

MY VOICE MATTERS

Report on a National
Consultation with
Mental Health
Service Users

Executive Summary



Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service



Mental Health Reform
Promoting Improved Mental Health Services

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by Pádraig Ó Féich, Kate Mitchell,
Sergio Pérez and Shari McDaid. | **2019**

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List of Abbreviations

A&E	Accident and Emergency
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
CHO	Community Health Organisation
CMHS(s)	Community Mental Health Service(s)
CMHT	Community Mental Health Team
ED	Emergency Department
EUPD	Emotionally Unstable Personality Disorder
GP	General Practitioner
HSE	Health Service Executive
MHC	Mental Health Commission
MHS(s)	Mental Health Service(s)
NLN	National Learning Network
OT	Occupational Therapist
PTSD	Post Traumatic Stress Disorder
TCD	Trinity College Dublin
UN	United Nations



Foreword



Ireland's national mental health policy, *A Vision for Change* which was published in 2006, set out a blueprint for developing modern, recovery orientated mental health services, rooted in principles of human rights, partnership and respect. The policy emphasised the importance of the individual being placed at the centre of the mental health system, being involved in a meaningful way in the planning, delivery and evaluation of their care, and having their individual needs met through the highest standards of mental health care. These components of mental health service delivery are affirmed through national guidelines and through international human rights standards.

Mental Health Reform's *My Voice Matters* national consultation on people's experiences of using the mental health services (MHSs) in Ireland provides an insight into the extent to which service users are experiencing the type of MHSs provided for under national and international standards. The consultation is the first national, large-scale survey in recent years to provide in depth and up-to-date feedback on the direct experiences of people who access community and inpatient MHSs. Giving voice to people with direct experience of using the services is integral to identifying areas of good practice, as well as informing the change required to effectively meet the needs of service users. Some limited comparisons can be made between findings from this

consultation and previous studies, including the Mental Health Commission's 2011 survey on inpatient mental health services, the Service User Executive Second Opinion Reports (published in 2009 and 2011, respectively), which reported on satisfaction levels among services users of the HSE MHSs and the annual UK Care Quality Commission's surveys, which look at the experiences of people receiving community mental health services.

The findings from Mental Health Reform's national consultation are important and timely. They provide key decision makers with national, independent feedback to inform mental health service planning and delivery. The findings are particularly pertinent in the context of the development of a new national mental health policy, due to be published in 2019, and the ongoing absence of a national mental health information system, that reports routine data on service delivery, as well as outcomes for service users.

The evidence from the national consultation shows that the experiences of mental health service users are mixed at best and significant efforts must be made to achieve modern, recovery-orientated and human rights focussed MHSs, as envisaged in national mental health policy more than a decade ago. It is imperative that change is implemented in a standardised manner to ensure consistency in MHS delivery across all parts of the country. Notwithstanding

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the valuable work that has been undertaken by HSE Mental Health¹, and many local MHSs, mental health staff and communities over the years, as the findings indicate, there is considerable variation in service users' experiences of the MHSs. While some participants may be experiencing services consistent with aspects of national policy and standards, many are not.

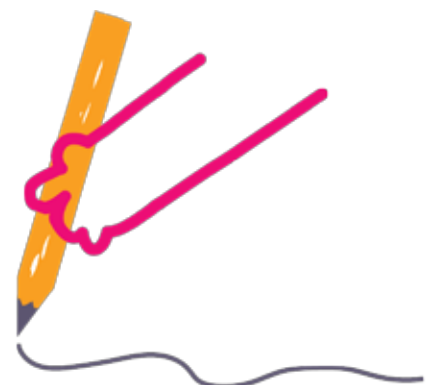
The *My Voice Matters* report captures, to a large extent, the current experiences of people who use the MHSs in Ireland and its findings and recommendations provide a firm platform for implementing the change required to ensure the appropriate services and supports are available for service users. Mental Health Reform's staff and Board of Management look forward to working collaboratively with the relevant stakeholders to support the implementation of the recommendations set out in this report. I would like to thank HSE Mental Health for their foresight and commitment to funding the national consultation. I would also like to thank Dr Shari McDaid and the team of staff at Mental Health Reform for producing this valuable and informative report. Special thanks go to the peer researchers and the other stakeholders involved, including Mental Health Reform's membership for supporting the delivery of the national consultation.

Finally, I would like to extend a thank you to all those who took the time and effort to complete the survey and share their experience and thoughts with us.



Professor Agnes Higgins
Chairperson
Mental Health Reform

¹ HSE Mental Health operates at national level and has responsibility for all mental health services, including in planning, operations, quality and service improvement.





Acknowledgements

Mental Health Reform would like to thank all those who assisted in carrying out the *My Voice Matters* project. Most importantly, we would like to thank each person who took the time to complete the survey and share their views and experiences of the mental health services in Ireland. Mental Health Reform aims to ensure that the findings from the *My Voice Matters* project not only inform our work going forward but help to shape the development of mental health policy, law and practice in Ireland.

We would also like to thank sincerely all those who have worked on the project in the past two years. Thanks to all the members of the research team, past and present, who worked tirelessly to bring this project to completion. We would like to acknowledge the work of Dr Esther Murphy in developing the initial design of the survey and of Oscar James for his role in refining the survey design, data collection and initial data analysis. Thanks also to the peer research assistants, Dr Mike Watts, Sharon Uí Chonghaile and Anthony O'Callaghan who helped to recruit and collect data from participants, and to the Steering Group for their assistance during the design of this project.

We must also acknowledge the support and advice of those who provided feedback on drafts of this report. These include

Mental Health Reform's Chairperson Agnes Higgins, Professor in Mental Health, School of Nursing & Midwifery, Trinity College Dublin (TCD), Kevin Cullen, Director of the Work Research Centre, Dr Louise Doyle, Associate Professor, School of Nursing & Midwifery, TCD, members of Mental Health Reform's Grassroots Forum and Health Service Executive (HSE) Mental Health Services senior staff.

A special thank you to Mental Health Reform's member organisations for promoting the survey. We would also like to thank those organisations and individuals external to Mental Health Reform's membership who helped to bring the project to the attention of individuals accessing their services.

Finally, we would like to acknowledge the support of the HSE for this project. Although the *My Voice Matters* project was conducted independently by Mental Health Reform, it would not have been possible without the funding provided by HSE Mental Health. The HSE's financial support for this national consultation of mental health service users and their family, friends and carers/supporters (FFCSs) shows a commitment to service improvement and to listening to the voices of people who use the mental health services.

