

MY VOICE MATTERS

Report on a National
Consultation with
Mental Health
Service Users



Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service



Mental Health Reform
Promoting Improved Mental Health Services

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Mental Health
Service Users

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
BPD	Bipolar Disorder
CBT	Cognitive Behavioural Therapy
CHO	Community Health Organisation
CMHS(s)	Community Mental Health Service(s)
CMHT	Community Mental Health Team
CPN	Community Psychiatric Nurse
DBT	Dialectical Behavioural Therapy
ED	Emergency Department
EUPD	Emotionally Unstable Personality Disorder
GP	General Practitioner
HSE	Health Service Executive
M	Mean
MHC	Mental Health Commission
MHS(s)	Mental Health Service(s)
NHS	National Health Service
NLN	National Learning Network
NPD	Narcissistic Personality Disorder
OCD	Obsessive Compulsive Disorder
OT	Occupational Therapist
PRA	Peer-Research Assistant
PTSD	Post Traumatic Stress Disorder
QSUS	Quality & Service User Safety Team
SD	Standard Deviation
SPSS	Statistical Package for Social Sciences
SZPD	Schizoid Personality Disorder
TCD	Trinity College Dublin
UN	United Nations
UNCRRPD	United Nations Convention on the Rights of Persons with Disabilities
WRAP	Wellness Recovery Action Plan





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



..The My Voice Matters report captures, to a large extent, the current experiences of people who use the mental health services 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...

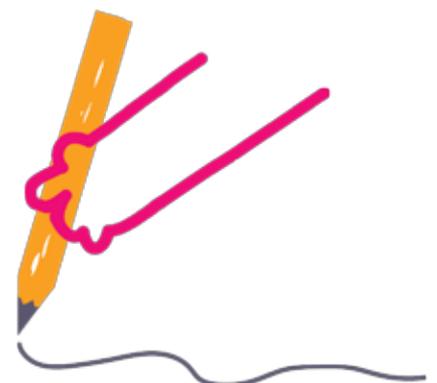
the valuable work that has been undertaken by HSE Mental Health¹, and many local MHSs, mental health staff and communities over the years, as the findings indicate, there is considerable variation in service users' experiences of the MHSs. While some participants may be experiencing services consistent 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 members, friends and carers/ supporters shows a commitment to service improvement and to listening to the voices of people who use the mental health services.

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EXECUTIVE SUMMARY





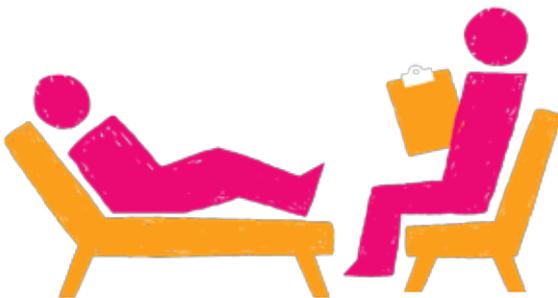
INTRODUCTION

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 this report.



Designing the Survey:

Survey design was carried out in a phased manner as follows (see appendix E for the survey):

- ✦ 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 this 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

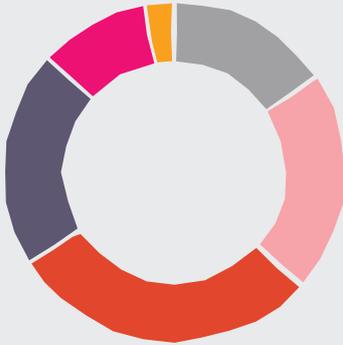
PARTICIPANTS

39.4 yrs

AVERAGE AGE

18-76 yrs

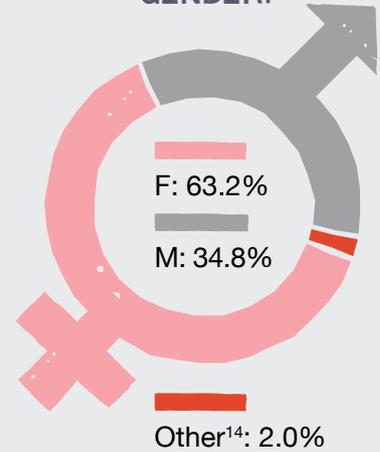
AGE RANGE



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:



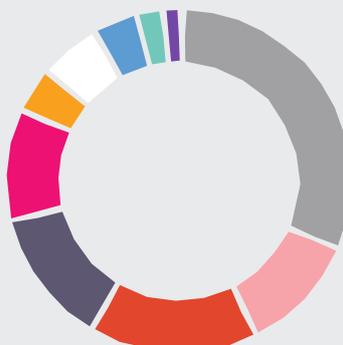
F: 63.2%
M: 34.8%

Other¹⁴: 2.0%



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.



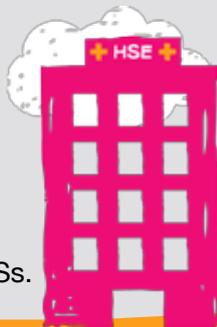
KEY QUANTITATIVE FINDINGS

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

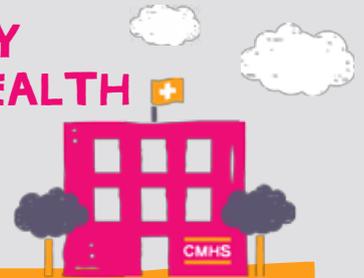


41.6% of participants indicated that they had **A POOR EXPERIENCE** of HSE MHSs

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 main 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?”

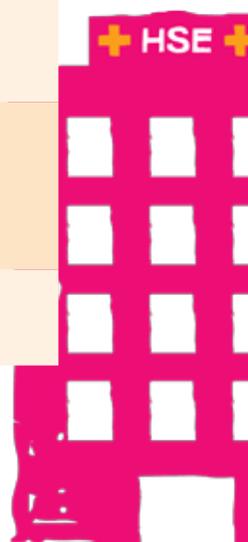
“A map and information card about the nearest emergency mental health service. Information about how the system works, who people are, what their function is, what the timelines are for things... even any information about assessment for Aspergers/ ASD [autism spectrum disorder] in adults”





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"

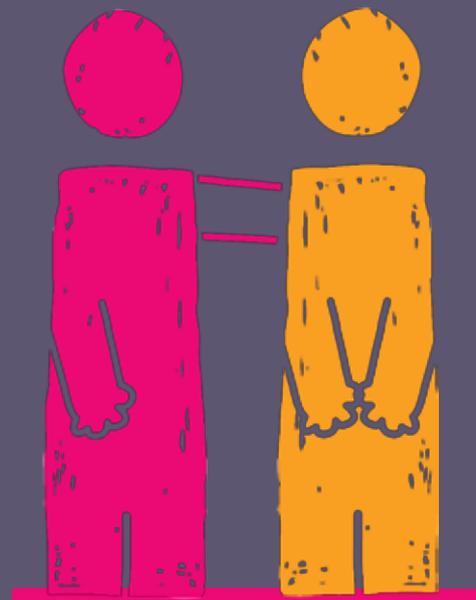
"I was listened to by most recent psychiatrist and she agreed that medication was not working and to take me off it after 15 years and also has re-referred me for additional therapy as again am finally being listened to"

"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"

"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!"

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

"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..



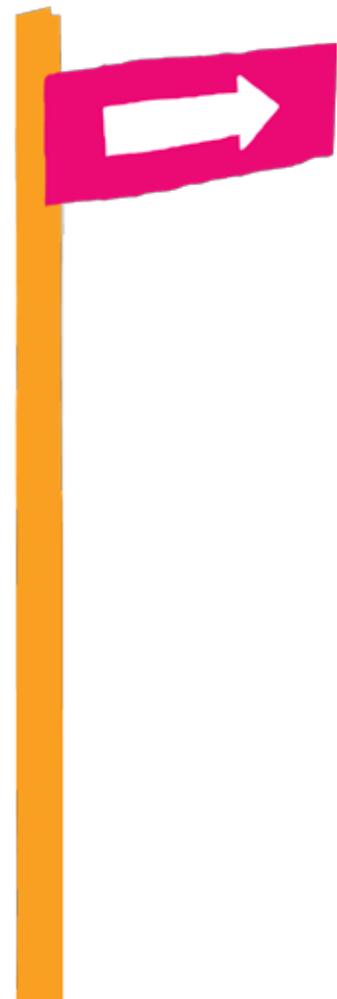
RECOMMENDATIONS

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.



INTRODUCTION

SECTION





1. INTRODUCTION

This report describes the key findings from Mental Health Reform’s national consultation on people’s experiences of using the mental health services (MHSs) in Ireland. The report focuses on the feedback from people with direct experience of receiving MHSs (for the purposes of this report, these individuals are referred to throughout as ‘service users’).¹⁸ A complementary report describes feedback from people who are family members, friends and carers/supporters of people who have used MHSs.

The overall aim of the study was 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. The survey gathered service user views on different aspects of MHS provision, including community mental health services (CMHSs), inpatient care, experiences of psychiatrists, crisis supports, the recovery ethos and the complaints process, as well as GP/primary care. See appendix E for the survey.

There is no doubt that the Health Service Executive (HSE) has undertaken significant initiatives in recent years to promote a more modern, recovery orientated public MHS. In November 2017, HSE Mental Health¹⁹ launched their National Framework for Recovery in Mental Health²⁰ for the purpose of developing the recovery approach in MHSs across Ireland.

This was complemented by a series of recovery guidance documents²¹ to support MHSs in the implementation of the Framework, with a strong emphasis on co-production and recovery education; and by a recovery strand in the Service Reform Fund. These resources have built on previous initiatives, such as the HSE’s Advancing Recovery in Ireland programme,²² as well as existing policy and standards, including *A Vision for Change*²³ and the Mental Health Commission’s (MHC) Quality Framework.²⁴ 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.

The mental health regulations, as set out under the Mental Health Act of 2001,²⁵ allow for the inspection and regulation of inpatient mental health units to protect the rights of people with mental health difficulties. The Expert Group Report on the Review of the 2001 Act makes extensive recommendations to strengthen such protections, of which a small number have already been implemented.²⁶ The MHC’s Quality Framework for MHSs²⁷ provides a

- 18 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.
- 19 HSE Mental Health operates at national level and has responsibility for all mental health services, including in planning, operations, quality and service improvement.
- 20 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.

- 21 E.g. HSE Mental Health Services. (2017). *Recovery education guidance document, 2018-2020: Supporting ‘A National Framework for Recovery in Mental Health 2018-2020’*: Dublin: HSE MHS. Also see: HSE Mental Health Services. (2017). *Co-production in practice guidance document, 2018-2020: Supporting the Implementation of ‘A National Framework for Recovery in Mental Health 2018-2020’*: Dublin: HSE MHS.
- 22 The initiative represented the first systematic approach to developing recovery orientated services at a national level, using a comprehensive organisational change methodology.
- 23 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.
- 19 Mental Health Commission. (2007). *Quality framework: Mental health services in Ireland*. Dublin: MHC.
- 25 Government of Ireland. (2001). *Mental Health Act*. Dublin: Stationery Office.
- 26 Expert Group. (2015). *Report of the expert group on the review of the Mental Health Act, 2001*. Dublin: Department of Health.
- 27 Mental Health Commission. (2007). *Quality framework: Mental health services in Ireland*. Dublin: MHC.



basis for ongoing quality improvement and standardisation across all MHSs. As part of the service user survey, participants with relevant experience were asked a series of questions about their experiences of inpatient MHSs.

More recently, investment has been made in service improvement initiatives in community mental health teams (CMHTs) across the country, with a particular focus on promoting the recovery ethos, including the social inclusion of service users. Further developments have been made through the establishment of the National Mental Health Quality and Service User Safety Team (QSUS) and the development of accountability structures such as the appointment of the Confidential Recipient, to receive complaints about the care and treatment of any vulnerable person receiving residential care in a HSE or HSE funded facility.

Notwithstanding actions carried out by HSE Mental Health and local HSE MHSs provision in the direction of national policy, there is a fundamental question as to how this is being translated in practice. To what extent are service users experiencing these changes on the ground?

Previous consultations evidenced concerns about implementation of the national mental health policy. In Mental Health Reform's 2015 public consultations the following issues were identified among attendees, including those with direct experience of using the services:

- ✳ a lack of appropriate, consistent emergency or out of hours services;
- ✳ a lack of knowledge or difficulty accessing key workers or advocates;
- ✳ inconsistent availability or quality of care across national MHSs;
- ✳ a lack of communication between services (i.e. referral between Child and Adolescent MHSs & Adult MHSs);
- ✳ over reliance on medication;

- ✳ an inconsistent approach to involvement of family members or carers/supporters;
- ✳ lack of awareness of how to access services;
- ✳ lack of continuity of care between service providers;
- ✳ lack of accessibility for particular groups of people e.g. individuals from the deaf community and those with an intellectual disability;
- ✳ lack of effective communication between service users and service providers;
- ✳ excessive waiting times for services.

