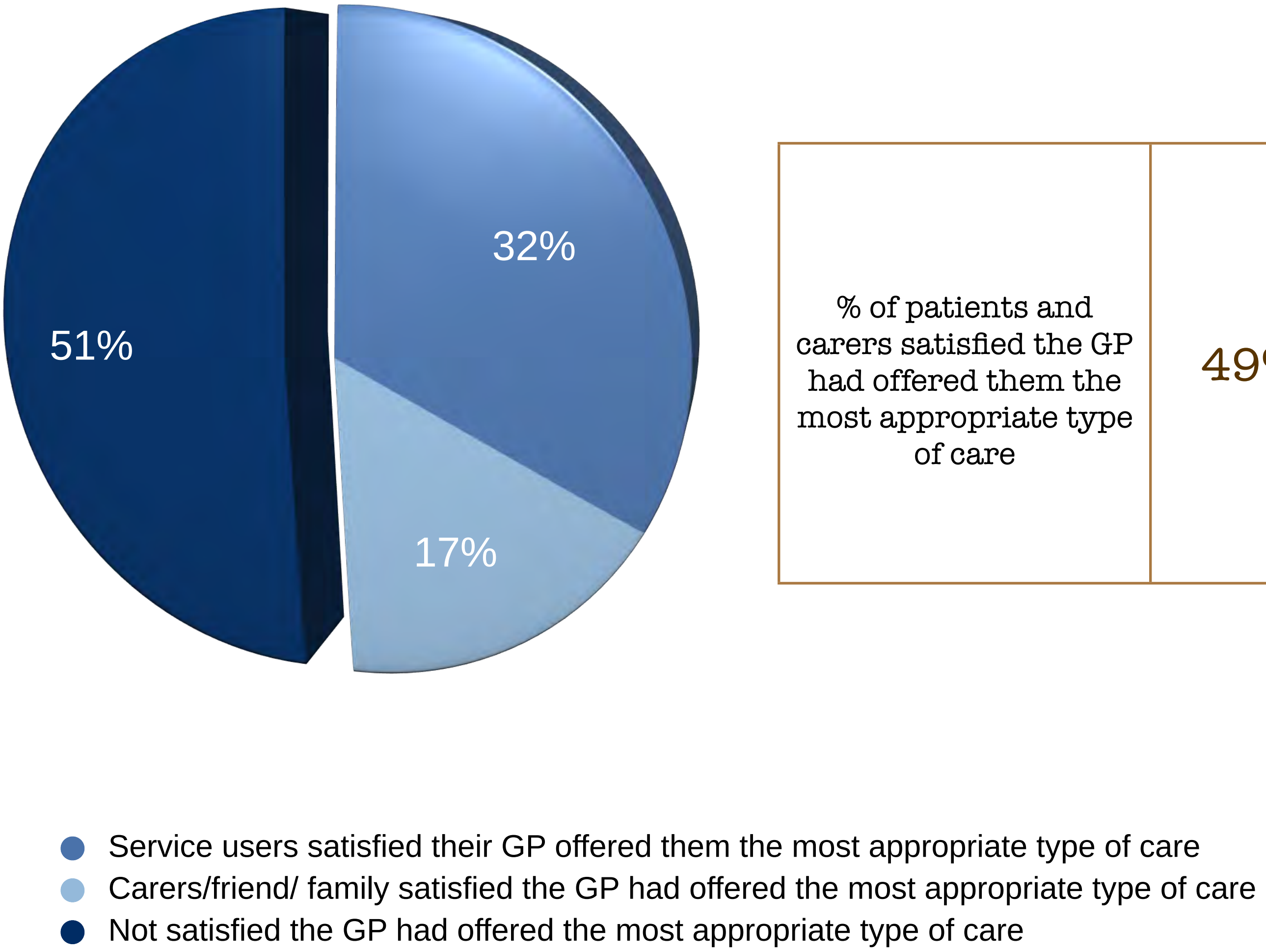
> *"Treatment and care should take into account patients' needs and preferences. People with a common mental health disorder should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals."*
>
> NHS National Institute for Health and Clinical Excellence (2011) Common Mental Health Disorders, Identification and Pathways to Care, NICE Guideline 123, p.6

What are we measuring?