About the Authors

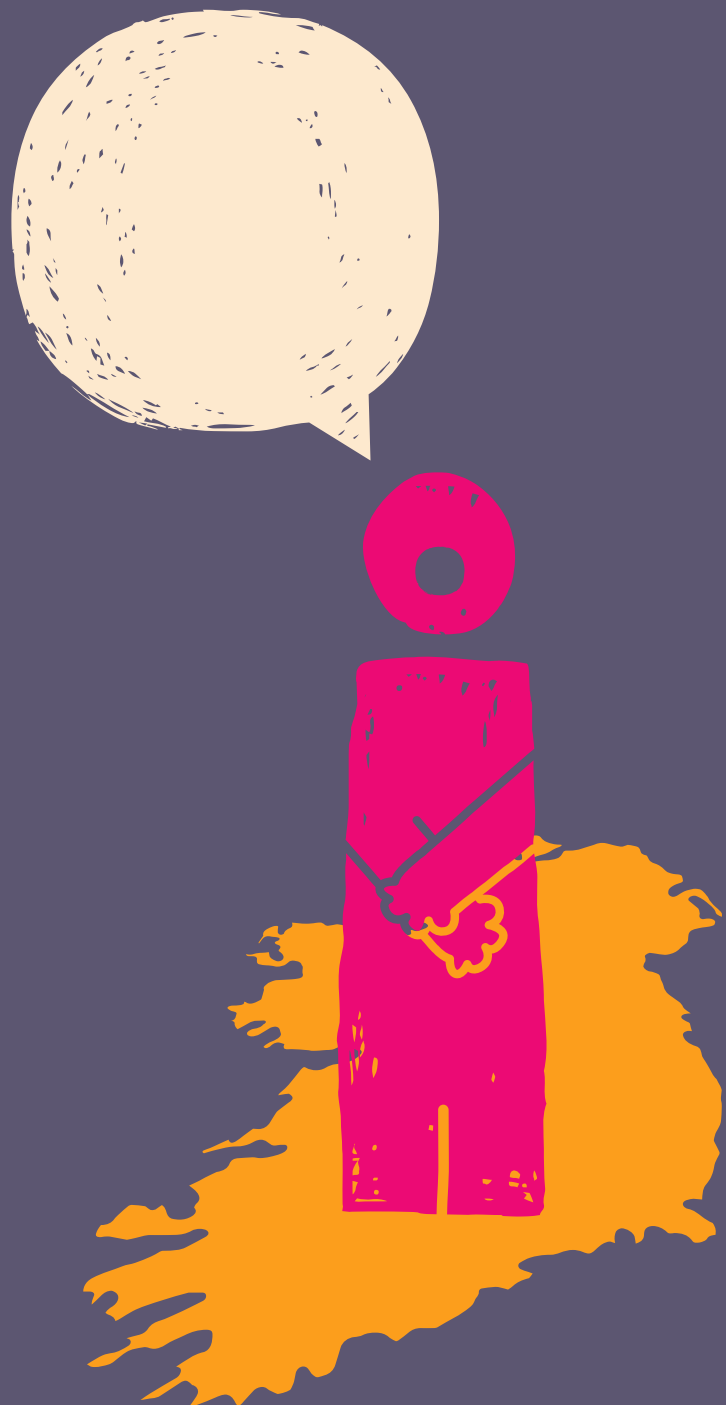
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EXECUTIVE SUMMARY

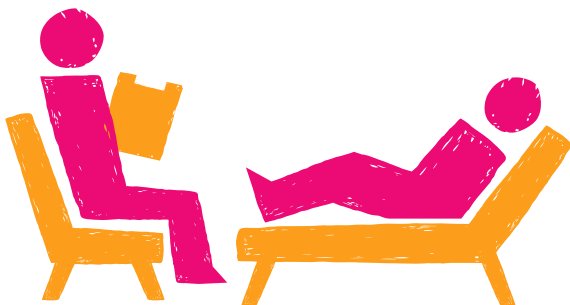




INTRODUCTION

This summary describes the key findings from Mental Health Reform's *My Voice Matters* national consultation on people's experiences of using the mental health services (MHSs) in Ireland. This report focuses on the feedback from people with direct experience of receiving MHSs (referred to throughout as 'service users').^{2,3}

The views of service users are central to developing MHSs in Ireland. The Government, the Health Service Executive (HSE) and all staff working in MHSs can benefit from receiving national, independent feedback on a regular basis from service users that can help to shape service planning priorities. It is Mental Health Reform's intention that the *My Voice Matters* project will assist the Government and the HSE in their efforts to improve Ireland's mental health system.



The HSE has undertaken significant work in recent years to promote a more modern, recovery orientated public MHS. In November 2017, HSE Mental Health launched its National Framework for Recovery in Mental Health to develop the recovery approach in MHSs across Ireland.⁴ This was complemented by a series of recovery guidance documents to support MHSs in the implementation of the Framework. These resources have built on earlier initiatives, such as the HSE's Advancing Recovery in Ireland programme,⁵ the Self-Harm Clinical Care Programme, as well as policy and standards, including *A Vision for Change*⁶ and the Mental Health Commission's (MHC) Quality Framework for MHSs.⁷ The establishment of the HSE's Mental Health Engagement Office has also represented a major move towards involving service users at all levels of planning for MHS delivery.

Notwithstanding actions carried out by HSE Mental Health and local HSE MHSs to shift MHS provision in the direction of national policy, there is a fundamental question as to how this has been translated in practice. To what extent are service users experiencing more comprehensive, recovery orientated and person-centred services on the ground?

- 2 A complementary report describes feedback from people who are family members, friends, carers and/or supporters of people who have used mental health services.
- 3 Mental Health Reform acknowledges that there are different views on the terms used to describe a person who uses the mental health services. Often terms such as "service user" "the person", "the individual" or "someone who uses the mental health services" are used. In order to be consistent, concise and clear, the term "service user" has been selected for the purposes of this report and is used throughout.

- 4 HSE Mental Health Services. (2017). *National framework for recovery in mental health: A national framework for mental health service providers to support the delivery of a quality, person-centred service 2018-2020*. Dublin: HSE MHS.
- 5 The initiative represented the first systematic approach to developing recovery orientated services at a national level, using a comprehensive organisational change methodology.
- 6 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.
- 7 Mental Health Commission. (2007). *Quality framework: Mental health services in Ireland*. Dublin: MHC.

Valuable feedback from service users has been collected through consultations carried out as part of the development of *A Vision for Change*⁸ and the MHC's Quality Framework.⁹ However, with some notable exceptions (e.g. *Your views of Mental Health Inpatient Services*¹⁰), there has been limited previous research published on the experiences of people accessing the MHSs in Ireland. This research has focused on inpatient units or subpopulations, with limited studies capturing a national sample of service users at different levels of the MHSs. As a result, Mental Health Reform identified the need for an independent, national, large-scale survey to provide in-depth and up-to-date feedback on the experiences of people who use the MHSs.

Specifically, this research aimed to explore the views and experiences of people who have used secondary and/or tertiary MHSs in the last two years about a range of mental health and related supports. Below is a brief summary of this research.

8 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.

9 Mental Health Commission. (2007). *Quality framework: Mental health services in Ireland*. Dublin: MHC.

10 Mental Health Commission. (2011). *Your views of mental health inpatient services*. Dublin: Mental Health Commission.





METHODOLOGY

This research employed a survey design which included closed and open-ended questions and surveyed people with experience of specialist MHSs in the last two years. A brief summary of the methodology used is outlined below. For more detail, see chapter two of the service user report.



Designing the Survey:

Survey design was carried out in a phased manner as follows:

- * Survey questions were drawn from a number of important studies examining peoples' experiences of MHSs (e.g. the MHC's survey of inpatient experiences in Ireland¹¹ and the UK Care Quality Commission's Community Mental Health Survey).¹²
- * Questions were developed based on previous consultations carried out by Mental Health Reform between 2011 and 2015.
- * Questions were organised by theme into sections to develop a working draft of the survey.
- * Cognitive interviews¹³ with 10 service users were carried out to test the survey.
- * The survey was updated based on the feedback received from these cognitive interviews.
- * Three focus groups with service users were then carried out, and again changes were made to the survey based on this feedback.
- * The updated draft survey was then reviewed by external researchers with survey design expertise.
- * A final in-house review was completed by Mental Health Reform staff.

Collecting the Data:

Survey responses were collected over a six-month period between November 2017 and April 2018. A large majority of participants completed the survey online through SurveyMonkey, while a minority completed paper versions of the survey and returned them by post.

Who Took Part?

Only individuals over the age of 18 years with experience of accessing community MHSs, inpatient MHSs and/or a psychiatrist in Ireland in the last two years were eligible to take part. In total, 1,188 participants who met these inclusion criteria were recruited using a multi-pronged approach to recruitment. For more information on recruitment and the sample, see section 2.3 of the service user report.