The MHC has consistently raised concerns about the lack of individualised supports in inpatient MHSs, as well as a lack of therapeutic and recreational programmes. The Commission has reiterated such concerns in its latest annual report.²⁸ In addition, the Inspector for MHSs has continually reported on the poor physical infrastructure of some mental health facilities that do not meet the needs of their service users.

Listening to and building on feedback from people with lived experience of the MHSs must be viewed as a key mechanism through which services, and the experiences of those accessing the services, can be improved. Valuable feedback from service users has been collected through consultations carried out as part of the development of *A Vision for Change*²⁹ and the MHC's Quality Framework for MHSs.³⁰ However, with some notable exceptions (e.g. *Your views of Mental Health Inpatient Services*³¹), there has been a

28 Mental Health Commission. (2018). *Mental Health Commission annual report including report of the inspector of Mental Health Services, 2017*. Dublin: MHC.

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

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

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



limited amount of research published on the experiences of people accessing the MHSs in Ireland.

Throughout 2014, the HSE Mental Health Division held a series of listening meetings across the country to consult with service users, family members and carers on their views of the MHSs for the purpose of informing service planning and improvement. These followed on from the National Service Users Executive's Second Opinion Reports which reported on satisfaction levels among service users of the HSE MHSs.^{32,33}

Mental Health Reform facilitated its own independent public consultations in different parts of the country between 2011 and 2015 on people's experiences of the MHSs. However, the coalition's previous consultations were less structured and less in depth than the *My Voice Matters* surveys.

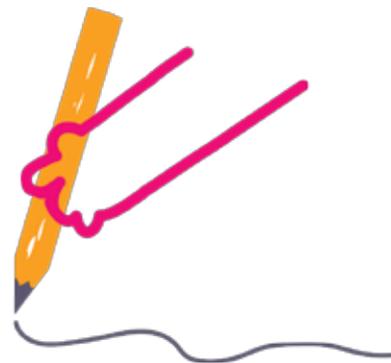
Notwithstanding the valuable feedback collected through these consultations, Mental Health Reform identified a need for a national, large-scale survey to provide in depth and up-to-date feedback on the experiences of people who access a range of MHSs and their family members, friends, carers/supporters.

The *My Voice Matters* national consultation was conducted independently by Mental Health Reform, from study and survey design, through to data collection, analysis and report writing. However, it must be acknowledged that the research was funded in whole by HSE Mental Health.

This support by HSE Mental Health is very encouraging in that it demonstrates a commitment among senior management to listen to the views of people using MHSs to inform service improvement. Preliminary findings of the research were presented to HSE Mental Health for feedback, in addition to an advance copy of the report being provided to the team prior to publication.

Mental Health Reform maintained full editorial control in the drafting and finalisation of the report; HSE Mental Health had no input in signing off on the report.

It is Mental Health Reform's intention that this report and its complementary report from the family, friends and carer/supporter perspective will assist the Government and the HSE in their efforts to improve Ireland's mental health system.



..The *My Voice Matters* national consultation was conducted independently by Mental Health Reform, from study and survey design, through to data collection, analysis and report writing..

32 National Service User Executive. (2009). *Summary report of the NSUE survey of members on Vision for Change: Have your voice heard... for a change.* Dublin: NSUE.

33 National Service User Executive. (2011). *Summary report of the NSUE survey of members on Vision for Change: Have your voice heard... for a change.* Dublin: NSUE.

METHODOLOGY





2. METHODOLOGY

2.1: Study Design

This research employed a survey design, which included closed and open-ended questions. Service users with experience of specialist MHSs in Ireland in the last two years were asked to complete the survey.

2.2: Survey Design

The service user survey was designed in a phased manner. Following a detailed literature review, survey questions were drawn from a variety of prominent studies of people's experiences of MHSs, e.g. the MHC's Inpatient Survey³⁴ and the UK Care Quality Commission's Community Mental Health Survey.³⁵ Where necessary, questions were tailored to the Irish context. Additional survey questions were also developed based on Mental Health Reform's previous consultations on people's experiences of the services carried out across Ireland between 2011 and 2015.

Proposed themes for the survey were discussed with the project Steering Group³⁶ and questions were then further developed and organised by theme into sections to develop a working draft of the survey. Themes were based on different aspects of MHS delivery, including mental health in primary care, CMHSs, inpatient MHSs and crisis services.

Next, in order to test each of the survey questions, a series of cognitive interviews³⁷ were conducted with 10 individual service users. Changes were made in accordance with the feedback received. Three focus groups with service users were then conducted to gather further feedback on the updated survey.

After further revision, the survey was reviewed by external researchers with survey design expertise before undergoing a final in-house review by Mental Health Reform staff. Once finalised, the survey was prepared in two formats: hardcopy and online versions.

This process resulted in the final survey, which consisted of 56 questions in total. These included multiple choice questions, 3-point, 5-point and 11-point Likert-type questions,³⁸ several 'tick all that apply' questions and a number of open-ended questions which facilitated more in depth feedback from service users. The survey was structured around different aspects of MHS delivery including CMHSs, the role of psychiatrists, inpatient care and crisis care. A small number of questions were included on participants' experiences of GP/primary care. It also included sections relating to the recovery ethos and holding services to account, as well as a variety of socio-demographic questions.

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

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

36 The Steering Group for the project consisted of two representatives from the HSE Mental Health Division Engagement Office, two staff members of Mental Health Reform, one expert by experience and one family carer/supporter. This steering group was only involved during the design phase of the project.

37 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

38 Used to measure people's attitudes by asking participants to indicate their feelings towards a statement on a scale ranging between two poles, e.g. strongly agree to strongly disagree.



2.3: Study Population and Sample

The target population was individuals with experience of using MHSs³⁹ in Ireland in the last two years. The specific inclusion criteria were:

- ✱ participants had to have had contact with CMHSs, inpatient MHSs, and/or a psychiatrist in the past two years.
- ✱ participants were required to be aged 18 years or older.

Snowball sampling was used to recruit the majority of the sample. This is a sampling technique where a 'sample is constructed from a base of initial contacts, who are asked to provide introductions to their associates, who, in turn, are asked to refer others'.⁴⁰ Although sometimes criticised as unrepresentative, Wright and Stein⁴¹ note that in certain circumstances, particularly when recruiting hidden, difficult to access or stigmatised populations, snowball sampling can result in a more representative sample than one drawn from a clinical or institutional setting. Snowball sampling was therefore considered an appropriate sampling method for the current survey.

Note that snowball sampling has been criticised because the final sample can be influenced by the initial participants. To combat this, rather than starting with a single group and allowing the sample to snowball from there, Mental Health Reform drew on its extensive network of over 70 member groups, as well as organisations and individuals external to Mental Health Reform, in an effort to have as large and diverse a starting group as possible. Mental Health Reform member organisations, Mental Health Reform advisory groups (including its Grassroots Forum), non-governmental

organisations external to Mental Health Reform's membership, primary care centres, employability companies, independent professionals and members of the Oireachtas were contacted and asked to bring the national consultation survey to the attention of people accessing their services. In addition, radio advertisements with a potential reach of 1.5 million people, alongside an extensive social media campaign, helped to increase awareness of the survey and facilitate recruitment.

Note that targeted sampling⁴² was also used to recruit people accessing outpatient CMHSs in a single community health organisation (CHO3). A sample of 274 participants were recruited in outpatient CMHSs. However, due to significant differences between this subsample and the overall sample, it was deemed inappropriate to include this subsample in the main analysis outlined in this report. For more information, see appendix B.

Some 1,512 participants responded to the survey. As noted, 274 participants were recruited in outpatient CMHSs and were excluded from the analysis outlined in this report. Some 50 participants were excluded either because they were under the age of 18 or because they not accessed psychiatry, community or inpatient MHSs in Ireland in the last two years. In total, 1,188 participants who met the inclusion criteria completed the survey (mean age: 39.4; age range: 18-76). There was a female to male gender ratio of approximately two to one (females: 63.2%; males: 34.8%; other gender identity⁴³: 2.0%). A wealth of socio-demographic information was gathered. This is outlined in table 2.1.

39 Experience at various levels, e.g. CMHSs, inpatient MHSs and/or contact with a psychiatrist.

40 Wright, R., & Stein, M. (2005). Snowball sampling. In K. Kempf-Leonard (Ed.), *Encyclopedia of social measurement* (Vol.3) (pp. 495–500). Boston, MA: Elsevier, p. 495.

41 Wright, R., & Stein, M. (2005). Snowball sampling. In K. Kempf-Leonard (Ed.), *Encyclopedia of social measurement* (Vol.3) (pp. 495–500). Boston, MA: Elsevier.

42 Targeted sampling is a systematic sampling method useful for recruiting hidden or difficult to access samples, where members of a specific group are targeted for recruitment. For a detailed description, see: Peterson, J. A., Reisinger, H. S., Schwartz, R. P., Mitchell, S. G., Kelly, S. M., Brown, B. S., & Agar, M. H. (2008). Targeted sampling in drug abuse research: A review and case study. *Field Methods*, 20(2), 155-170. doi: 10.1177/1525822X08314988

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

**Table 2.1: Socio-demographic profile of service user survey sample**

Age Group	%	n*
18-25	15.8%	185
26-34	21.1%	247
35-44	29.3%	342
45-54	20.7%	242
55-64	10.5%	123
65 or older	2.6%	30
Gender	%	n
Female	63.2%	408
Male	34.8%	741
Other Gender Identity	2.0%	24
Educational Attainment	%	n
No formal education/primary education only	3.9%	45
Lower secondary	11.5%	134
Upper secondary	21.1%	247
Third level non-degree	24.7%	289
Third level degree	23.5%	275
Post graduate qualification	15.2%	178
Ethnic/Cultural Background	%	n
Irish (including Irish Traveller)	91.6%	1078
English/Scottish/Northern Irish/Welsh	4.2%	49
Other ethnic/cultural background ⁴⁴	4.2%	49
Relationship/Marital Status	%	n
Single	59.3%	697
Married	21.9%	258
Separated	6.3%	74
Cohabiting	5.9%	69
Divorced	4.0%	47
Other (including widowed and civil partnership)	2.6%	31

⁴⁴ Although a variety of different responses were given (e.g. African, Indian, etc.), all categories with less than 1.0% were combined with the 'other' category.



Sexuality/Sexual Identity⁴⁵	%	n
Straight/Heterosexual	77.4%	920
Lesbian/Gay	6.9%	82
Bisexual	9.2%	109
Other Sexual Identity ⁴⁶	2.1%	25
Work/Employment Status	%	n
Paid full or part-time employment	34.8%	407
Unable to work due to chronic illness/disability	23.0%	269
Unemployed	16.4%	192
Student	14.2%	166
Retired	4.3%	50
Looking after the family home	3.0%	35
Housing Status	%	n
Home you own/pay a mortgage for	32.2%	376
Home that a family member owns/pays a mortgage for	26.5%	310
Private rented accommodation	19.3%	225
Local Authority rented accommodation	10.1%	118
Rented from a voluntary housing association	3.9%	46
Renting with support of rent supplement or housing assistance payment	3.3%	39
Community house/hostel	2.6%	30
Homeless accommodation	0.9%	10
Other ⁴⁷	1.2%	14
Chronic Illness/Disability⁴⁸	%	n
Yes	51.5%	578
No	48.5%	545

**Note that the column listing the number of participants in each category does not sum to 1,188, the total number of participants who took part. Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

45 Participants could tick all options that applied to them. It was therefore possible to choose multiple sexual identities.

46 '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. Other sexual identity could include, but is not limited to, asexual, demisexual or pansexual.

47 Examples of participant responses here included 'Traveller specific accommodation', 'Staying in different houses belonging to friends/family members - not fixed' or 'Living in my home and waiting for it to be repossessed'.

48 Participants were presented with a list of illnesses and disabilities and asked to tick all that applied to them. The most common were as follows: difficulty remembering/concentrating (23.6%); 'other' (18.3%); a learning difficulty (9.3%); difficulty with pain and/or breathing (9.3%); and difficulty with basic physical acts (7.4%).



Participants were also asked a number of questions about their engagement with MHSs. Table 2.2 outlines participant responses to these questions.

Table 2.2: Mental health related information.