3. % of patients and carers satisfied their GP had offered them the most appropriate type of care

" I was shipped out, cried my eyes out and came out worse than I went in."

" There was no discussion about alternatives other than increasing their



% of patients and carers satisfied the GP had offered them the most appropriate type of care	49%

Type of help offered by GP

What change do we want to see?

	TODAY	IN A YEAR'S TIME THIS SHOULD BE...
% of patients and carers satisfied the GP had offered them the most appropriate type of care	49%	83%

> *"There needs to be more time for discussing your problems with your GP, you could be going in distress and it takes you time to be able to talk about how you're feeling"*

> *"If you were a new person you know...we have learnt quite a lot over the years, but for somebody that hasn't maybe been in our positions and is just going in – I pity them – the doctor would just prescribe them medication and that's it – no other talk or nothing"*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year after her brother's de
Magee says her demand fo
ereaved families hasn't be

Staying linked into services after attending A&E

At both the GP and at A&E people told us that getting proper follow up was essential - this is especially true following an attendance at A&E where people felt they needed to remain "linked in" to services.

"Card Before You Leave isn't being used the way it should at A&E, people aren't getting it"

In January 2011, the then Minister for Health Michael McGimpsey MLA launched a new appointment card system for people who present at A&E in mental health distress who are discharged after an initial assessment records that they are 'low risk'. The new system provides that on discharge from any A&E in Northern Ireland, the patient will receive an appointment card with the date and time of their follow up appointment for a full mental health assessment. The scheme was known as 'Card Before You Leave' and was campaigned for by service users and carers in the Belfast Mental Health Rights Group who felt that people needed a lifeline.

Since then, however, there are concerns that the scheme is not being implemented properly on the ground with some people receiving a follow up phone call offer of an appointment and worryingly, others leaving with nothing.

Under International Human Rights Law - we have a right to the highest standard of mental health care:

> *"The treatment and care of every patient shall be based on an individually prescribed plan, discussed with the patient, reviewed regularly, revised as necessary and provided by qualified professional staff"*

Principles for the protection of persons with mental illness and the improvement of mental health care- Adopted by General Assembly resolution 46/119 of 17 December 1991- Principle 9(2)

Under Government's own policy;

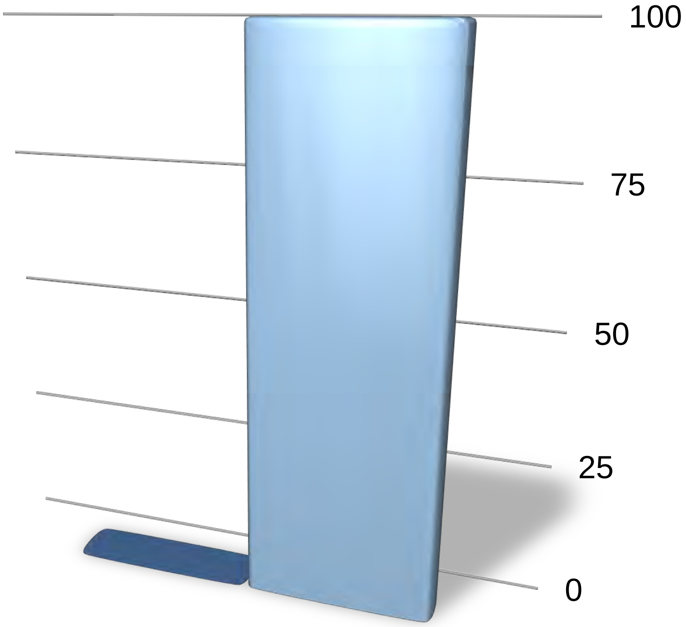
> *"The scheme provides a next day mental health follow-up service for patients who attend an Emergency Department (ED) with self harm or thoughts of suicide and who have been identified as low risk to themselves or others. The scheme aims to ensure that any patient being discharged from the ED receives a card prior to discharge, giving details of contact numbers for support and details of their follow-up care."*
>
> HSC (2013) Evaluation of the effectiveness of the Card Before You Leave Scheme, p.3

What are we measuring?