11 Mental Health Commission. (2011). *Your views of mental health inpatient services*. Dublin: Mental Health Commission.

12 UK Care Quality Commission. (2017). *Community mental health survey: Quality and methodology report*. London: UK Care Quality Commission.

13 The cognitive interviewing approach is used to evaluate sources of response error in survey questionnaires, see: Willis, G.B. (1999). *Cognitive interviewing: A "how to" guide*. Presented at the 1999 Meeting of the American Statistical Association. Research Triangle Park, NC: Research Triangle Institute. For more information on cognitive interviewing, see: Memon, A., Meissner, C.A., & Fraser, J. (2010). The Cognitive Interview: A meta-analytic review and study space analysis of the past 25 years. *Psychology, Public Policy and Law*, 16(4), 340-372. doi:10.1037/a0020518.

1,188

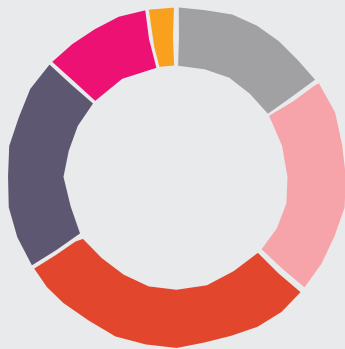
PARTICIPANTS

39.4

AVERAGE AGE

18-76

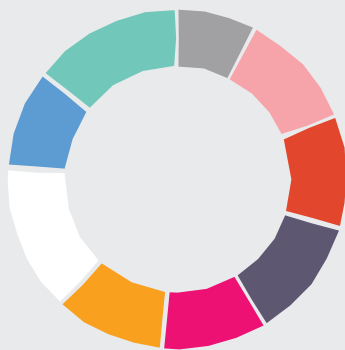
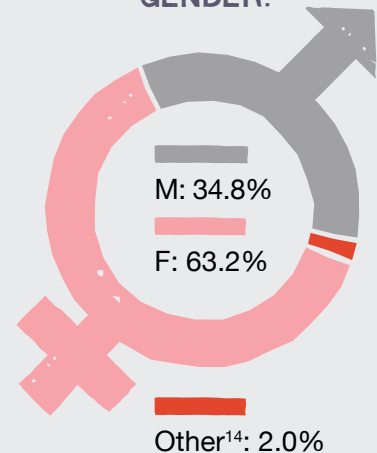
AGE RANGE



AGE GROUPS:

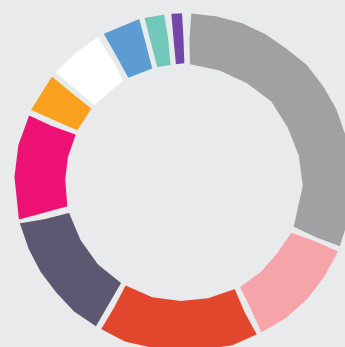
18-25:	15.8%
26-34:	21.1%
35-44:	29.3%
45-54:	20.7%
55-64:	10.5%
65+:	2.6%

GENDER:



COMMUNITY HEALTH ORGANISATION (CHO) AREA:

CHO1:	4.6%	CHO4:	15.2%	CHO7:	19.3%
CHO2:	10.0%	CHO5:	9.3%	CHO8:	9.1%
CHO3:	8.1%	CHO6:	7.4%	CHO9:	16.8%



MAIN DIAGNOSIS¹⁵:

Depression:	31.2%	Bi-polar disorder:	12.8%	Post-traumatic stress disorder (PTSD):	4.2%
Schizophrenia / Schizoaffective disorder:	11.1%	Personality disorder:	10.5%	An eating disorder:	2.5%
Anxiety disorder:	15.9%	Other:	4.4%	Prefer not to say:	1.7%
		Not been given a diagnosis:	5.8%		

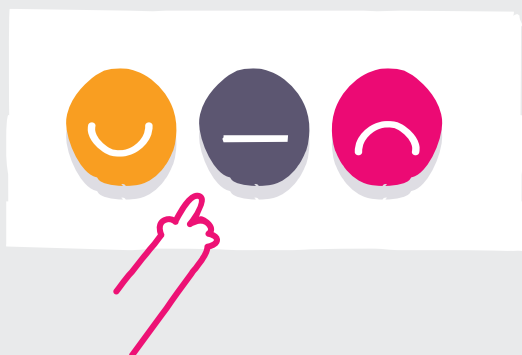
¹⁴ 'Other' was included as a response option so that individuals did not feel forced to respond within a paradigm that they do not agree with. The term 'other' could include, but is not limited to trans-male, trans-female, gender non-binary, gender-fluid and intersex.

¹⁵ Mental Health Reform understands that not everybody agrees with the mental health diagnosis they have been given, or with the biomedical approach to mental health.



KEY QUANTITATIVE FINDINGS

This is a selection of key findings from the service user survey. For a more detailed presentation of the findings, see chapter three of the service user report.



OVERALL EXPERIENCE OF HSE MHSs

On a scale ranging from 0 ('I had a very poor experience') to 10 ('I had a very good experience'), participants were asked to indicate how satisfied they were with their overall experience of the HSE MHSs.



41.6%

of participants indicated that they had **A POOR EXPERIENCE** of HSE MHSs

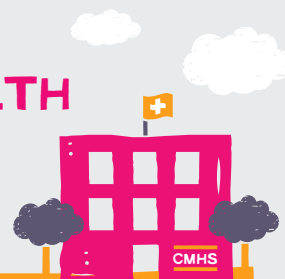
29.1%

indicated having **NEITHER A GOOD NOR POOR EXPERIENCE** while

29.2%

indicated having **A GOOD EXPERIENCE** of HSE MHSs.

COMMUNITY MENTAL HEALTH SERVICES (CMHSs)



41.7%

of participants felt that they were **'ALWAYS'** treated with dignity and respect by CMHSs,

38.7%

felt that they were **'SOMETIMES'** treated with dignity and respect and

19.5%

reported that they **DID NOT FEEL** like they were treated with dignity and respect by CMHSs.

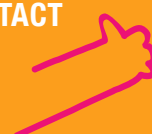
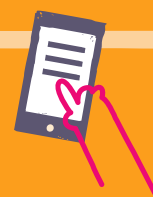
LESS THAN HALF (47.7%)

reported that they **HAD THE CONTACT DETAILS** of a designated mental health professional (a key worker) in their community mental health team (CMHT) to provide them with support.

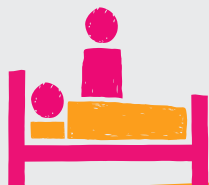
Those who reported **HAVING CONTACT DETAILS** of a key worker were

2.3 TIMES MORE LIKELY

to **REPORT A GOOD OVERALL EXPERIENCE** of HSE MHSs than were those without contact details of a key worker.



INPATIENT CARE



27.9% of participants with inpatient experience felt that they were **'ALWAYS'** treated with dignity and respect by the MHSs during their inpatient experience;

32.8% felt that they were **'MOSTLY'** treated with dignity and respect;

30.5% felt that they were treated with dignity and respect **'SOME OF THE TIME'**; and

8.8% felt that they were **'NEVER'** treated with dignity and respect by inpatient MHSs.

Participants were most dissatisfied with the **THERAPEUTIC SUPPORTS**

(46.0%)
DISSATISFIED

and the **RANGE OF RECREATIONAL ACTIVITIES** available as an inpatient.

(45.4%)
DISSATISFIED

EXPERIENCES OF PSYCHIATRISTS

One-third (32.5%) of participants felt that they were 'always' well supported and listened to by their current psychiatrist; over one in five (22.9%) felt that they were 'mostly' well supported and listened to; more than one-quarter (28.8%) felt that they were 'sometimes' well supported and listened to; and one in six (15.8%) felt that they were 'never' well supported or listened to by their current psychiatrist.