Have you had contact with the following services in the last two years? (tick all that apply)	%	n
Psychiatrist	82.2%	977
CMHSs	73.5%	873
Inpatient MHSs ⁴⁹	30.1%	357
Do you use or have access to private mental health care?	%	n
Yes ⁵⁰	44.4%	489
No	55.6%	613
How long have you been in contact with HSE MHSs?	%	n
Less than one year	10.6%	117
One to five years	30.6%	338
Six to 10 years	15.1%	167
More than 10 years	31.1%	344
'No longer in contact with HSE MHSs'	10.0%	111
Don't know/can't remember	2.5%	28
Please select the closest to your main diagnosis:	%	n
Depression	31.2%	350
Anxiety Disorder	15.9%	178
Bi-polar disorder	12.8%	144
Schizophrenia (including schizoaffective disorder)	11.1%	124
Personality Disorder	10.5%	118
'Have not been given a diagnosis'	5.8%	65
Other ⁵¹	4.4%	49
Post-Traumatic Stress Disorder (PTSD)	4.2%	47
Eating Disorder	2.5%	28
'Prefer not to answer'	1.7%	19

49 Of these, 75.0% identified their own experience only as voluntary experience, 12.6% identified their experience as only involuntary experience and 12.4% reported they had both voluntary and involuntary inpatient experience.

50 Participants were asked to indicate if they had access to any of the following: private psychiatrist (16.7%); private therapist/counsellor (33.2%); private CMHSs (10.4%); and/or private inpatient MHSs (10.0%). Participants were said to have access to private mental health care of some kind if they indicated access to any of these private services. The proportion with some form of access to private mental health care was high (44.4%); however, approximately one third of all participants indicated that had access to 'a private therapist/counsellor', which may have contributed considerably to the proportion categorised as having access to some form of private mental health care.

51 'Other' represents any participant who selected 'other' as the option under the diagnosis question.



What is your Community Health Organisation catchment area?	%	n
CHO Area 1 (Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan):	4.6%	54
CHO Area 2 (Galway, Roscommon, Mayo):	10.0%	117
CHO Area 3 (Clare, Limerick, North Tipperary/East Limerick):	8.1%	95
CHO Area 4 (Kerry, North Cork, North Lee, South Lee, West Cork):	15.2%	178
CHO Area 5 (South Tipperary, Carlow/Kilkenny, Waterford, Wexford):	9.3%	109
CHO Area 6 (Wicklow, Dun Laoghaire, Dublin South East):	7.4%	87
CHO Area 7 (Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West):	19.3%	226
CHO Area 8 (Laois/Offaly, Longford/Westmeath, Louth/Meath):	9.1%	107
CHO Area 9 (Dublin North, Dublin North Central, Dublin North West):	16.8%	197

*Note that the column listing the number of participants in each category does not sum to 1,188, the total number of participants who took part. Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.

2.4: Data Collection

Data collection took place over approximately a six-month period between November 2017 and April 2018. The primary method for data collection was through SurveyMonkey, an online survey tool; however, paper versions of the survey were available to any participant on request.

A large majority of participants completed the survey online. Research has found that online surveys have several advantages over traditional survey methods,^{52,53,54}

including that online surveys can reach more potential participants quickly, they can reduce bias and measurement error⁵⁵ as a result of questions relating to stigmatised topics (like mental health) and they can enhance participation of stigmatised populations.

Research has also found that the quality of the data gathered via online surveys is at least as good as traditional survey methods.^{56,57} Online data collection was therefore considered an appropriate and potentially effective method of data collection in this context.

- 52 McCabe, S. E. (2004). Comparison of web and mail surveys in collecting illicit drug use data: A randomized experiment. *Journal of Drug Education*, 34(1), 61-73. doi:10.2190/4HEY-VWXL-DVR3-HAKV
- 53 McCabe, S. E., Boyd, C. J., Couper, M. P., Crawford, S. D., & D'Arcy, H. (2002). Mode effects for collecting alcohol and other drug use data: Web and U.S. mail. *Journal of Studies on Alcohol*, 63, 755-762. doi:10.15288/jsa.2002.63.755
- 54 Rhodes, S. D., Bowie, D. A., & Hergenrather, K. C. (2003). Collecting behavioural data using the World-Wide Web: Considerations for researchers. *Journal of Epidemiology and Community Health*, 57, 68-73.

- 55 The difference between the measured value of a quantity and its true value, see: Dodge, Y. (2003). *The Oxford Dictionary of statistical terms*. Oxford: Oxford University Press.
- 56 Gosling, S. D., Vazire, S., Srivastava, S., & John, O. P. (2004). Should we trust web-based studies? A comparative analysis of six preconceptions about Internet questionnaires. *American Psychologist*, 59, 93-104. doi: 10.1037/0003-066X.59.2.93
- 57 Whitehead, L. (2011). Methodological issues in Internet-mediated research: a randomized comparison of internet versus mailed questionnaires. *Journal of medical Internet research*, 13(4). doi: 10.2196/jmir.1593



A minority of participants completed paper versions of the surveys. In some cases, this was done with the assistance of a facilitator working for a Mental Health Reform member organisation. Paper versions of the survey were made available to meet the needs of people who were not comfortable using and/or did not have access to computers. Participants who requested a paper version of the survey were provided with a survey pack including a consent form, an information sheet (see appendix A) and a stamped addressed envelope to return their completed survey.

All participants were instructed to read an information sheet about the *My Voice Matters* project. They were then required to indicate that they had read the information sheet and that they consented to take part by ticking a box.

2.5: Data Analysis

Survey data were exported from the SurveyMonkey platform to SPSS, the statistical analysis software (version 25). Data were then cleaned and ineligible participants (e.g. individuals under the age of 18 or those who indicated that they had not accessed MHSs in the last two years) were excluded from the final data set. A descriptive analysis of the data was carried out using SPSS. Valid percentages⁵⁸ are reported throughout this report. However, where missing cases exceed 5% of responses, this is noted. Note that all figures are rounded to the nearest tenth and may not add to exactly 100%.

⁵⁸ Valid percent is the percent when all missing responses are excluded from calculations. For example, if 1000 participants answered a question (missing responses = 188), the missing cases would be excluded from calculations and the 1000 responses would equal 100%.

Only participants with relevant experience were asked particular questions. For example, only participants who indicated they had accessed CMHSs in the last two years were asked questions about their experiences of CMHSs. In these cases, the size of the sample eligible to answer these questions (n) was reported at the beginning of the relevant sections. Similarly, the eligible sample for a question (n) was only reported for the purpose of follow-up questions, when participants who responded in a particular way to one question were asked a follow-up question. For example, the number of participants who reported that they had the contact details of a key worker was reported because these participants were then asked a follow-up question, do you feel well supported by your key worker?

In an effort to examine predictors that were associated with service users' overall experience of HSE MHSs, an ordinal logistical regression was carried out. Potential predictors were identified based on the following:

- ✳ a review of past research
- ✳ previous consultations with service users, carers and supporters
- ✳ a preliminary analysis of the data gathered from this survey

The potential predictors identified for inclusion in this analysis include: age; gender; having the contact details of a key worker; having a written recovery/care plan; involvement in decisions about medication; continuity of care (how frequently a service user had a change of psychiatrist) and choice of treatment (whether or not a participant had been referred to talking therapy). For more information, see section 3.1.1.





Participants were also asked two open-ended questions as part of the survey. These questions were as follows:

- ✱ Is there any service that was not available to you that you would have benefitted from?
- ✱ What positive experiences have you experienced of HSE MHSs?

Due to the large number of responses, a conventional content analysis⁵⁹ was considered the most appropriate method of analysis. This was carried out in accordance with the guidelines outlined by Erlingsson and Brysiewicz⁶⁰:

- ✱ first, the responses were read and re-read to become familiar with the data and to note initial ideas for codes
- ✱ second, primary codes were formulated⁶¹
- ✱ third, due to the large number of primary codes, these codes were collated into subcategories
- ✱ finally, these subcategories were collated into categories. Note that a response could have been assigned to several categories simultaneously.

59 A content analysis aims to reduce large amounts of text into a systematically organised summary of key results based on the frequency with which particular codes and categories are evident in the data.

60 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.

61 When using this method to analyse interviews, an additional step may be required before primary codes are formulated. One can divide the text into smaller parts referred to as meaning units, see: Erlingsson and Brysiewicz. (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. These meaning units are then collated to develop primary codes. However, the majority of responses to the open-ended questions included in the service user survey were short; therefore, dividing responses into smaller meaning units was deemed unnecessary.

2.5.1: Unavailable Service That Participants Would Have Benefitted From:

Responses to this question were coded independently by two members of the research team. There was an agreement (intercoder reliability) rate of 89.7%. All disagreements were resolved by another member of the research team. Note that not all participants responded to this question and not all responses were codable.⁶² In total, 710 responses to this question were deemed codable (codable response rate: 59.8%).

2.5.2: Positive Experiences of HSE MHSs:

Again, responses were coded independently by two members of the research team. There was an agreement (intercoder reliability) rate of 82.3%. All disagreements were resolved by another member of the research team. In total, 929 responses to this question were deemed codable (codable response rate: 78.2%).

Note that the qualitative and quantitative findings are reported together where the qualitative feedback relates directly to a quantitative question. For example, when asked whether there was any service that was not available to them that they would have benefitted from, talking therapy was frequently reported by participants. These qualitative findings are reported in section 3.7.2 following a survey question specifically about talking therapy.

Many participants responded to the open-ended questions with feedback that was not specific to that question. These responses were coded and categorised along with the question specific responses and are reported in the qualitative feedback sections in chapter three.

62 Responses were deemed not to be codable if a response lacked sufficient information to be accurately coded or was unintelligible in the context of the question asked, e.g. in response to the question relating to beneficial services that were unavailable, responses that could not be coded included 'Bobe', 'don't know', 'ok', or 'R'.



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. For example, the word 'what' was added to clarify the following 'that is [what] was urgently needed'. Similarly, where participants used abbreviations, these abbreviations were clarified, e.g. 'ADHD [attention deficit hyperactivity disorder]'. This was done to increase the accessibility for the reader by avoiding the excessive use [sic.]. All edits or additions to quotes are marked using squared brackets, e.g. [names a place].

2.6: Ethical Considerations

Full ethical approval was granted from the research ethics committee in Waterford University Hospital. Among the key ethical issues considered were the following: ensuring fully informed consent; confidentiality and anonymity of survey participants; and data protection.

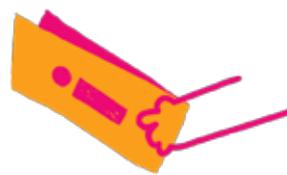
To ensure fully informed consent, detailed information about the project was made available in a variety of ways in the lead up to and during the recruitment process. As part of the recruitment campaign, posters, leaflets and information sheets were made available to individuals and organisations to ensure that potential participants had all relevant material (see appendix A). Importantly, before filling in the survey, all participants were required to read information about the project and indicate the following by ticking a box:

- ✳ that they understood the purpose of the study
- ✳ that they understood that their responses would be confidential
- ✳ that they understood that no identifiable information would be collected to ensure their anonymity
- ✳ and that they freely consented to take part

Steps like these ensured that potential participants were able to access detailed information about the project and its benefits before they gave consent and took part.

Confidentiality and anonymity were central to the approach taken by this project. No identifiable information was collected as part of the survey. For example, as noted above, rather than requiring a signature to indicate consent, participants were simply required to tick a box. Also, when cleaning the data, steps were taken to ensure that any data that were potentially identifiable was anonymised.

Finally, a number of steps were taken to ensure that the data were securely stored and only accessible to Mental Health Reform's research team working on the project. As noted above, survey responses were gathered using an online survey platform. These data were only accessible via a password protected account. When these data were exported to SPSS for detailed analysis, they were stored in a password protected folder to which only the Mental Health Reform research team had access. All completed paper versions of the surveys were stored in a locked cabinet in a locked office until entered into SPSS, after which they were destroyed.



..detailed information about the project was made available in a variety of ways in the lead up to and during the recruitment process..

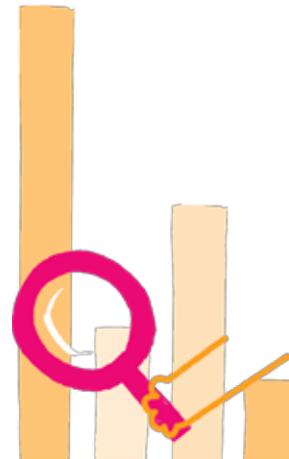
SERVICE USER SURVEY FINDINGS





3. SERVICE USER SURVEY FINDINGS

In this chapter, findings from the service user survey are outlined. The chapter is divided into the following sections: overall experience of HSE MHSs; CMHSs; inpatient care; experiences of psychiatrists; crisis care; MHS staff; types of mental health treatment and supports; recovery; the complaints process; GP/primary care; and additional qualitative feedback.



3.1: 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. Some 41.6% indicated that they had a poor experience (scores between 0 and 3), 29.1% indicated that they had neither a good nor poor experience (scores between 4 and 6), while 29.2% indicated that they had a good experience (scores between 7 and 10) of HSE MHSs (see figure 3.1). On average, participants' overall experience was neither good nor poor (M=4.25; SD=3.18).^{63,64}

Figure 3.1: Overall experience of HSE MHSs.