4. % of patients discharged from A&E in need of follow up who received a written appointment card with the date and time of their follow up appointment (a Card Before You Leave)

> " I was at the Mater for 13 hours only for them to give me a lifeline number "

% of patients discharged from A&E in need of follow up who received a written appointment card with the date and time of their follow up appointment (a Card Before You Leave)	0%



No-one we spoke to had received a Card Before You Leave appointment following discharge from A&E.

29% of those who should have received Card Before You Leave, later received a follow up phone call with an offer of an appointment but 71% were left with nothing.

What change do we want to see?

	TODAY	IN A YEAR'S TIME THIS SHOULD BE...
% of patients discharged from A&E in need of follow up who received a written appointment card with the date and time of their follow up appointment (a Card Before You Leave)	0%	90%

> “There should be a Card Before You Leave duplicate card for carers”

> “Card Before You Leave needs to be forced more - people aren’t getting it”

Knowing where to go when you need help and having enough information to make the best choices for you

" There are people out there who are not well and they don't know where to go or how to go "

Despite recent high profile media campaigns, people are still telling us that information about where to go to get help is lacking. Often the information is very limited, only available online and just not accessible to those in crisis. Or people are told that their choice to go to A&E when in distress is 'wrong' which many feel compounds the stigma attached to mental illness.

One service user told us that for the information to be helpful, it has to be written by someone who knows what its like;
"*"It has to be someone coming in that has had mental illness, not somebody getting it off a laptop, reading notes – anyone can do that but it's getting to the true issues..."*
 A mental health group from Co.Derry, S.T.E.P.S investigated the effectiveness of previous media campaigns and discovered through a Freedom of Information request that not enough attention was paid to information provision for those in rural areas.

4 NEWS DERRY POST TUESDAY

Public Health Agency 'failing' people living in rural areas

Under International Human Rights Law - we have a right to information to help us make the best choices about our health;

> *"Obligations to fulfil the right to health require the State to undertake actions that create, maintain and restore the health of the population. Such obligations include : …(iv) supporting people in making informed choices about their health"*

UNCttESCR General Comment 14, para. 37

Under Government's own policy;

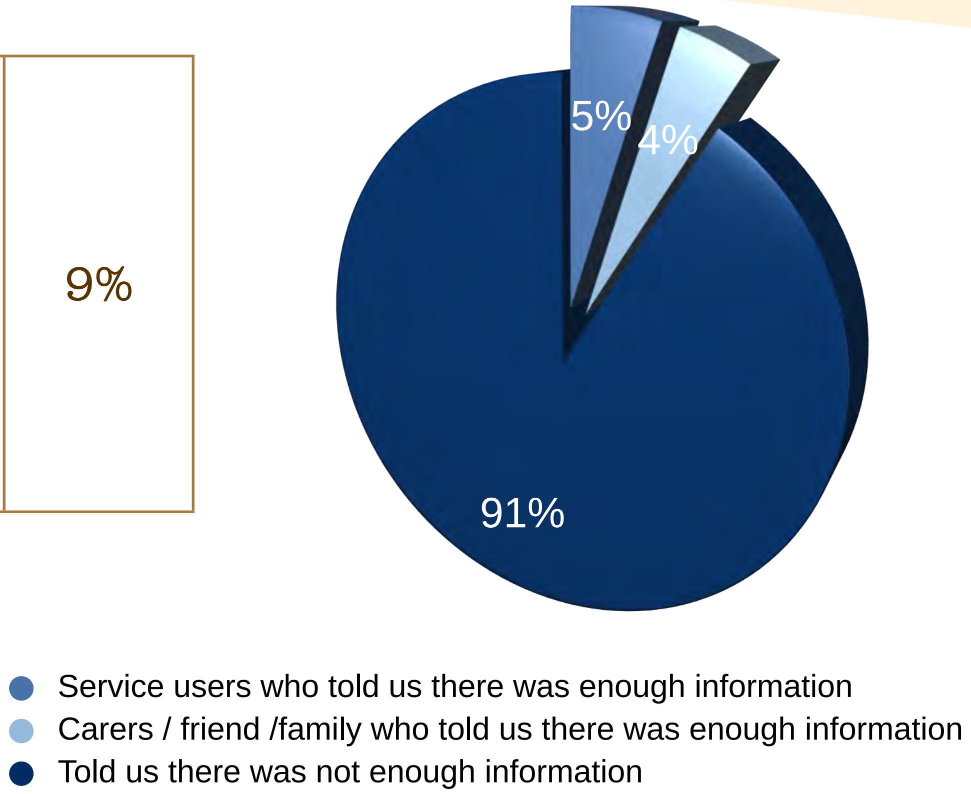
The Health and Social Care's current campaign aimed at ensuring people have information to ensure people "choose the right option" called "Choose Well" is available to watch, listen to or read about, in a variety of languages, with specific information by Trust area. It covers self care, pharmacy, GP, Out of Hours GP and A&E. It contains no information relevant to mental health and help available for people in distress/crisis.