MORE THAN HALF
(55.9%)

reported having had a **CHANGE OF PSYCHIATRIST AT LEAST ONCE** in the last two years,

while **ONE IN SIX**

(16.1%)

reported having had a change of psychiatrist **'MORE THAN FOUR TIMES'** in the last two years.



The frequency with which participants had a change of psychiatrist and the impact of said change on their treatment and care were negatively related, indicating that the more frequently participants had a change of psychiatrist, the more negatively they perceived the impact of these changes on their treatment and care.

Those who **HAD NOT** had a change of psychiatrist in the last two years were

1.6 TIMES MORE LIKELY

to report a good overall experience of HSE MHSs than were those who **HAD A CHANGE OF PSYCHIATRIST** three or more times in the last two years.



CRISIS CARE



Three in every ten (30.2%) participants reported having gone to an emergency department (ED) to seek support for their mental health difficulty in the last two years. Of these,

ALMOST HALF

(49.3%)

DISAGREED THAT THEY GOT THE SUPPORT THEY NEEDED as a result, while one third (33.7%) agreed.

Of those who reported accessing CMHSs in the last two years, one in five participants (20.8%) reported that they have someone in the CMHSs who they can contact out of office hours in case of a crisis.

Of those who reported that they **HAVE SOMEONE IN THE CMHSs THAT THEY CAN CONTACT OUT OF HOURS** in case of a crisis, more than **FOUR IN EVERY FIVE**

(82.1%)

AGREED that they **GOT THE HELP THEY NEEDED FROM THE CMHT DURING A CRISIS**, while 6.4% disagreed.



TYPES OF TREATMENT AND SUPPORTS

SIX IN 10 PARTICIPANTS

(60.3%)

reported a **HIGH FOCUS ON MEDICATION** as part of their treatment and care.

Approximately one in five (19.0%) indicated that their treatment was totally focused on medication. Some 24.7% reported a moderate focus on medication, while less than one in six (15.1%) reported a low focus on medication.



One in four participants (24.6%) reported that they were 'definitely' involved as much as they would like in decisions about the medicines they take, while one-third (33.5%) indicated that they were involved as much as they would like 'to some extent' and

OVER ONE-THIRD

(38.8%)

indicated that **THEY WERE NOT INVOLVED AS MUCH AS THEY WOULD LIKE IN DECISIONS ABOUT THE MEDICINES THEY TAKE** (don't know/can't remember: 3.1%).



Of those who reported that they were not involved as much as they would like in decisions about the medicines they take,

FOUR IN EVERY FIVE

(80.3%)

indicated that **THEY WOULD LIKE TO BE INVOLVED** in these decisions.



Those who were involved as much as they would like in decisions about the medicines that they take were 2.5 times more likely to report a good overall experience of HSE MHSs than were those who were not involved as much as they would like in decisions about the medicines they take.

THREE IN EVERY 10

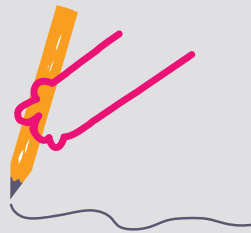
(31.4%)

reported **NEVER HAVING BEEN REFERRED TO TALKING THERAPY BY HSE CMHSs**, while six in every 10 (59.2%) indicated that they had.



Of those who were referred to talking therapy, less than a third of participants (31.2%) were waiting for under a month before accessing this support, less than one-quarter (23.7%) reported waiting between one and three months, more than one-quarter (27.5%) reported waiting between three and 12 months, and approximately one in six (17.6%) reported waiting more than a year to access this support.

RECOVERY



TWO-THIRDS of participants

(66.2%)

reported that they **DID NOT HAVE A WRITTEN RECOVERY/CARE PLAN** developed with their mental health team,

while approximately one in five (22.7%) reported that they had a written recovery/care plan (don't know/can't remember: 11.1%). Of those who reported that they did not have a written recovery/care plan (n=774), three in four (74.9%) reported that they would like to have one.

Those with a **WRITTEN RECOVERY/CARE PLAN** were

2.2 TIMES MORE LIKELY

to report a **GOOD OVERALL EXPERIENCE OF HSE MHSs** than were those without a recovery/care plan.



One-third of participants (32.5%) agreed that 'someone on my mental health team frequently talks to me about recovery as part of my treatment', while almost half (46.4%) disagreed.

When asked whether a member of their mental health team talked to them about their strengths as a core part of their recovery/care plan, one in six participants (16.0%) answered 'yes, definitely', one in four (25.3%) answered 'to some extent' and almost half (48.4%) answered 'no but I'd like to' (don't know/can't remember: 10.2%).

When asked whether their CMHT took into account how their mental health difficulty affects other aspects of their life, one in four (26.6%) responded 'yes, definitely', 30.8% responded 'yes, to some extent', while over a third (35.0%) responded 'no' (don't know/can't remember: 7.7%).

THE COMPLAINTS PROCESS



A third of participants (34.0%) reported that they had 'never wanted to complain about the MHS',

WHILE OVER HALF

(53.0%)

reported that they **'WANTED TO COMPLAIN but did not'** make a complaint

and 13.1% reported that they 'wanted to complain and did' lodge a complaint. Of those who did complain,

OVER HALF

(52.1%)

reported that **'NOTHING HAD BEEN DONE ABOUT THEIR COMPLAINT'**,



one in five (19.3%) reported that the issue had been 'resolved satisfactorily', one in six (16.4%) reported that they had received an apology, and one in eight (12.1%) reported that their quality of service had suffered as a result.

Approximately nine in every ten participants (88.8%) reported that no one in the HSE MHSs had let them know how to complain about the MHSs.

GP/PRIMARY CARE

ALMOST HALF of participants

(49.0%)

reported **HIGH LEVELS OF SATISFACTION** with the mental health care received from a GP,



while approximately one in four reported moderate (27.2%) and low (23.8%) levels of satisfaction.

Two-thirds (65.8%) agreed that their GP gave them enough time to speak about their mental health difficulty, 15.6% neither agreed nor disagreed, and 18.7% disagreed.



SUMMARY OF QUALITATIVE FINDINGS

As part of the survey, participants were asked a number of open-ended questions which gave them the opportunity to express their views in greater detail than did the closed questions on the survey.¹⁶ This section outlines the findings from an analysis of participants' responses to the open-ended questions. This analysis was carried out in accordance with the guidelines set out by Erlingsson and Brysiewicz¹⁷ (see sections 2.5 of the service user report for more detail).

Note that all quotes are presented as written by participants and are therefore authentic to the writer. Quotes were only altered if potentially identifiable information (e.g. names or locations) were conveyed or where additional clarity was needed (e.g. to clarify an acronym used by a participant). All edits or additions to quotes are marked using squared brackets, e.g. [names a place].

Table 1: Beneficial services that were unavailable.

Question:	Is there any service that was not available to you that you would have benefitted from?
Talking Therapy	A number of participants indicated that they had difficulty accessing talking therapy. Of these, many reported difficulties accessing specific types of talking therapy (e.g. cognitive behavioural therapy, dialectical behavioural therapy or schema therapy). Others wanted more talking therapy and some expressed frustration with the talking therapy they had received.
Access to Specific Disciplines on the CMHT	Some participants expressed frustration at a perceived shortage of key staff on the CMHT, leading to delays and/or difficulties accessing members of the CMHT. Some participants described how delays in accessing relevant professional support had a detrimental effect on their mental health.
Alternative Recreational and/or Therapeutic Services	Some participants expressed a desire for music therapy, art therapy and/or physical/outdoor activities.