OVERALL EXPERIENCE WITH THE HSE MHSs



63 M stands for the mean or average score of the sample. SD stands for standard deviation, which indicates the amount of variation in participant responses. A low SD indicates that most responses are grouped close to the mean or average, while a high SD indicates that there is more variation in responses. Note that reporting the median and mode for a Likert scale is considered more accurate; however, the M and SD are reported throughout this report as they are more accessible for readers. See appendix D for the medians and modes for each of the Likert scale questions.

64 This M and SD are based on an 11-point rating scale ranging from zero (I had a very poor experience) to ten (I had a very good experience).

When asked about their positive experiences of HSE MHSs, some participants wrote in very general terms about their experiences of the services. A proportion of participants responded in a generally positive manner but did not elaborate (e.g. *“Very positive experiences”*; *“A very high quality of care in general”*). However, a larger proportion of participants, responded in a generally negative manner, despite being asked specifically about their positive experiences of HSE MHSs. These participants reported that they had not had any positive experiences of HSE MHSs (e.g. *“None, the whole experience was horrendous”*; *“Not going back. My experience was awful”*; *“None”*).

..participants reported that they had not had any positive experiences of HSE MHSs..

3.1.1: Predicting Overall Experience of HSE MHSs:

This section outlines the results of an ordinal logistic regression analysis which was carried out to identify factors that help predict service users’ overall experience of the HSE MHSs.

Potential factors were identified based on the following: a review of past research; previous consultations with service users and their carers and supporters; and a preliminary analysis of the data gathered from this survey. The potential predictors included in this analysis were age, gender, having the contact details of a key worker (yes or no), provision of a written recovery/care plan (yes or no), involvement in decisions regarding medication (yes or no), continuity of care (how frequently a service user had a change of psychiatrist categorised as ‘never’, ‘1-2 times’ and ‘3 or more times’) and choice of treatment (whether or not a participant had been referred to talking therapy).

Note that not all participants were required to answer all of the survey questions used in this regression analysis. For example, only participants who reported accessing a psychiatrist in the last two years were asked to indicate how frequently they had a change of psychiatrist in the last two years. Only participants who answered all of the survey questions used in this regression were included in this analysis. This resulted in a sample of 420 participants or 35.4% of the overall sample. A summary of this analysis is presented below. For detailed statistical information, see table one in appendix C.

Age: Age was found to be a significant predictor of participants’ overall experience of the HSE MHSs (see table one, appendix C). Findings indicated that for every one-year increase in age, the odds of reporting a good overall experience of HSE MHSs increased by 1.8%. Although this does not sound like a large increase, for a ten-year increase in age, the odds of reporting a good overall experience of HSE MHSs increases by 18%.⁶⁵

Gender: Female was used as the reference group in this analysis. Findings indicated that gender was not a significant predictor of participants’ overall experience of the HSE MHSs (see table one, appendix C).

Contact details of a Key Worker:

Participants were asked if they had the contact details of a designated mental health professional in their community mental health team (a key worker) to provide them with support. Those with contact details of a key worker were used as the reference group in this analysis.

Participants with contact details of a key worker were found to be significantly more likely to report a good overall experience of the HSE MHSs (see table one, appendix C). Findings indicated that those with contact details of a key worker were 2.3 times more likely than those without contact details of a key worker to report a good overall experience.

Provision of a Recovery/Care Plan:

Participants were asked if they had a written

⁶⁵ Note that the interpretation of the odds ratio is different for age than for the other predictor variable as it is the only continuous variable included in this model.



recovery/care plan developed with their mental health team. Those who reported having a written recovery/care plan were used as the reference group in this analysis.

Participants with a written recovery/care plan were significantly more likely to report a good overall experience of HSE MHSs than were those without a written recovery/care plan (see table one, appendix C). Findings showed that those with a recovery/care plan were 2.2 times more likely to report a good overall experience than those without a recovery/care plan.

Involvement in Decisions about

Medication: Participants indicated whether they were involved as much as they would like in decisions about the medication that they take.⁶⁶ Those who indicated that they were involved were used as the reference group in this analysis.

Participants who reported being involved as much as they would like in decisions about the medication they take were significantly more likely to report a good overall experience of HSE MHSs than those who were not involved (see table one appendix C). Findings showed these participants were 2.5 times more likely to report a good overall experience than those who were not involved.

Continuity of Care: Participants who reported accessing a psychiatrist in the last two years were asked how often they had a change of psychiatrist in that time.⁶⁷

Those who had a change of psychiatrist three or more times in the last two years were taken as the reference group.

Participants who reported having had no change of psychiatrist in the last two years were significantly more likely to report a good overall experience of HSE MHSs than were those who had a change of psychiatrist three or more times. Specifically, 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 than were those who had three or more changes of psychiatrists in that time.

However, those who had a change of psychiatrist once or twice in the last two years were not significantly more likely to report a good overall experience of HSE MHSs than were those who had three or more changes of psychiatrist in that time (see table one, appendix C).

Choice of Treatment: Based on their responses to one of the survey questions,⁶⁸ participants were categorised as those who had been referred to a talking therapy by HSE CMHSs and those who had not been referred to a talking therapy by HSE CMHSs. Those who indicated that they had been referred to a talking therapy were taken as the reference group for this analysis. Whether participants had been referred to a talking therapy by HSE CMHSs was not found to be a significant predictor of overall experience of HSE MHSs (see table one, appendix C).

66 Participants were asked whether they had been involved as much as they would have liked in decisions about the medication they take. Participants had the following response options: 'yes, definitely', 'yes, to some extent', 'no but I wanted to be', 'no but I did not want to be' and 'don't know/can't remember'. To create a binary 'yes or no' variable all positive responses were recoded as 'yes' and all negative responses were recoded as 'no'. The 'don't know/can't remember' responses were recoded as missing.

67 Note that the question did not differentiate between voluntary and involuntary change of psychiatrist. The exact question was: 'In the last 2 years, how often have you had a change of psychiatrist?' Most changes are at the behest of the MHSs, e.g. due to staff changes, but a minority may happen by choice of the service user. Participants had the following response options: 'never', 'once', 'twice', '3 to 4 times', 'I used to have a psychiatrist but I don't have one any longer' and 'never

had a psychiatrist'. These were recoded into the following categories: 'never', '1-2 times' and '3 or more times'. The remaining responses were recoded as missing.

68 Participants were asked the following: 'if you were referred to talking therapy by HSE community mental health services, how long was the waiting time before accessing this support?'. Response options included eight different waiting times ranging from 'no waiting time' to '18 months or longer'. Additional response options included 'never referred to talking therapy by mental health services' and 'don't know/can't remember'. To create a binary variable (referred to talking therapy or not referred to talking therapy), all responses that indicated a referral to talking therapy were recoded as 'referred to talking therapy', while the one response option that indicated no referral to talking therapy was recoded as 'not referred to talking therapy'. All 'don't know/can't remember' responses were recoded as missing.



3.2: Community Mental Health Services (CMHSs)

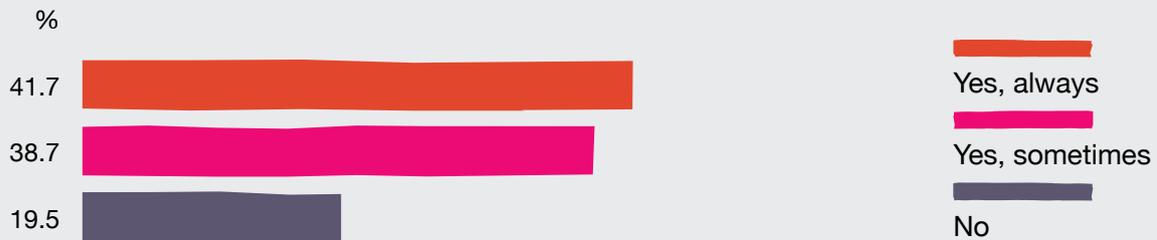
Almost three-quarters of participants (73.5% or n=873) indicated that they had contact with CMHSs in the last two years. These participants were presented with a series of questions relating to CMHSs.

When asked ‘overall in the last two years, did you feel that you were treated with dignity and respect by community mental health services?’, 41.7% felt that they were ‘always’ treated with dignity and respect, 38.7% felt that they were ‘sometimes’ treated with dignity and respect and 19.5% did not feel that they were treated with dignity and respect (see figure 3.2).⁶⁹

Figure 3.2: Extent to which participants felt that they were treated with dignity and respect by their CMHSs.



OVERALL IN THE LAST TWO YEARS, DID YOU FEEL YOU WERE TREATED WITH DIGNITY AND RESPECT BY YOUR CMHSs?



Related Qualitative Feedback:

The importance of being treated with dignity and respect was reflected in the qualitative data. When asked about their positive experiences of the HSE MHSs, many participants described feeling listened to, supported and being treated with dignity and respect by HSE MHS staff and the positive impact this had on their recovery.

“As an inpatient in [names the service] 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”

“I was treated with dignity and listened to by one psychologist I saw. This interaction made all the difference to me in my recovery”

Some wrote positively about what they perceived as a person centred approach, in which service users received non-judgemental support and felt respected, while others described how they felt listened to and understood.

“Always empathetic and not judgemental”

However, it is important to note that these experiences of being treated with dignity and respect were not universal, as indicated by the 58.2% of participants who felt that they were, at best, sometimes treated with dignity and respect by their CMHSs (see figure 3.2 for more detail).



3.2.1: Key workers:

Almost half of participants (47.7%) reported that they had the contact details of a designated mental health professional (a key worker) in their CMHT to provide them with support. Over half (51.1%) reported that they did not and 1.3% reported that they were in the process of getting the contact details of a key worker (see figure 3.3).⁷⁰ Of those who reported having contact details for a key worker (n=377), six in every ten (59.2%) reported that they ‘definitely’ felt well supported by their key worker, one in four (24.7%) reported that they felt well supported ‘to some extent’, while one in six (16.2%) reported that they did not feel well supported by their key worker (see figure 3.3).

Figure 3.3: Contact details for, and feeling well supported by, a key worker.



In response to a related question, one in five (20.8%) reported that they had someone in the CMHSs who they could contact out of office hours in case of a crisis. Two-thirds (65.4%) reported that they did not have someone they could contact out of office hours in case of a crisis, while one in seven (13.8%) were unsure (see figure 3.4).⁷¹ Those who reported that they have someone in the CMHSs that they can contact out of hours in case of a crisis (n=165) were asked to indicate the extent to which they agreed with the following statement: ‘In the last 12 months if I needed support during a crisis, I got the help I needed from my CMHT’. More than four in five (82.1%) agreed⁷² that they got the help they needed, while 6.4% disagreed⁷³ (see figure 3.4). On average, these participants agreed that they got the help they needed from the CMHT during a crisis (M=4.27; SD=0.94).⁷⁴

70 Although only valid percentages are reported here, note that this item had a high proportion of missing values (9.4%).

71 Although only valid percentages are reported here, note that this item had a high proportion of missing values (8.9%).

72 This is a composite of all ‘agree’ (29.9%) and ‘strongly agree’ (52.2%) responses.

73 This is a composite of all ‘disagree’ (5.1%) and ‘strongly disagree’ (1.3%) responses.

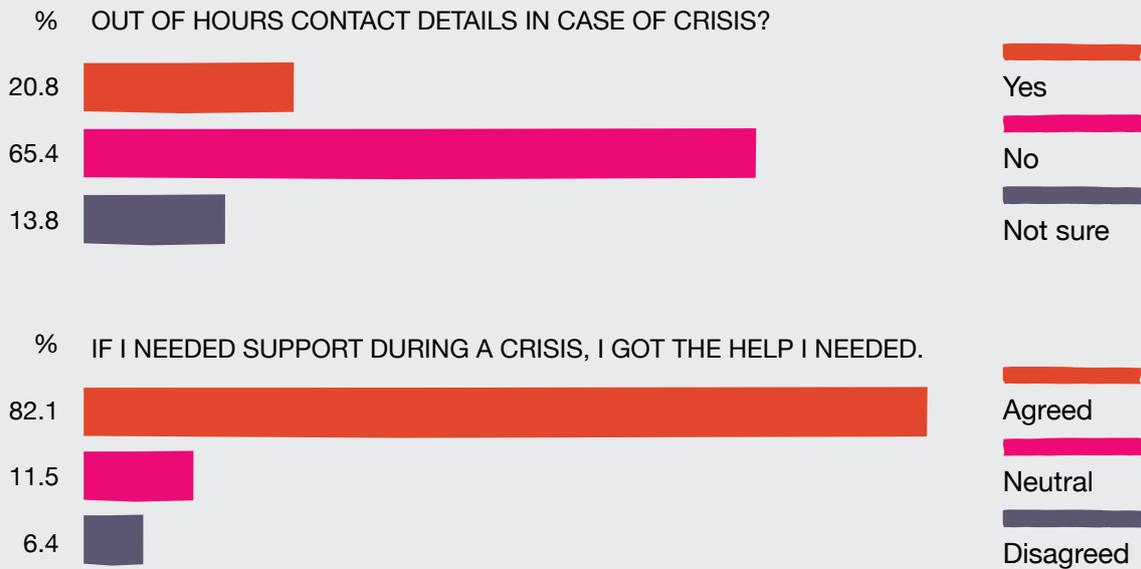
74 This M and SD are based on a five-point rating scale ranging from one (strongly disagree) to five (strongly agree).