What are we measuring?

5. % of patients and carers who told us there was enough information about where to go to get help when in mental health distress/ crisis

> "Only option I was ever given with GP was that he had to come into the surgery for an appointment - he wouldn't go in and GP wouldn't come out to house - what am I supposed to do then"

% of patients and carers who told us there was enough information about where to go to get help when in mental health distress / crisis	9%



The majority of people (40%) told us that when they did get information about where to go when in mental health distress / crisis, it was from a family or friend. Less than a fifth of people (18%) told us they found information online, with many mentioning social media e.g. Facebook as a source. Just over one in ten people (13%) told us they found information from ads in newspapers, on the radio or the tv.

What change do we want to see?

	TODAY
% of patients and carers who told us there was enough information about where to go to get help when in mental health distress	9%

IN A YEAR'S TIME THIS SHOULD BE...
90%

"They need to simplify the referral routes – if someone is in crisis"

"All the routes for help should be highlighted"

"If the doctors could give you an information pack, with all the information about other community support that is available and groups in your area, that would help"

Being part of important decisions government makes about mental health services

At a time of massive change in the provision of health care, the impacts of government decisions on people who use services can be huge.

" We listened to what you said, but by the way we didn't take any heed of it"

Members of Co.Derry based group S.T.E.P.S told of their frustration at recent changes to the location of Community Mental Health Team appointments. Of those who were affected by the change in location, none had been given the opportunity to be a part of the decision, despite all of them wishing to have been given the opportunity to be involved. All of those we spoke to had only been told after the decision to change the location was made and all told us that the change had caused them difficulties with one young person telling us that to get to the new location required them to take four buses there and two home.

Others who had participated in health service involvement structures told us they felt “patronised” and the Belfast Mental Health Right’s Group’s experience of sitting on the Card Before You Leave Implementation Board showed that decision makers reserved the power to make ‘big’ decisions such as the decision to dissolve the Board, for themselves with no service user and carer involvement.

Under International Human Rights Law - we have a right to participate in a way which is active, free and meaningful, in all decisions government make about the health service;

> *“The formulation and implementation of national health strategies and plans of action should respect, inter alia, the principles of non-discrimination and people’s participation. In particular, the right of individuals and groups to participate in decision-making processes, which may affect their development, must be an integral component of any policy, programme or strategy developed to discharge governmental obligations under article 12.”*

UNCttESCR General Comment 14, para. 37

Under Government's own policy;

> "*Under the Health and Social Care (Reform) Northern Ireland Act 2009, 4 HSC organisations have a statutory requirement to involve service users, carers and the public in the planning, commissioning, delivery and evaluation of services...The involvement of people is not however, a one off project or exercise; it must be integrated in the culture of our organisations. It must be a part of everyday working practice, underpinning all our processes and decisions. It must be an integral part of commissioning, service design, development and delivery.*"