¹⁶ Closed-ended questions are questions where participants are asked to pick from a selection of fixed response options, while open-ended questions require participants to respond in their own words.

¹⁷ Erlingsson, C., & Brysiewicz, P. (2017). A hands-on guide to doing content analysis. *African Journal of Emergency Medicine*, 7(3), 93-99. doi:10.1016/j.afjem.2017.08.001.

Difficulty Accessing Specific Support Services	Some participants mentioned services specifically targeted towards particular mental health difficulties, e.g. accessible addiction services, services for adults with autism, trauma specific services and more.
Out of Hours/ Crisis Services	The need for 24/7 crisis orientated services was a prominent feature of participant responses. Participants also conveyed the need for out of hours services to accommodate those individuals unable to access services due to work commitments.
Peer Support Services	Some participants mentioned peer support services, e.g. group therapy sessions, social groups, or peer advocates.
Social Inclusion Support Services	Services geared towards providing people experiencing a mental health difficulty with support in other areas of their life, e.g. housing, employment and welfare, were mentioned by some participants.
Information and Education Services	Participants expressed that better information for service users about mental health and MHSs could allow them to better manage and/or recover from their specific difficulty.
No Additional Services Required	Some participants responded to this question simply with 'no', 'none', or some variation of these terms.
Other Services	Some participants mentioned follow-up services, particularly post discharge from inpatient services; post-natal services that do not require the separation of mother and child; and more and/or better youth MHSs.



..The need for 24/7 crisis orientated services was a prominent feature of participant responses. Participants also conveyed the need for out of hours services to accommodate those individuals unable to access services due to work commitments..

"Regular talk therapy"

"Talk therapy with someone who is qualified to deal with bipolar disorder, anxiety, depression, self-harm, sexual abuse and substance disorder."

"An in house psychologist as there has not been one in my region for 7 years which is frankly a disgrace"

"Art therapy, music therapy, exercise program"

"Group exercise/fitness program. Ultimately my mental health began to improve when I (reluctantly) joined a fitness class ... Two weeks before joining the class I had a clear and definite plan to end my life"

"Anyone who specialises in trauma and PTSD. help with ADHD [attention deficit hyper activity disorder]."

"There was nothing else that I felt would benefit me"

"Outside of office hours. No professional to turn to when in crises- at the weekend for example. Makes no sense that people in this day and age still have to go to A&E [accident and emergency] as first resort. Doesn't help the patients"

"Community support groups, peer groups, activity groups"

"Services for Eating Disorders"

"Housing or rent support? ... I've had depression/anxiety disorders for 25+ years. As a result, I have [had] a series of low paid jobs, failed relationships and live at home with my parents. What kind of life is it with no opportunity for independence?"

"A map and information card about the nearest emergency mental health service. Information about how the system works, who people are, what their function is, what the timelines are for things... even any information about assessment for Aspergers/ ASD [autism spectrum disorder] in adults"

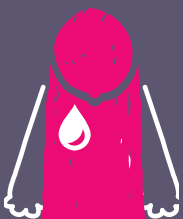




Table 2: Positive experiences of HSE MHSs.

Question:	What kind of positive experiences have you experienced from HSE MHSs?
Positive experiences of staff	Participants shared their positive experiences of MHS staff at every level of the MHSs and across disciplines. Some wrote of how kind and compassionate inpatient staff had been to them, while others wrote positively about specialist mental health staff and described how beneficial it was for them to access a professional with expertise in treating their specific mental health difficulty.
Therapies and facilities	Positive experiences of HSE MHS therapies and facilities.
Recovery and discovery	Experiences in which HSE MHSs facilitated/supported their recovery and/or the discovery of skills and strategies to cope with or better manage their difficulties day-to-day.
Dignity and respect	Positive experiences in which participants felt listened to, supported and treated with dignity and respect by HSE MHSs.
Crisis and outreach MHSs	Positive experiences of crisis care and HSE mental health outreach services were assigned to this category.
Community and voluntary groups	Positive experiences of community and voluntary groups that provide mental health related services and supports.
Direct access to services	Positive experiences in which participants were able to access required services in a timely manner.
Empowerment and involvement	Experiences where HSE MHSs were described as having promoted both the empowerment of participants and the involvement of participants in their treatment and care.
Primary care	Positive experiences of primary mental health care.



"Nurses were kind and supportive despite being understaffed and busy"

"A very good psychiatrist, some of the nurses in hospital were very caring understanding and giving of their time. The community liaison and social workers were all very helpful"

"Art therapy"

*"A nice atmosphere on the ward
Very clean Healthy food Beautiful garden to walk in Well-equipped art room"*

"I have benefitted greatly under the newer recovery model of treatment ... getting involved with the [names area] recovery college"

"I have learned valuable coping tools to manage my daily life"

"Always treated with kindness and respect"

"As an inpatient in '[names place]' I was treated with dignity and respect and the staff were extremely supportive"

"Being treated with dignity and great care. The psychiatrist was wonderfully caring and empathic. It was a positive and life-changing experience"

"Fab community nurses who are passionate but overworked"

"Getting to know the team, face to face contact available, crisis team are terrific"

"A couple of times I required a psychiatrist app. immediately and was given to me"

"After years of suffering in silence (because of stigma) my GP offered me community therapy swiftly and at no cost"

"Clubhouse in [names place] has helped my recovery has offered me more options like education housing community supports than medical team input patients"

"I am having a very positive experience with the NLN [National Learning Network]"

“I had one consultant who made me feel respected, cared for and opinions valued”

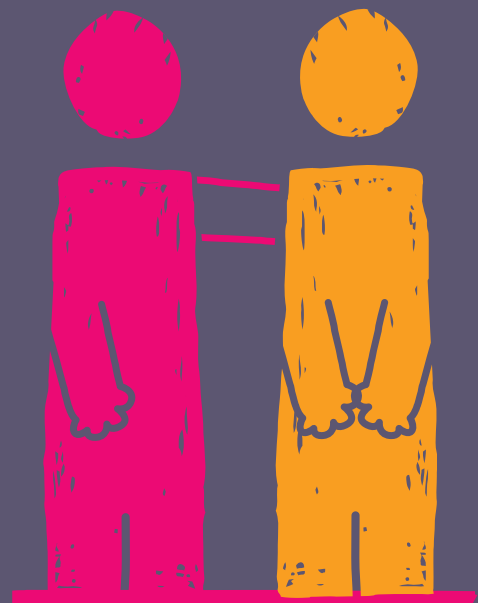
“I was listened to by most recent psychiatrist and she agreed that medication was not working and to take me off it after 15 years and also has re-referred me for additional therapy as again am finally being listened to”

“I had one GP that actually listened to me and was very empathetic”

“I found a local peer support group and am involved as a member of the board”

“Employment. Housing. Helped me to get a passport and go on holiday twice. Helped me to improve my literacy”

“They saved my life. My therapist especially who has gone above the call of duty in providing help and care to me. The mental health team were brilliant and I had a wide variety of supports and therapies in the day hospital until it was shut down”



..participants wrote positively about specialist mental health staff and described how beneficial it was for them to access a professional with expertise in treating their specific mental health difficulty...



Although participants were asked specific questions, many took the opportunity to share their views and experiences even when not specific to the questions asked. Instead, many chose to spontaneously share negative experiences they had had or to raise what they perceived as important issues relating to the provision of MHSs in Ireland. Table three lists a selection of the issues most commonly reported.

Table 3: Additional issues raised without prompt by participants.