Figure 3.4: Contact details of, and help received from, a CMHS member during a crisis.



DO YOU HAVE SOMEONE IN THE CMHSs WHO YOU CAN CONTACT OUT OF OFFICE HOURS IF YOU HAVE A CRISIS AND, IF SO, DID YOU GET THE HELP YOU NEEDED FROM YOUR CMHSs DURING A CRISIS?



Related Qualitative Feedback:

These findings relating to key workers were also reflected in the qualitative data. When asked whether there were any services that were not available to them that they would have benefitted from, many participants expressed a desire for an accessible key worker, with some describing the potential benefits of having a key worker.

“Being given a key worker to assess my needs. This would allow me to make informed choices about my recovery. I think this would have enabled me to progress through the service more quickly with the obvious cost savings for the HSE”



“A key worker who I could contact in times of crisis, especially as it is extremely difficult to get a hospital bed when in crisis”



3.3: Inpatient Care

Almost one-third of participants (30.1%; n=357) reported that they had inpatient experience in the last two years. Of these, 75.0% identified their own experience only as voluntary experience, 12.6% identified as having had only involuntary experience and 12.4% had both voluntary and involuntary inpatient experience.

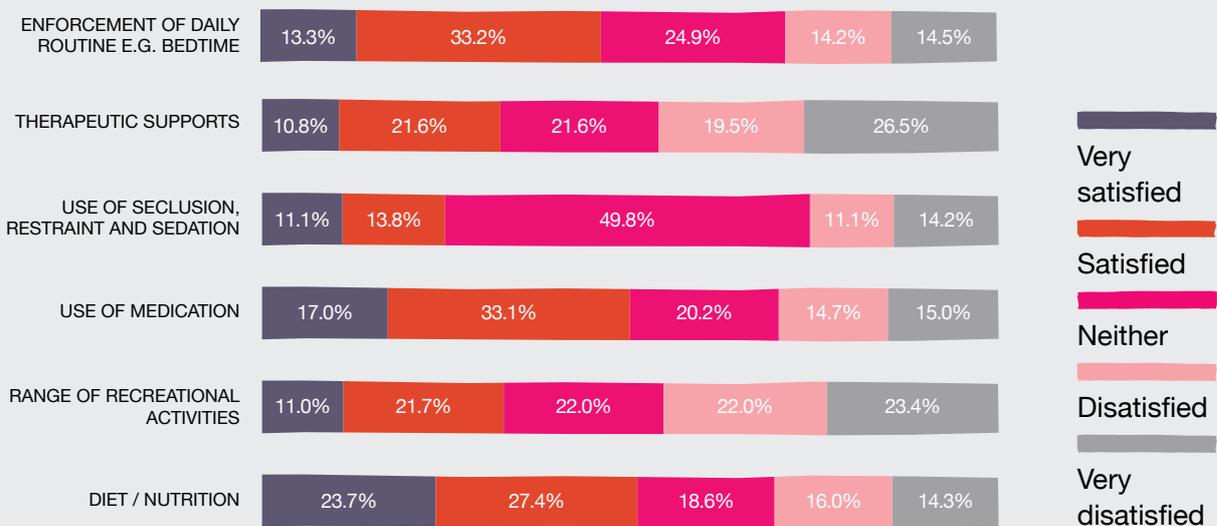
On a scale ranging from one (never) to four (always), these participants were asked to indicate how often they felt they were treated with dignity and respect by the MHSs during their inpatient experience. Approximately one in four participants (27.9%) reported that they 'always' felt treated with dignity and respect by the MHSs during their inpatient experience; one-third (32.8%) reported that they 'mostly' felt treated with dignity and respect; three in every 10 (30.5%) reported that they felt treated with dignity and respect 'some of the time'; and less than one in 10 (8.8%) reported they were never treated with dignity and respect by MHSs during their inpatient experience.

Participants with inpatient experience in the last two years were also asked to indicate the extent to which they were satisfied with a variety of aspects of their inpatient experience. Figure 3.5 summarises participant responses to these questions. Participants were most satisfied with the following aspects of their inpatient experience: diet/nutrition (51.1% satisfied), the use of medication (50.1% satisfied) and enforcement of daily routines (46.5% satisfied). Participants were most dissatisfied with the therapeutic supports (46.0% dissatisfied) and the range of recreational activities (45.4% dissatisfied). There were approximately equal proportions of participants who were satisfied (24.9%) and dissatisfied (25.3%) with the use of seclusion, restraint and sedation during their inpatient experience. This question also had the highest proportion of missing responses (9.0%) and a large proportion of neutral responses, likely because not all participants would have experienced seclusion, restraint and/or sedation during their time as an inpatient.

Figure 3.5: Satisfaction with aspects of inpatient care.



HOW SATISFIED WERE YOU WITH THE FOLLOWING ASPECTS OF YOUR INPATIENT EXPERIENCE?



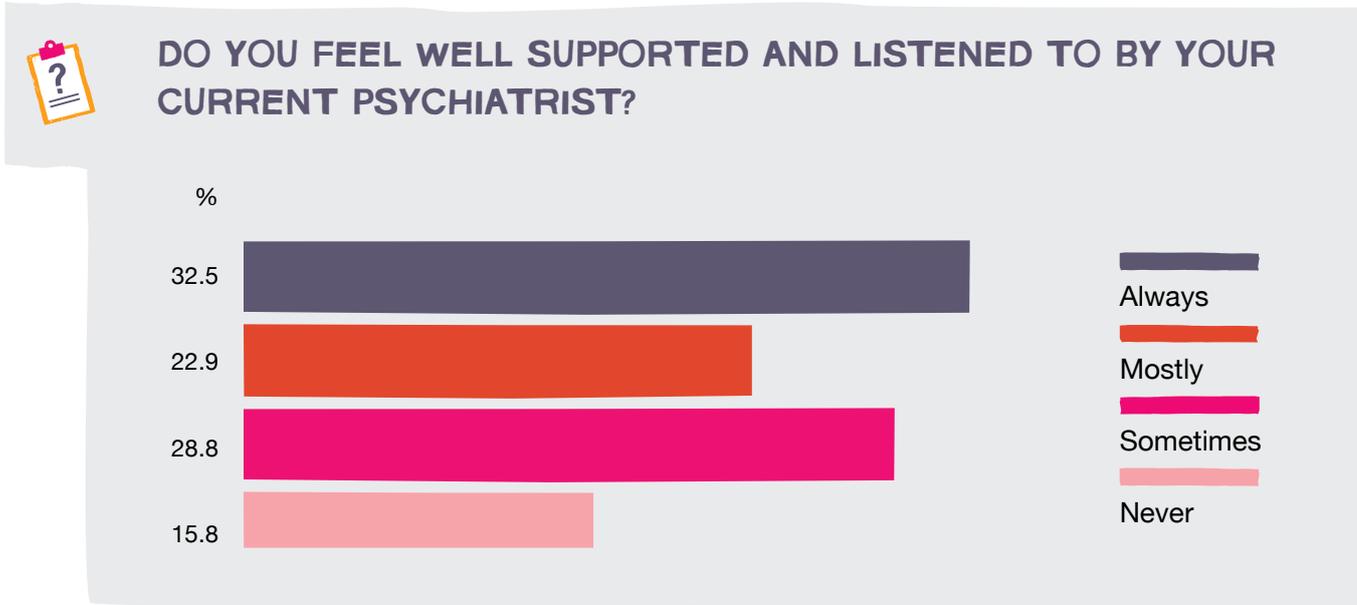


3.4: Experiences of Psychiatrists

As the clinical lead responsible for service user treatment, psychiatrists play a powerful role in making decisions about the person's care and treatment regime. Most, if not all, service users will see a psychiatrist upon accessing the MHSs. For this reason, the survey included several questions relating directly to participants' recent experiences of psychiatrists. More than four in every five participants (82.2% or n=977) indicated that they had had contact with a psychiatrist within the last two years.

These participants were asked whether they felt well supported and listened to by their current psychiatrist.⁷⁵ One-third (32.5%) 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 approximately one in six (15.8%) felt that they were 'never' well supported or listened to by their current psychiatrist (see figure 3.6).

Figure 3.6: Feeling well supported and listened to by current psychiatrist.



Participants were also asked to indicate how often they had experienced a change of psychiatrist in the last two years.⁷⁶ Approximately one-third (34.8%) reported never having had a change of psychiatrist in the last two years, while over half (55.9%) reported having had a change of psychiatrist at least once in the last two years. A considerable minority of one in six (16.1%) reported having had a change of psychiatrist 'more than four times' in the last two years. In response to the same question, 9.3% reported that they 'no longer have a psychiatrist'.

⁷⁵ The responses of participants who reported 'no longer having' and 'never having had' a psychiatrist were excluded. Therefore, only the responses of participants who indicated that they currently have a psychiatrist (n=875) are reported for this question.

⁷⁶ Note that the question did not differentiate between voluntary and involuntary change of psychiatrist. The exact question was: 'In the last 2 years, how often have you had a change of psychiatrist?' Most changes are at the behest of the MHSs, e.g. due to staff changes, but a minority may happen by choice of the service user.

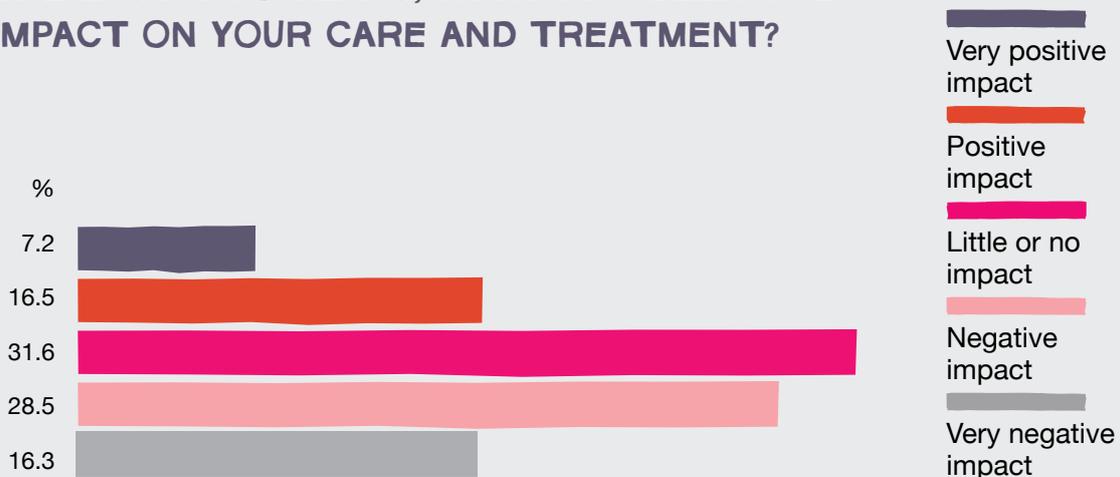


Participants who reported that they had a change of psychiatrist at least once in the last two years were asked to indicate the impact of this change on their care and treatment.⁷⁷ The reported impact on participants' care and treatment varied. Almost double the proportion of participants reported that having a change of their psychiatrist had a negative impact on their care and treatment (44.8%) than reported that such a change had a positive impact (23.7%). Some 31.6% of participants reported that having a change of psychiatrist had little or no impact on their care or treatment (see figure 3.7).

Figure 3.7: The impact of having a change of psychiatrist on treatment and care.



IF YOU HAD A CHANGE OF PSYCHIATRIST IN THE LAST TWO YEARS, WHAT HAS BEEN THE IMPACT ON YOUR CARE AND TREATMENT?



There was a significant negative correlation between the frequency with which participants had a change of psychiatrist and the impact of this change, indicating that the more frequently participants had a change of psychiatrist, the more negative the perceived impact of these changes on their treatment and care.⁷⁸

3.5: Crisis Care

As noted, those who reported having someone in the CMHSs who they could contact out of office hours in case of a crisis (20.8%; n=165) were asked whether they got the support they needed from CMHSs during a crisis. On average, these participants agreed that they got the help they needed from the CMHT during a crisis (M=4.27; SD=0.94).⁷⁹ Approximately four in every five agreed⁸⁰ (82.1%) that they got the help they needed, 6.4% disagreed⁸¹ and 11.5% neither agreed nor disagreed.