HSC, PHA (2012) Valuing People, Valuing their Participation : Strategy for Personal and Public Involvement for the Public Health Agency and Health and Social Care Board, p.14

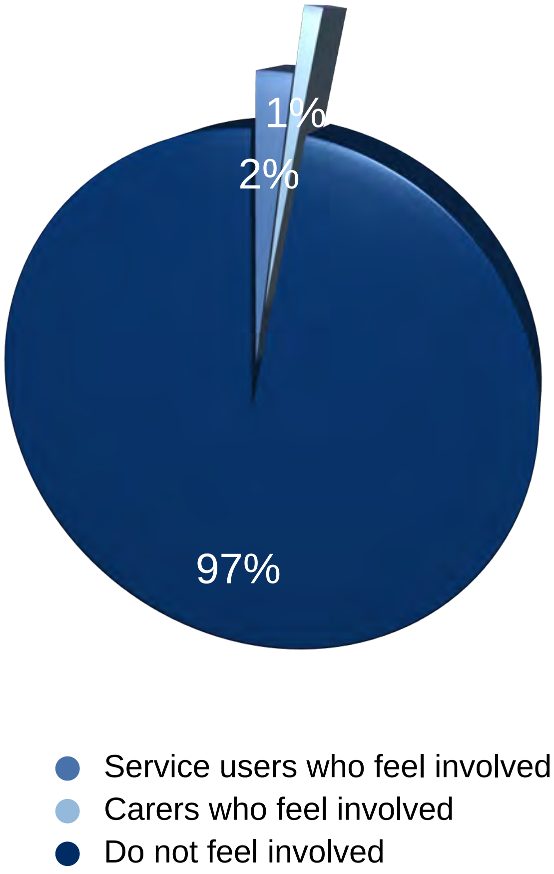
What are we measuring?

6. % of patients and carers who told us they feel involved in decisions government makes about mental health services

Campaigners take fight to Stormont

BY KIERAN HUGHES

Gerard McCartan



% of patients and carers who told us they feel involved in decisions government makes about mental health services	3%

What change do we want to see?

	TODAY	IN A YEAR'S TIME THIS SHOULD BE...
% of patients and carers who told us they feel involved in decisions government makes about mental health services	3%	73%

"They don't have time to come and speak to people or groups about what their concerns are or how they feel they are being failed but that's what's needed."

"They don't involve people decisions are made before we're told"

Mental Health Rights Campaign

Holding Mental Health Services to Account....

	TODAY	IN A YEAR'S TIME THIS SHOULD BE...
% of patients and carers who thought waiting times for an appointment with the GP were unsatisfactory or very unsatisfactory	44%	14%
% of patients and carers who thought waiting times at A&E were unsatisfactory or very unsatisfactory	66%	14%
% of patients and carers satisfied the GP had offered them the most appropriate type of care	49%	83%
% of patients discharged from A&E in need of follow up who received a written appointment card with the date and time of their follow up appointment (a Card Before You Leave)	0%	90%
% of patients and carers who told us there was enough information about where to go to get help when in mental health distress	9%	90%
% of patients and carers who told us they feel involved in decisions government makes about mental health services	3%	73%

A final note

The Human Rights Based Approach used by the Mental Health Rights Campaign

The research presented here was carried out by groups across Northern ireland using an human rights based approach developed by PPR and cited by the United Nations as an example of best practice in giving communities the tools to claim rights and hold government to account.

The right to health is contained within the International Covenant on Economic Social and Cultural Rights, an international treaty that the UK and Ireland governments have signed up to.

By signing up to this treaty government, and through it, public health service delivery bodies have promised to respect, protect and fulfill our right to health. A big part of this commitment is that government always have to show that they are taking steps to ensure that things are getting better, and that even if money is tight, like during a recession, they still have to protect the vulnerable. To test if the decisions government are making about this issue would make things better, the groups measure how much or how little progress government are making across a number of indicators (we have referred to them as issues here) and set benchmarks which they have to meet over a certain time period (we have referred to them as targets here in the “in a year’s time this should be” box).

To find out more about the PPR Human Rights Based Approach and how groups can use it, visit www.pprproject.org