Waiting times	Some participants expressed dissatisfaction with long waiting times for and delays in treatment and care.
Issues with MHS staff	Some participants raised issues they had experienced with MHS staff, e.g. poor communication between staff (at various levels) and service users and a lack of time for service users.
Continuity of care	Some participants referred to problems with continuity of care, e.g. excessive staff rotation and the strain this places on service users as they are required to 'repeat', 're-explain', 'start from scratch', and, in some cases, 're-live' difficult experiences; the lack of follow-up services and how this could lead to feelings of isolation and even the deterioration of their mental health.
HSE MHS system	Some participants described what they perceived as shortcomings in the HSE MHS system, e.g. staff shortages, a lack of facilities, a lack of accountability in the system, or gaps in service provision in certain areas.
Access issues	Some participants referred to difficulties accessing key services they require. These access issues were often related to or as a result of the issues outlined above. For example, for many of these participants, staff shortages and long waiting lists (often attributed to staff shortages) led to difficulties accessing services.



..Some participants referred to... the lack of follow-up services and how this could lead to feelings of isolation and even the deterioration of their mental health..

“I was offered no services and was told there was likely to be waiting lists of up to 2 years. I was forced to use private care at a huge cost to me otherwise I have no idea where I would be now”

“When having to see a psychiatrist that there’s some continuity of care , rather than different doctors having to be explained my life story all the time”

“It has been 7 years since my first contact before I have gotten the help I need which I do feel the course of time waiting made a lot of things worse in my life”

“My local mental health service has 1 vacancy they have not filled for a psychologist, and the only other psychologist in the centre has been out on maternity leave since I have started going there over a year ago”

“I am still waiting for help”

“More discussion about your illness and medication. Staff being more open with patients”

“Service is crisis driven. Woefully underfunded so only most desperate get crisis care for a short period... need to be holistic”

“Nurse Counsellor never answered phone, never replied to voice mails or to texts when I was in crisis”

“Lack of knowledge in professionals regarding EUPD [Emotionally Unstable Personality Disorder]”

“I was extremely depressed, self-harming and suicidal in December and received an appointment to see a psychiatrist at [hospital] the following June. I was lucky that a family member could lend me the €300 to see a psychiatrist privately and wow, she could see me the following week!”

“Was put with a psychotherapist who repeatedly told me she was in training and not equipped to give me the support I need”

“Stop changing psychiatrist all we need is to talk to someone we know and trust”





CONCLUSIONS

In his most recent report, the United Nations (UN) Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health acknowledges that power imbalances have dominated the relationship between MHSs and users of services. Ultimately this has created an environment where people are undermined in making decisions about their own health, meaning human rights violations can and do occur.

The introduction and development of national and international standards has sought to break down traditional power asymmetries, to empower individuals and make them agents of change rather than passive recipients of care.

Mental Health Reform's *My Voice Matters* consultation with service users is the first national, large-scale survey in recent years to provide in depth and up-to-date feedback on the direct experiences of people who access community and inpatient MHSs.

The evidence indicates that the experiences of service users are mixed. Some participants may be experiencing services consistent with aspects of national policy and standards. This is reflected in reports by participants of the following: positive experiences with mental health staff; feeling listened to; being treated with dignity and respect; being provided opportunities to be involved in their own care; having a recovery/care plan; being involved in conversations about recovery and being referred to talking therapies by the MHSs.

However, notwithstanding efforts made by successive governments and their agencies, primarily the HSE MHSs, to achieve a modern, recovery orientated

MHS, the evidence indicates that many service users are not experiencing this type of service. There is a lack of consistency and standardisation in MHS delivery, which is clearly demonstrated in the varying experiences of service users. This has been shown in mixed reports of participants getting access to therapeutic programmes and fundamental supports such as the appointment of designated key workers and the availability of 24/7 crisis responses by CMHTs.

It appears that the core principles underpinning national mental health policy, with a particular emphasis on the recovery ethos, have not been uniformly embedded in the day-to-day operation of MHSs across the country. A large majority of participants reported having no individual recovery/care plan and a high focus on medication as part of their treatment and care. Only a minority reported being involved as much as they would like in decisions about the medication they take; many reported that their CMHT did not talk to them about recovery or how their mental health difficulty affects other areas of their life, and less than half felt that they were always treated with dignity and respect by community MHSs. Mental Health Reform is of the view that there is a fundamental requirement for a system-wide change, which empowers service users to make decisions about their own care and treatment, in line with national and international standards.

The Government, the HSE and all staff working in mental health and related support services can benefit from receiving national, independent feedback from service users on a regular basis, to facilitate service planning and improvements in practice. The availability of feedback from service users is integral to the process of identifying areas for

service improvement, given their direct experience of using the services. In the absence of a national mental health information system, which collects routine data on service delivery, as well as outcomes for service users, the availability of feedback provided through consultations such as the *My Voices Matters* study becomes increasingly important.

The publication of this first *My Voice Matters* national consultation is also very timely, in that the Oversight Group on the review of *A Vision for Change*, tasked with overseeing the development of a new policy for mental health, is expected to complete its report in 2019. The *My Voice Matters* report represents one way of giving voice to service users in the development of updated mental health policy, which will inform service delivery at all levels and cross sections of the mental health system. The views of people who use MHSs must be at the heart of mental health policy direction. These findings can aid the Oversight Group to develop recommendations focussed on areas that service users currently experience as dissatisfactory. So too, the findings can inform the Department of Health's deliberations on mental health policy and their oversight of the HSE's MHS delivery.

Ultimately, we hope that the findings will lead to policy and service delivery that will enhance protection of the human rights of service users and ensure that the current gaps in service provision are adequately addressed.

Mental Health Reform, in its role as the leading national coalition on mental health, will continue to drive progressive reform of the MHSs and supports in Ireland. The findings from this report (and its complementary report on family members, friends and carers/supporters) provide a strong evidence base for changes required in the MHSs. Mental Health Reform will disseminate these reports and bring the findings and recommendations to the attention of key stakeholders, including the HSE MHSs, the Department of Health, the Minister with responsibility for mental health and the MHC. Mental Health Reform will advocate for the timely and effective implementation and monitoring of the report's recommendations in order to ensure improved experiences of people who use the MHSs.



..Mental Health Reform's *My Voice Matters* consultation of service users is the first national, large-scale survey in recent years to provide in depth and up-to-date feedback on the direct experiences of people who access a range of mental health services..