⁷⁷ Those who reported that they 'never' had a change of psychiatrist or that they 'never had a psychiatrist' were excluded, resulting in n=629.

⁷⁸ $Sr\text{ho} = -.36$, $p < .001$; Mean impact of change on treatment and care decreased as frequency of change increased. Those who had a change of psychiatrist once in the last two years had a mean impact score of 3.29 (SD=1.04), those who had a change twice had a mean impact score of 2.84 (SD=1.15), those who had a change three to four times had a mean impact score of 2.64 (SD=1.13) and those who had a change of psychiatrist more than four times in the last two years had a mean impact score of 2.20 (SD=1.05). Lower scores are indicative of a more negative impact on treatment and care. Note that correlation does not necessarily imply causation.

⁷⁹ This M and SD are based on a five-point rating scale ranging from one (strongly disagree) to five (strongly agree).

⁸⁰ This is a composite of all 'agree' (29.9%) and 'strongly agree' (52.2%) responses.

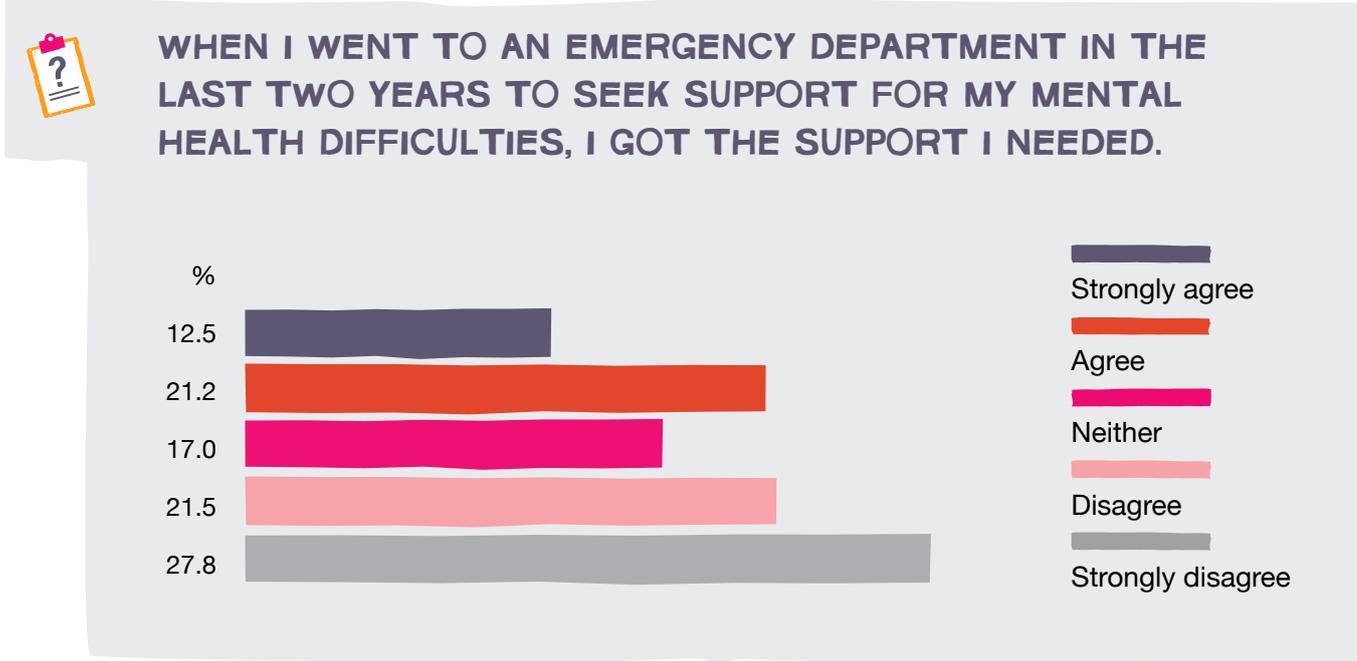
⁸¹ This is a composite of all 'disagree' (5.1%) and 'strongly disagree' (1.3%) responses.



Three in every 10 participants (30.2%; n=357) reported having presented at an emergency department (ED) to seek support for their mental health difficulty in the last two years. Of those, one-third (33.7%) agreed that they got the support they needed, while half (49.3%) disagreed (see figure 3.8). On average, these participants neither agreed nor disagreed that they got the support they needed (M=2.69; SD=1.40).⁸²

ED waiting times to see a mental health professional varied as follows: 0-2hrs: 13.3%; 2-4hrs: 17.0%; 4-6hrs: 12.7% (0-6hrs: 43.0%); 6-12hrs: 33.1%; 12-18hrs: 10.7%; and >18hrs: 6.5%. An additional 6.5% reported that they never saw a mental health professional when they attended the ED.

Figure 3.8: Support when attending an ED for mental health specific care.



Related Qualitative Feedback:

Views and experiences of crisis care were also prominent in the qualitative feedback. When asked whether there were any services that were unavailable to them that they believe would have been beneficial, the need for more and/or better crisis MHSs was frequently reported. Many participants expressed a desire for specialist 24/7 crisis services to eliminate the need to present at busy EDs in distress, and/or a service or professional that could be contacted at any time in case of, or leading up to, a crisis.

“If there was a middle ground service that I could attend when I am in crisis. I have never felt “unwell” enough to go to A&E [accident and emergency] but have had strong thoughts of harming myself, but the thoughts of going to A&E for help was daunting”

82 This M and SD are based on a five-point rating scale ranging from one (strongly disagree) to five (strongly agree).

Related Qualitative Feedback:

“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 as first resort. Doesn’t help the patients”

crisis or while recovering is people around you whom are meant to be there to help, treat you like a piece of crap on the world, like its my fault so why should they do anything. It’s hard enough to ask for help”

“Yes, when I attended the emergency department when suicidal I had to wait in the waiting room with everyone else when I was not in the correct frame of mind for 10+ hours ... it is not an appropriate setting for someone in crisis and makes you worse. You wouldn’t send a person with a broken arm to a psychiatric unit and tell them to wait 10+ hours for a general physician to see them so why do it to someone with mental health issues”

Some participants described the support they received during a crisis as ‘good’, ‘appropriate’ and/or ‘timely’. Others wrote positively about the quality of care they received while in crisis and the work of the home care/treatment teams specifically.⁸³

“Quick admission to hospital following my crisis and initial diagnosis. Very good inpatient care with fantastic key worker. Helpful and sympathetic staff”

“I had to use the home crisis team at one stage. The intense home visits and personal attention and care were absolutely superb”

When asked about their positive experiences of HSE MHSs, participants shared positive experiences of crisis care. In contrast to the above, some described positive experiences of attending an ED during a crisis.

“Once when I was taking to A&E following an overdose, I had two nurses (just A&E staff) and the care I received was amazing. All they did was take a second to speak to me like a human being!!! Mental health still has a lot of stigma around it so the last thing you need while experiencing a

“As I said before home treatment team and early psychosis team were excellent in [names county] I really liked the home treatment team”

Participants also shared positive experiences of HSE mental health outreach services. Specifically, many spoke highly of the community mental health staff who carried out home visits.

⁸³ These are rapid response teams geared towards helping individuals in crisis to avoid admission into inpatient hospitals by supporting them in their homes.

“CPN [community psychiatric nurse] is excellent”

“Fab community nurses who are passionate but overworked”

“The community liason and social workers were all very helpful”

“I have used the Eating Disorder program in [names county], the professionalism and kindness shown to me by the staff in the program was excellent”

Positive experiences of HSE MHS staff were by far the most common type of positive experience shared by participants.

Despite being asked about their positive experiences of HSE MHSs, other participants spontaneously raised negative issues they had experienced with MHS staff. Some described what they perceived as poor communication between staff and service users, while others complained about what they perceived as a lack of time for service users among staff.

3.6: MHS Staff

When asked what kind of positive experiences they had of HSE MHSs, many participants shared their positive views and experiences of MHS staff at every level of the MHSs and across the disciplines. For example, 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.

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

Some participants also expressed that HSE MHS staff need to be better trained, particularly in relation to specific mental health difficulties.

“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”

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

“A psychiatrist listened and gave me time”

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

Related Qualitative Feedback:

Others shared experiences of feeling 'ignored', 'dismissed' or being treated in a 'disrespectful' manner.

"I've seen more than twenty psychiatrists in the last four years, countless therapists, a few psych nurses and psychologists, and generally speaking they have had a profoundly negative impact on my mental health through their incompetence, unwillingness to listen, patronising tendencies, or sheer ignorance of how to talk to someone having mental health problems ... almost every other encounter with the HSE MH [mental health] sector has left me feeling despair, confusion, distress, shame, or embarrassment"

"The disrespectful attitude of staff (being asked to leave mid-session and wait in corridor so someone else could have the room)"



..some participants also expressed that HSE MHS staff need to be better trained, particularly in relation to specific mental health difficulties..



3.7: Types of Mental Health Treatment and Supports

Participants were presented with a series of questions relating to their mental health treatment and the supports that were available to them. These included questions relating to the use of medication during their care and treatment, the availability of talking therapies, and the supports that CMHSs provided directly or referred them to. This section concludes with a summary of participant responses to the following open-ended question: ‘is there a service that was not available to you that you would have benefitted from?’

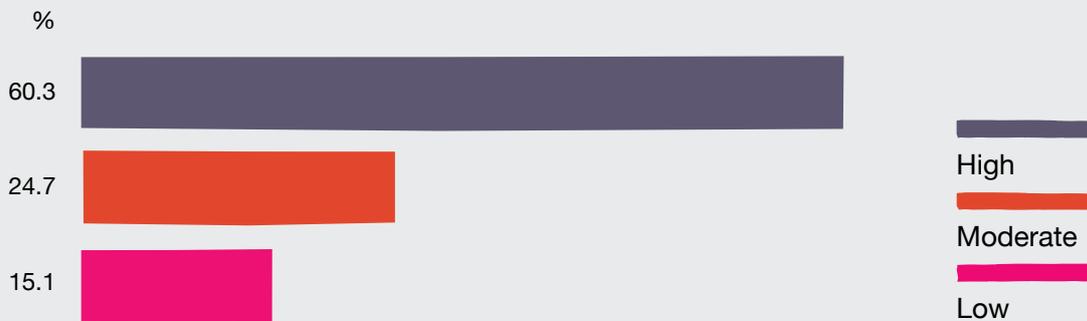
3.7.1: Medication:

All participants were asked to indicate the extent to which medication had been the main focus of their care and treatment plan on a scale ranging from 0 (no focus on medication) to 10 (totally focused on medication; see figure 3.9). More than half of all participants surveyed (60.3%) reported a high focus on medication (scores ≥ 7), with approximately one in five (19.0%) indicating that their treatment was totally focused on medication. One in four (24.7%) reported a moderate focus on medication (scores between 4 and 6), while approximately one in seven (15.1%) reported a low focus on medication (scores between 0 and 3).⁸⁴ On average, participants reported that the extent to which medication was the main focus of their care and treatment plan was high (M=6.60; SD=3.00).⁸⁵

Figure 3.9: Focus on medication.



PLEASE INDICATE THE EXTENT TO WHICH MEDICATION HAS BEEN THE MAIN FOCUS OF YOUR TREATMENT AND CARE.



Participants were asked whether they were involved as much as they would like in decisions about the medicines they take. One in four participants (24.6%) answered ‘definitely’, one-third (33.5%) answered ‘to some extent’ and approximately four in every 10 (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 (n=452), four in five (80.3%) indicated that they would like to be more involved in these decisions, while one in five (19.7%) reported that they did not want to be more involved.

⁸⁴ Although only valid percentages are reported here, note that this item had a high proportion of missing values (7.4%).

⁸⁵ This M and SD are based on an 11-point rating scale ranging from zero (no focus on medication) to ten (total focus on medication).



3.7.2: Talking Therapy:

Of those who reported accessing CMHSs in the last two years, almost one-third (31.4%) reported never having been referred to talking therapy by HSE CMHSs. Six in every ten (59.2%) indicated that they had been referred to talking therapy by HSE CMHSs (DK/can't remember: 9.5%).⁸⁶

There was considerable variation in waiting times to access talking therapy. Of those who were referred to talking therapy (n=442), less than one-third (31.2%) reported waiting less than a month before accessing this support, less than one-quarter (23.7%) reported waiting between one and three months and over one-quarter (27.5%) reported waiting between three and 12 months. Approximately one in six (17.6%) reported waiting more than a year to access talking therapy.

Related Qualitative Feedback:

When asked whether there were any services that were unavailable to them that they believe would have been beneficial to them, one of the most common services requested by participants was talking therapy.