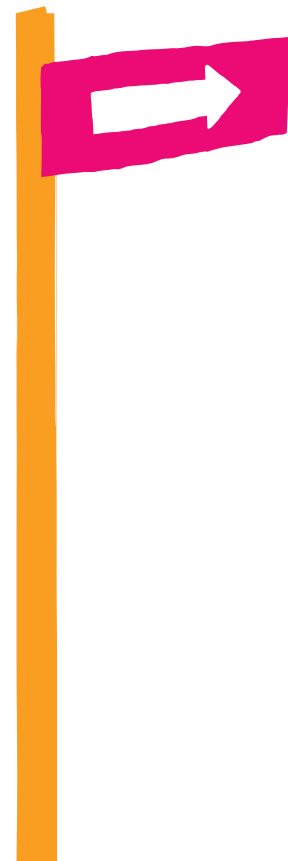


RECOMMENDATIONS

1. Multidisciplinary team members should be adequately trained and supported by management to talk to service users about recovery, to talk to them about their strengths and to discuss how their mental health difficulty affects other areas of their life. This should be complemented by the national roll out of the recovery education strategy with support and input from service users and family, friends and carers/supporters.
2. HSE MHSs should develop and implement action plans to enhance active listening among mental health professionals operating in all CMHTs. Such measures should include identifying why professionals do not engage in active listening, the barriers to active listening, and the solutions to overcoming such barriers.
3. HSE MHSs should ensure that an individual recovery/care plan is developed in partnership with each service user following contact with MHSs, and is regularly updated in collaboration with the service user. Service users should be made aware of where their care plan is kept and should have access to the plan at all times.
4. HSE MHSs should ensure that service users, and in particular individuals who are engaged with MHSs on a long term basis, have the opportunity to develop a consistent relationship with a named psychiatrist on the team, and not be subject to frequent changes of psychiatrist. Service users should also be provided the opportunity to develop consistent relationships with other disciplines on the team.
5. HSE MHSs should ensure full cover in terms of multi-disciplinary supports to account for staff absences among the professional disciplines.
6. All HSE MHSs should ensure that each individual accessing services is appointed a key worker and is given contact details for this individual. Service users should be provided with a key worker for as long as they are engaged with the MHSs.
7. HSE MHSs should provide opportunities for all service users to be involved in decisions about their medication, including the type of medication they are being prescribed, and be fully informed about potential risks and benefits. Service users should also be provided with information about their diagnosis and have it explained to them by a member of the CMHT in a way that they understand.
8. HSE MHSs should ensure that talking therapy is a core component of the service offering and is readily available on an extended basis where necessary. Waiting times for talking therapy should be reduced to a maximum of 3 months.
9. Every HSE MHS should provide a 24/7 response to be made available to existing service users who are in crisis. Service users (and their family members/carers/supporters) should be clearly made aware of what to do in the event of a crisis.
10. HSE MHSs should ensure that a range of recreational activities, social inclusion and therapeutic supports for individuals (e.g. music therapy, art therapy, social prescribing, supported

employment, and tenancy sustainment) accessing outpatient and inpatient facilities are widely available to support their care, treatment and recovery.

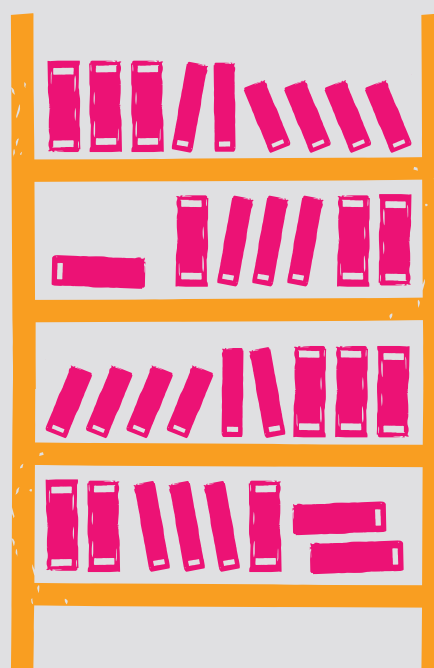
11. Service users should be informed by GPs and their mental health team about local charity and voluntary sector community supports. Building on Yourmentalhealth.ie, HSE MHSs should ensure that a list of local resources is developed and made available for service users in every community.
12. HSE MHSs should ensure that every service user is informed, following contact with the MHSs, by a member of the multidisciplinary team of the HSE's complaints process and how to make a complaint about the MHSs. HSE MHSs should ensure that all service users can avail of an independent advocate to support them in making a complaint. The Government should ensure that there is a direct route to an independent complaints process for people accessing MHSs.
13. This consultation on people's experiences of the MHSs should be conducted every two years to ensure that the HSE and other key stakeholders are receiving national independent feedback from service users on a regular basis. This would facilitate priority setting by the Minister with responsibility for Mental Health, Department of Health and HSE for annual service plans.
14. HSE Mental Health should produce a time-lined action plan in 2019 to implement these recommendations. A senior staff member in HSE Mental Health should be assigned responsibility for overseeing the development and implementation of the action plan.
15. The Minister with responsibility for mental health should ensure accountability in the implementation of these recommendations through ongoing monitoring and evaluation.





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RESPONSE OF THE GRASSROOTS FORUM

Mental Health Reform's Grassroots Forum (GRF) is made up of people with experience of the mental health services and family, friends and carers/supporters.¹⁸ The GRF is core to Mental Health Reform's work. We are consulted on all new Mental Health Reform policy positions, and our views are incorporated in the development of these positions. In recent years we have fed into Mental Health Reform's policy submissions on the review of *A Vision for Change*, the national mental health policy, and Mental Health Reform's analysis on reform of the Mental Health Act, 2001. We have also met with key decision-makers to voice our concerns about challenges faced by people with mental health difficulties.

Overall, Mental Health Reform's national consultation has been very valuable in facilitating service users to share their experiences of the MHSs in Ireland. It is encouraging that there are a number of positive findings from the consultation, including that the majority of survey participants reported being referred by HSE MHSs to talking therapy and that more than half of participants reported feeling mostly or always listened to by their psychiatrist. However, the findings also show that many participants had negative experiences and that there were a lot of mixed views about the MHSs. For example, we noted the long waiting times to access talking therapy for a number of survey participants, and consider that some wait times are excessive and unacceptable for people in mental distress.

Continuity of care, and in particular, service users having the opportunity to develop a long-term, consistent relationship with a psychiatrist, is key to promoting positive outcomes for service users. The national consultation findings show that the more frequently participants had a change of psychiatrist, the more negatively they perceived the impact of these changes on their treatment and care. We believe that service users should be provided with the same psychiatrist for a minimum of one year, where a psychiatrist continues to be needed. Where a change in psychiatrist is necessary (e.g. due to a doctor resigning or going on leave) there should be a transition process between the old and new psychiatrist. This could include, for example, the new psychiatrist attending the final appointment(s) with the service user and old psychiatrist to ensure a smooth transition between the two. It is also important that there is a standard approach to how psychiatrists engage with service users, so that they are visibly friendlier and more open to hearing the views of the service user. At the moment, psychiatrists in MHSs across the country have different ways that they communicate with service users, and people experience wide variation in their interactions with psychiatrists.

¹⁸ Members of the Forum are nominated by MHR member organisations and participate as nominees of their organisation. Currently, there are approximately 15 active members.

..Service users also need opportunities to talk about their emotions and feelings and how these fit within the context of their lives...



In addition, while it is concerning that many service users do not have the contact details of a key worker, it is encouraging that those who do are more likely to have a positive experience of the MHSs. A contactable key worker should be mandatory for every service user, so as to improve their experiences of the MHSs.

In line with the findings of the national consultation, we would like to acknowledge the positive work of mental health staff. Mental health staff often have to work in very stressful environments and this can have a negative impact not only on the staff but also on the quality of care they provide to service users. In order to improve the experiences of service users, the ongoing staff shortages in MHSs need to be addressed, including the replacement of staff when they go on leave. There is also a need for more multi-disciplinary support across the community mental health teams so that service users can benefit from different types of therapies. Overall, it is crucial that mental health staff are empathetic, friendly and welcoming to all individuals coming into contact with their services. We think that this will require cultural change, across the services, where staff are encouraged and supported to engage and communicate more effectively with service users and their family, friends and carers/supporters. It is important to recognise that many service users are lonely; better communication by MHS staff could help in reducing such feelings of loneliness and isolation.

People who took part in the surveys reported mixed experiences of inpatient services. The findings show that there is a need to invest in inpatient mental health services to improve therapeutic supports and recreational activities. Supports such as relaxation courses, meditation and yoga programmes should be provided, as well as access to gardens and other therapeutic amenities. There is also a need for proper staffing in inpatient services to ensure service users have access to these programmes and

activities, as well as improvements in basic facilities e.g. shower units. Overall, attending hospital for mental health care should be a therapeutic experience which promotes rest and recovery. It should not be a traumatic experience. In creating more therapeutic and welcoming inpatient services, more individuals will be encouraged to look for help from the MHSs when they need it, and are more likely to do so on a voluntary basis. While outside the scope of the national consultation findings, it is crucial that service users are informed of their rights when they go into hospital for mental health care. The mental health tribunal process should also be improved so that service users have a more positive and less intimidating experience of the mental health tribunals.