“Regular talking therapy”

“Talk therapy while an inpatient would have been very beneficial. I was given a diagnosis and medication and sent on my way. If it wasn't for my private therapist, I was left feeling hopeless ...”

Participants expressed difficulties accessing specific types of talking therapy which would have been beneficial. Common examples included cognitive behavioural therapy (CBT), dialectical behavioural therapy (DBT) and schema therapy. Participants also expressed frustration with waiting times for talking therapy and the effect this had on their mental health.

“Yes DBT its was recommended and then just impossible to get. It's supposed to be my best chance of escaping my cycle of attempts”

“There are huge waiting lists in my area. Such as psychologist, Cognitive Behavioural Therapy appointments They always recommend seeing private therapists, not sure if the service is available within the HSE.”

“DBT therapy has only become available recently and I feel that when I first entered the service I could have availed from even a CBT referral and it has been 7 years since my first contact before I have gotten the help I need ... I do feel the course of time waiting made a lot of things worse in my life. I believe this is due to how busy the service is and was rather than lack of caring on the teams part”

⁸⁶ Although only valid percentages are reported here, note that this item had a high proportion of missing values (14.2%).

Related Qualitative Feedback:

Another issue raised by participants was the amount of talking therapy on offer, with some expressing their belief that current levels of availability are insufficient. These participants recommended that talking therapy should be extended or time-unlimited, as this would allow them and their mental health team to better manage their difficulties on an ongoing basis.

“Continual talking therapy”

“More counselling - not just a set number of weeks but until I felt ready to move on”

“I was thrown from support to support growing up as everything had a time limit. People going through mental health issues, especially young people, need stability and security. I hated having to share my life story and open up years of pain again to someone new. I hated learning to trust someone and having them tell me after 8 weeks or a few months that they were no longer going to help me”

Several participants expressed dissatisfaction with the talking therapy they had received. These participants highlighted their need for ‘proper’ talking therapy, therapy with a professional with experience of counselling individuals with the same or a similar difficulty to their own, and/or therapy where they felt ‘listened to’.

“Proper counselling ... Being listened to properly and actually heard and not being treated like a half-wit”

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

Views like these were not universal. When asked about their positive experiences of the HSE MHSs, some participants spoke positively about the therapies and facilities they availed of. Some participants wrote about their experience of accessing specific types of therapies and the positive impact this had for them. These therapies included (but were not limited to) different types of talking therapy (e.g. CBT, DBT or schema therapy), support groups, as well as alternative therapies, like music therapy, art therapy, or exercise.

“The year I spent with the psychologist for CBT was invaluable”

“Anxiety management course very useful. Also sessions in relaxation room in day center was good”

“Mindfulness 8 week course. Art therapy. I still use both to date and it is a game changer”

As regards HSE MHS facilities, these participants shared their view that the facilities were, in their experience, of a high standard.

“A nice atmosphere on the ward, Very clean, Healthy food. Beautiful garden to walk in well-equipped art room”





3.7.3: Access to Mental Health Professionals:

Participants who reported using CMHSs in the last two years were presented with a list of different types of mental health professionals and asked to indicate which, if any, they had accessed.⁸⁷ The mental health professional reported as most commonly accessed by participants in HSE CMHSs was a psychiatrist (69.3%). The mental health professional reported as least commonly accessed was a speech and language therapist (1.7%). However, it should be noted that not all participants require the support of all the mental health professionals listed. Some 7.9% reported that they had accessed none of the mental health professionals listed. Table 3.1 summarises participant responses.

Table 3.1: Proportion of participants who received various supports from HSE CMHSs.

Type of Support	Received by (%)
Psychiatrist	69.3
Community psychiatric nurse	40.5
Counsellor or psychotherapist	28.4
Occupational therapist	26.8
Psychologist	25.4
Social worker	23.6
Peer support worker	4.2
Family therapist	3.8
An advocate	2.9
Speech and language therapist	1.7
Other	5.6
None of the above	7.5

Some of these supports may not have been required by all service users. Therefore, these figures should be interpreted with caution.

⁸⁷ This was a 'tick all that apply' question, therefore the proportions listed in table 3.1 do not sum to 100%.

Related Qualitative Feedback:

In response to the open-ended questions, many participants took the opportunity to share their views and experiences of the HSE MHSs more broadly, even when not specific to the questions asked. Instead, without prompt, many chose to raise what they perceived as important issues relating to the provision of MHSs in Ireland. Chief among the issues spontaneously raised by participants in response to both open-ended questions was waiting times and the resulting delays accessing the treatment and supports they require. Participant responses included (but were not limited to) delays accessing specific therapies and the services of specific types of mental health professionals, many of which are listed in table 3.1 above.

“I have been on a waiting list for over 5 YEARS for courses on how to deal with panic attacks and anxiety. I have never received an update to say where I am on the list even”

“Long term psychologist service and not having to start from scratch again with a 4 year waiting list. I could well be dead by then”

“I was waiting 18 months for cbt with clinical psychologist. This would have benefited hugely at an earlier stage. Occupational therapy too would be greatly beneficial as earlier intervention”

“I waited for 2 and a half years to see social worker”

“Therapy keeps being promised but nearly two years later nothing’s materialised yet”

The self-reported waiting times experienced by some participants ranged from several months to several years.

“As I had to wait 2 months to access the service at all, it was all rather pointless in the end. Shame on you”

“Psychologist as the waiting list was up to 8 months”

“There didn’t seem to be anything available WHEN I needed it. I’ve just gotten a letter asking if I still wanted to BE ON THE WAITING LIST for psychiatric care. I was put on the list TWO YEARS ago”

“Psychology, still waiting 5+ years”

Some went on to describe how having to wait long periods of time to receive the care they required had a detrimental effect on their mental health. Others wrote of how they were ‘encouraged’, ‘pushed’, and/or ‘forced’ to pay for private MHSs, often at considerable personal expense. For those who could afford this option, it often resulted in financial strain, while those who could not afford this were required to continue waiting or rely on the support of a carer and/or supporter.

Related Qualitative Feedback:

“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”

“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”

“I was extremely depressed, self-harming and suicidal in December and received an appointment to see a psychiatrist at [names place] 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! I am aware others may not have family and friend support and I am grateful I had as that is what kept me alive”

Participants also expressed frustration at what they perceived as a shortage of key staff, resulting in long delays and/or difficulties accessing the services particular staff provide.

“Local mental health team didn’t have a psychologist on staff for over 2 years and when one was finally hired I was told without a doubt that I would never receive a referral despite there being near universal agreement (from private psychiatrist and psychologist) that is [what] was very urgently needed”

“Having had already a diagnosis of acute anxiety and depression, being diagnosed with PTSD opened pandoras box. I was then left on a waiting list for the RCC [rape crisis centre] for 4 months (having been put on a crisis list after assessment), and a minimum of 1 year (approx.) for psychology service - without doubt the worst few months I’ve ever experienced”

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

When specifically asked about their positive experiences of the HSE MHSs, some participants wrote about the lack of significant waiting times and/or the ease with which they had accessed required services and supports. Others wrote positively about particular staff members and how they played an important role in reducing delays.

Related Qualitative Feedback:

“Always there when you ring in need of help in bad times”

“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”

When asked if there were any services that may have been beneficial to them but that were unavailable, many participants expressed a belief that they would have benefitted from the services of specific types of mental health professionals but were unable to access these services, e.g. a psychologist or an occupational therapist.

“Outpatient services are inadequate. I would benefit from OT, [occupational therapist] psychology, community mental health nurse and psychiatrist but these are not available. All I ever got as an outpatient was an appointment with s [a] psychiatrist every couple of months”

“I would have liked to see a psychiatrist and/or psychologist - I was told I was referred to both but never seen either”

As already noted, many participants expressed a desire for an accessible key worker, with some describing the potential benefits of having a key worker (see section 3.2 for more detail).



..many participants expressed a belief that they would have benefitted from the services of specific types of mental health professionals but were unable to access these services, e.g. a psychologist or an occupational therapist..



3.7.4: Mental Health Supports:

Participants were presented with a list of supports and asked to indicate which, if any, HSE CMHSs had linked them with as part of their recovery/care plan in the last two years.⁸⁸ Table 3.2 summarises the responses. The largest proportions of participants reported that they had either not been linked with any supports by HSE CMHSs (33.2%) and/or had found out about these supports themselves (34.5%). Of those who were linked with supports by HSE CMHSs, the most common supports participants reported being linked with were recovery programmes, e.g. Wellness Recovery Action Plan (WRAP; 20.5%). The proportion of participants who reported that they had been linked with any of the remaining listed supports fell below 20%. The least common support participants reported being linked with by HSE CMHSs was online mental health supports (7.4%).

Table 3.2: Proportions of participants linked in with community supports by HSE CMHSs.

Type of Support	Received by (%)
Recovery programmes, e.g. WRAP	20.5
Educational programmes	14.1
Social welfare entitlements	14.0
Voluntary organisations, e.g. GROW, Aware, Suicide or Survive	13.2
Peer support	9.7
Employment support	9.6
Housing support	8.6
Online mental health supports	7.4
'I found out about supports by myself'	34.5
'I was not linked into any community supports by the MHS'	33.2
DK/can't remember	4.7

Some of these supports may not have been required by all service users. Therefore, these figures should be interpreted with caution.

⁸⁸ This was a 'tick all that apply' question, therefore the proportions listed in table 3.2 do not sum to 100%.

Related Qualitative Feedback:

When asked about their positive experiences of the HSE MHSs, many participants chose instead to share their positive experiences of community and voluntary groups that provide MHSs and supports. To be clear, these are non-statutory organisations, as distinct from public HSE MHSs; some of these are included in table 3.3 above, e.g. WRAP, GROW, Aware. The community and voluntary groups most commonly raised included the following: Clubhouse International, a member led community based model for people experiencing mental health difficulties working together towards recovery; Pieta House, a non-profit organisation that provides specialised treatment programmes for those who have suicidal ideation or engage in self-harming behaviour; and the National Learning Network (NLN), who provide training and specialist support for those who, for a variety of reasons including mental health difficulties, find it difficult to gain employment.

“Clubhouse in [names place] has helped my recovery, has offered me more options like education, housing, community supports than medical team”

“Found Pieta House the most helpful service that I accessed ... Overall I think the system is broken and it was the encouragement and empathy provided by Pieta House that encouraged and assisted my situation was a result of a magnitude of life changing events”

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

“Going to [names the service] daily, making new friends, art and craft, going for walks, community activities”

..many participants chose instead to share their positive experiences of community and voluntary groups that provide MHSs and supports..



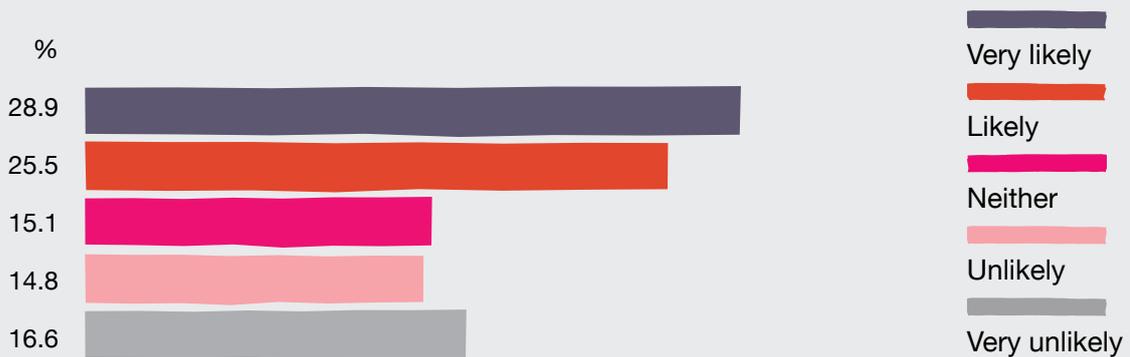


Participants were asked how likely they would be to use online support or apps as part of their therapy if it was available. More than half (54.4%) indicated that they were likely to do so, while less than a third (31.4%) indicated that they were unlikely to do so (see figure 3.10). On average, participants were neither likely nor unlikely to use online support or apps as part of their therapy if it was available ($M=3.36$; $SD=1.40$).⁸⁹

Figure 3.10: Likelihood of using online supports or apps as part of therapy.



HOW LIKELY ARE YOU TO USE ONLINE SUPPORT OR APPS AS A PART OF YOUR THERAPY IF IT WAS AVAILABLE?



3.7.5: Unavailable Service That Participants Would Have Benefitted From:

As noted, participants were asked whether there were any services unavailable to them that they believe would have been of benefit. The most common types of services and supports alluded to by participants in response to this question are outlined below.

Talking therapy services:

As noted, talking therapy was one of the most common services requested by participants (see section 3.7.2 for more detail).

Mental health professional services:

As noted, many participants expressed a belief that they would have benefitted from the services of specific types of mental health professionals but were unable to access these services (see section 3.7.3 for more detail).