It is encouraging that service users who are involved in decisions about their medication are more likely to have a positive experience of the MHSs. However, it appears from the national consultation surveys that this group is in the minority, with decisions about medication resting largely at the discretion of the psychiatrist. It is important that service users are facilitated and encouraged to be partners in their own mental health care. This includes being told about the medications they are given and the potential risks and benefits of these medications. Mental health professionals should actively listen and take on board the views of service users about the medications they are prescribed; it is service users who experience the effects of medication and know what works best for them in terms of their individual recovery.

Service users also need opportunities to talk about their emotions and feelings and how these fit within the context of their lives. The MHSs are not currently set up to work well with the whole person and, in our experience, service users are often not provided opportunities to engage in talking therapy. The findings from the national consultation show extremely long wait times to access talking therapy for some service users, with wait times of more than a year. We think there

should be considerably shorter waiting times to access talking therapies, i.e. no more than two weeks. It is not acceptable for a person to have to wait a number of months to see someone to talk to when they are in need of this kind of support.

A mental health advocate can play a key role in a person's recovery. Advocates can promote the implementation of a service user's individual care/ recovery plan, explain the person's rights to them, including their right to a mental health tribunal, if detained under the Mental Health Act 2001, and assist a person in retaining control over various aspects of their lives. This may include working with the person to reduce the risk of them losing their job or their home or making the necessary arrangements for childcare. Often these aspects of life require communication and negotiation skills that some service users are not equipped with when they are unwell and/or will struggle with over the course of their lifetime. The appointment of an advocate becomes even more important where service users do not have any family members or friends who can advocate on their behalf, including, for example, people from ethnic minority groups who may have no family residing in Ireland. An advocate would also be of benefit in ensuring people with particular needs, e.g. interpretation services, have access to the necessary resources. Peer supports are also important in ensuring service users have someone they can talk to who understands what they're going through.

It is encouraging that service users with access to an individual recovery/care plan are more likely to have a positive experience of MHSs. However, it is deeply concerning that not all survey participants reported having a recovery/care plan. The importance of a plan should not be underestimated as knowing there are set goals and a tailored plan to meet such goals is helpful for the service user in their recovery. The GRF are of the view that

individual recovery/care plans should be mandatory for all service users accessing community or inpatient mental health services and should address all aspects of the person's life. The plan should include specific information on discharge and follow-on supports, to ensure that the ongoing mental health needs of service users are adequately addressed. Following discharge from MHSs, service users can often feel aimless and isolated and are at risk of relapse and readmission to the MHSs. We think it is important to have designated follow-on care to support service users' ongoing recovery, including in the areas of housing and employment.

For many people in mental distress there is no out of hours support available outside of Accident and Emergency Departments (A&E). This is problematic as A&Es can be very chaotic environments, with untrained staff in mental health and long wait times to be seen by a mental health professional. We think there should be alternatives for service users in crisis, including, for example, an 'out of hours' phone line, a separate waiting area in A&E and/or a crisis liaison officer that can be contacted out of hours. Overall, there is a need for enhanced crisis services in all parts of the country.



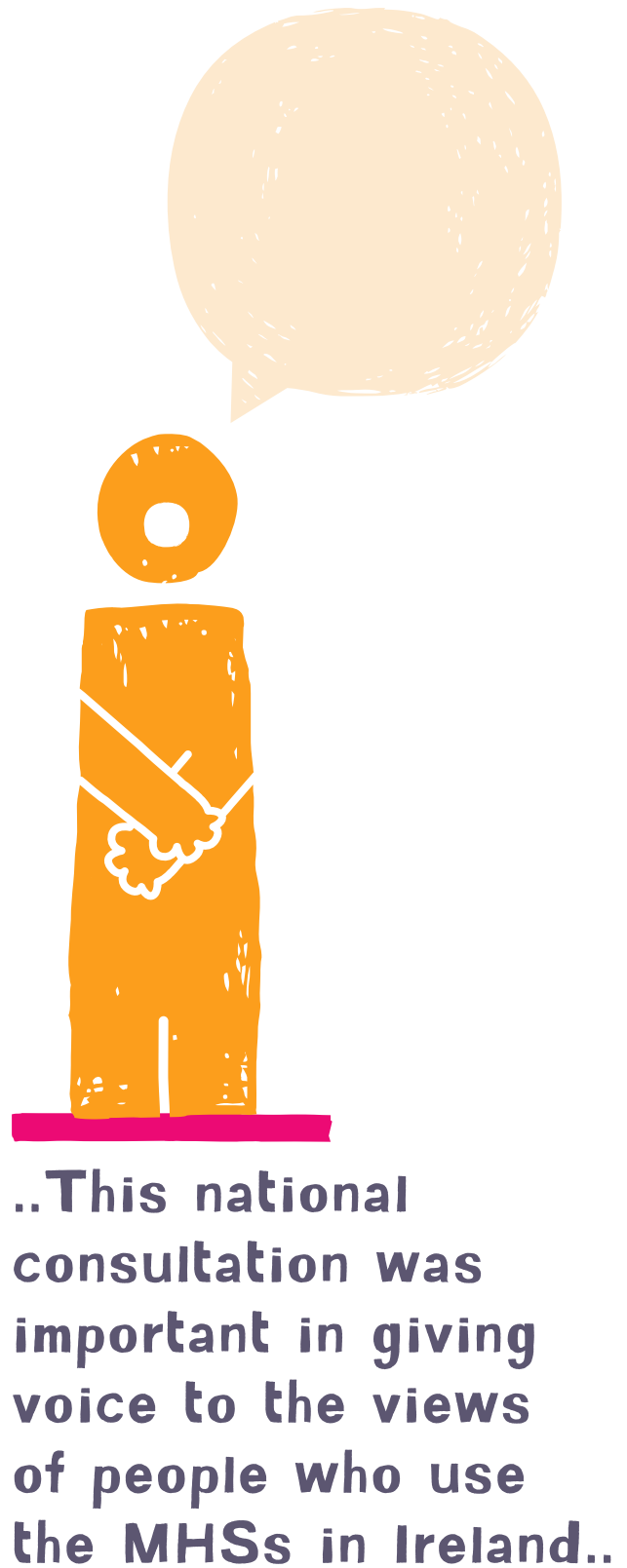
..it is crucial that mental health staff are empathetic, friendly and welcoming to all individuals coming into contact with their services..



There is also a need for better information about the complaints process among service users. Some very practical measures should be taken, for example, increasing the amount of information displayed in MHSs about the complaints process. Service users should also be supported to make complaints, with the assistance of an advocate for example, and the fear of making a complaint which often deters service users from making one should be addressed by the MHSs.

Access to a GP with mental health experience and knowledge is important for service users and their family, friends and carers/ supporters. While many people who took part in the national consultation surveys reported positive experiences of their GP, we believe there are many doctors who do not have the necessary skills in mental health. Overall, GPs need better training in mental health, including when to refer a person to specialist mental health services.

While the positive experiences of service users should be acknowledged, there are many individuals who reported poor experiences of the MHSs through the national consultation surveys. These experiences are not acceptable and highlight the need to improve the quality and consistency of mental health service delivery across the country. This will require a system wide cultural change that can support practical measures, e.g. the implementation of clear standards for MHSs on working with service users. This national consultation was important in giving voice to the views of people who use the MHSs in Ireland. There is a need, however, for an ongoing consultation process to ensure service users have a key role in improving the MHSs through collaborative service planning. This is crucial in ensuring the human rights of service users, in particular their rights to dignity and autonomy, are protected.





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