Alternative recreational and/or therapeutic services:

Some participants expressed a belief that alternative therapies and activities would be beneficial to them and promote recovery. Participants alluded to specific alternative therapies that they believed would benefit them, the most prominent of which were music therapy and art therapy.

“Art therapy, music therapy, exercise program”

Highlighting the benefits of physical activities for some mental health difficulties, some participants expressed a desire for more physical/outdoor activities to be incorporated into their treatment e.g. yoga or walking, while others wanted meditative and mindfulness services.

“Mindfulness, meditation”



Related Qualitative Feedback:

“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”

“Mindfulness, yoga, exercise therapy”

Difficulty specific services:

Participant responses collated into this category related to an inability to access and/or a need for services specifically targeted towards particular mental health difficulties. For example, some participants highlighted a lack of accessible addiction services, others expressed a belief in the need for more services specifically geared towards supporting adults with autism, while some highlighted what they perceived as a lack of and need for services aimed at treating and supporting those with experiences of trauma.

“Services to support adults with autism”

“Addiction services”

“Post-traumatic stress treatments”

Other examples included (but were not limited to) dual diagnosis services, eating disorder specific services (e.g. dietician services) and obsessive compulsive disorder (OCD) specific services.

Out of hours/Crisis services:

Out of hours services, particularly crisis orientated services, were a common feature of participant responses. Participants’ views and experiences of crisis care are outlined in detail in section 3.5. However, in a related issue, participants also conveyed the need for out of hours services to accommodate those individuals unable to access services due to work commitments.

“Psychology or psychotherapy outside of office hours. I need my job to get by and could not take a half day once a week to attend at the clinic”

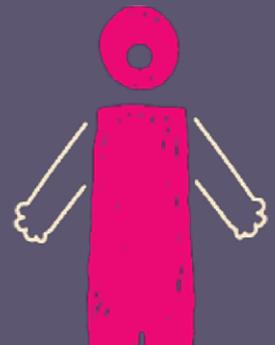
“Because I work full time I haven’t been able to take part in wrap programme or cbt courses”

Peer support services:

These participants believed that more peer supports should be available. Some expressed a need for group therapy sessions, while others believed that simply having the support of others with experience of similar difficulties, whether socially or therapeutically, would be of great benefit to them.

“Group sessions would have been very helpful”

“Community support groups, peer groups, activity groups”



Related Qualitative Feedback:

“Peer support would have really helped me. Really. I found it informally in an involvement centre in Carlow but I think a peer supporter as a key worker could’ve helped me navigate a very disparate and impersonal system”

Social inclusion support services:

Highlighting the need for a holistic approach to mental health, some participants believed they would have benefitted from services geared towards providing them with support in other areas of their life, e.g. housing, employment and welfare.

“Housing help, employment help ... I have received no support so am pursuing this myself information on social welfare, housing”

“Jobs should be available for people who are capable of getting a job. Government needs to draw up a plan that makes it possible to take patients from disability”

“Someone who is fully knowledgeable about Social Welfare / Illness Benefit / Disability application processes, entitlements and payments. Had a lot of trouble being given false information / told they did not know how to help me”

Some stressed the detrimental impact difficulties in these and other areas of life can have on a person’s mental health, while others expressed a desire to lead ‘a normal

life’ and their need for additional supports to achieve this goal. Such supports would serve to promote social inclusion.

“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?”

“To find a home, I survived so much hell by telling myself when I was bigger and stronger I could have my family and bring them home and show the world how much love I have inside sadly lies a battered child tells himself to survive but im an adult now and no [know] the truth the world is horrible and I will never be that good man and never bring my partner and son home thankfully I have a good life insurance plan and that could give them a home”

Information and education services:

These participants expressed a desire for better mental health related information and education services. Some wanted more and/or better information about the services and supports available to them, while others believed that education about mental health in general and their difficulty specifically would have been very beneficial but, in their experience, was lacking.

Related Qualitative Feedback:

“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 in adults”

“Going to talks on mental health issues”

“To be given knowledge about my depression and the type of depression”

“Education on my illness – psychosis”

These participants conveyed their belief that better information and education for service users about mental health and MHSs could allow them to better manage their specific difficulty.

“A service in which you’re educated on how to manage your illness in school and work would have been great ... there’s no ‘let’s learn about BPD [Bipolar Disorder], NPD [Narcissistic Personality Disorder] or SZPD [Schizoid Personality Disorder] classes”

“Courses to give me tools to cope with the disorder”

“Confidence building classes and help understanding my diagnosis ... to help my quality of life and managing it”

In a related point, some conveyed their belief that better education about mental

health for all could help to reduce the stigma associated with experiencing a mental health difficulty and encourage people to talk about and care for their own mental health.

“I would have also benefited from a representative of the HSE coming in and doing some workshops and maybe an information day with my school. A lot of schools across the country have poor knowledge or acceptance of mental health so it would be amazing for an external force to come in and positively influence young people in taking care of their mental wellbeing”

No additional services or supports required: Not all participants who responded to this question believed that there was a service that was not available that would have benefitted them. A number of participants explicitly stated as much, responding to this question simply with ‘no’, ‘none’, or some variation thereof. Some went on to express their satisfaction with the available services.

“There was nothing else that I felt would benefit me”

“No. I was and continue to be very very well looked after. Thanks to my Consultant and councillor I am still alive”

Community-based services and supports: Participants described what they perceived as a lack of local community-based services and the strain this can place on individuals, while some described having to travel long distances to access required services.

“In my local town I would like more support and help and there is none”

“I am a private patient and I don’t have local support from the local team”

“No community care. Received inpatient care in Dublin twice. Attended day patient programmes at the same hospital (including going to Dublin every Monday for a year). See my psychiatrist in Dublin. Saw a psychologist in Dublin (went to Dublin every Tuesday another year). I am not from a rural area, but [names place]”

Other services: Other potentially beneficial services were reported but by fewer participants. For example, some participants described a lack of follow-up services, particularly post discharge from inpatient services, and stated that such services would have been very beneficial for them.

“A follow up 6 monthly check in to touch base with the councillor would help to keep things under control”

“Follow ups. I got medicated while in hospital and tossed out to nothing”

Similarly, some participants expressed a need for post-natal services that do not require the separation of mother and child.

“Inpatient care for me and my baby. I had postnatal depression, anxiety and OCD. My baby was only a few weeks old and I was breastfeeding. My gp and psychiatrist wanted me to be admitted to the hospital for care but I could not keep the baby with me in the hospital. I was too distressed by the idea of

being separated from my baby so I refused admission ... I did not get the care I needed as I could not keep my baby with me in the hospital”

“Maternal mental health facilities that do not require mother to be separated from baby. Women with post-natal depression would be more likely to seek help if it meant that they could be treated in hospital with their baby with them. I’ve known a few mums who have suffered because they had to be admitted to psych ward and baby was kept at home. Others who won’t seek help because they fear being separated from their baby. There are no maternal mental health services properly provided by the hse”

Others expressed a desire for more and/or better youth MHSs, although the fact that this feedback was rare may have been due to the adult sample.

“Services for teenagers. As I was only just over 18 was put into adult services and group therapies consisted of me often being the youngest and finding it hard to fit in. I felt my concerns and worries about school were often nothing compare to the older people’s worries about money and work etc. Would of benefitted from having other people my age about”

“Local mental health services for under 18s”



3.8: Recovery

Approximately one in five participants (22.7%) reported having a written recovery/care plan developed with their mental health team. Two-thirds (66.2%) reported that they had no written recovery/care plan (don't know/can't remember: 11.1%; see figure 3.11). Of those who reported that they did not have a written recovery/care plan (n=774), three-quarters (74.9%) indicated that they would like to have one, while one-quarter (25.1%) reported that they were 'not interested anyway'.

Figure 3.11: Written recovery/care plan.



DO YOU HAVE A WRITTEN RECOVERY/CARE PLAN DEVELOPED WITH YOUR MENTAL HEALTH TEAM?

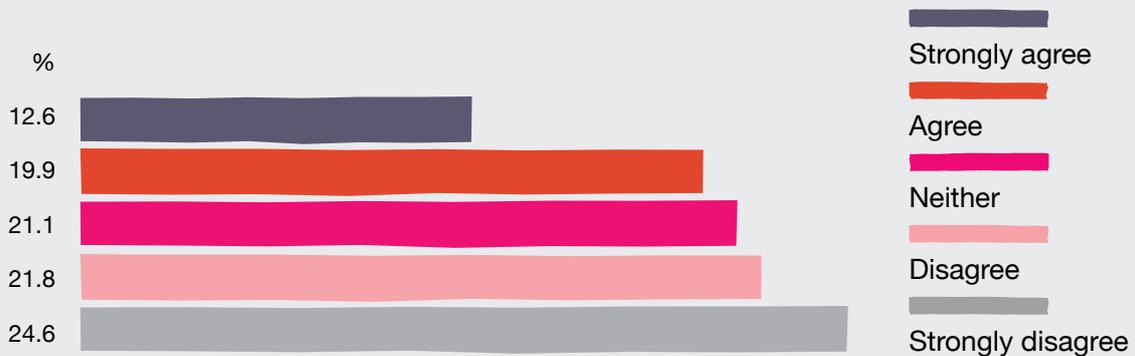


Participants were asked to indicate the extent to which they agreed with the following statement: 'someone on my mental health team frequently talks to me about recovery as part of my treatment'. One-third of participants (32.5%) agreed with this statement, while almost half (46.4%) disagreed (see figure 3.12). On average, participants neither agreed nor disagreed that someone on my mental health team frequently spoke to them about recovery as part of my treatment (M=2.74; SD=1.36).⁹⁰

Figure 3.12: Discussion of recovery as part of treatment.



SOMEONE IN MY MENTAL HEALTH TEAM FREQUENTLY TALKS TO ME ABOUT RECOVERY AS PART OF MY TREATMENT



⁹⁰ The M and SD are based on a five-point rating scale ranging from one (strongly disagree) to five (strongly agree).



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%).

Participants who reported that they had accessed CMHSs in the last two years were asked whether their CMHT took into account how their mental health difficulty affected other aspects of their life. Approximately one-quarter (26.6%) responded ‘yes, definitely’, less than one-third (30.8%) responded ‘yes, to some extent’, while over one-third (35.0%) responded ‘no’ (don’t know/can’t remember: 7.7%).⁹¹

As part of the survey, participants were asked to indicate their ‘main diagnosis’. Of those who responded to the ‘main diagnosis’ question⁹², fewer than one-third (30.0%) reported that their diagnosis had been explained to them in a way that they understood. Four in every 10 (40.6%) reported that their diagnosis had been explained to them in a way they understood ‘to some extent’, while approximately one-quarter (26.2%) reported that their diagnosis had not been explained to them in a way they understood (don’t know/can’t remember: 3.2%).

Related Qualitative Feedback:

When asked about their positive experiences of HSE MHSs, several participants wrote about how MHSs facilitated/supported their recovery and/or the discovery of skills to cope with or better manage their difficulties day-to-day. Some wrote positively of what they perceived as a recovery orientated approach, while others conveyed the importance of information, training and recovery education.

“At my local mental health training center I have benifitted greatly under the newer recovery model of treatment. I have had and continue to recieve enormous help from a life coach and facilitator, to guitar lessons and choir practice and getting involved with the [names area] recovery college”

Information, training and education about how to cope with and manage specific mental health difficulties was highlighted as being key to 1) developing a better understanding of their mental health difficulty and 2) developing coping skills and strategies. For some participants this resulted in ‘a better life’ and improved health outcomes.

“Helped to bring me back from the brink on two separate occasions. Helped me to understand and unload my harmful thoughts & anxiety. Helped me to cope short term”

“I have learned valuable coping tools to manage my daily life”

“Improved functioning in daily life. Attending services helped me gradually cope with being out of my house and around other...”

⁹¹ Although only valid percentages are reported here, note that this item had a high proportion of missing values (10.3%).

⁹² Excluding those who ‘had not been given a diagnosis’ or ‘preferred not to answer’, the figures reported here are based on the responses of 1,033 participants.

Related Qualitative Feedback:

people again. I feel less stigma and blame towards myself for needing help. It has helped me to step out of my comfort zone and gradually make positive changes”

In addition, participants shared experiences of HSE MHSs empowering service users and promoting their involvement in their own treatment and care, a central component of the recovery approach. Some participants alluded to the empowerment they felt simply by having the opportunity to voice their opinions and feeling listened to when they did so. Others expressed the importance of feeling like a joint partner in their own care. Some participants wrote that they were encouraged to get involved in their community, in some cases in peer support roles, which enabled them to support those experiencing similar difficulties.

“The best experience was being referred to the local peer support group for a WRAP programme. I am now on the board of management of the support group and have met lovely people there”

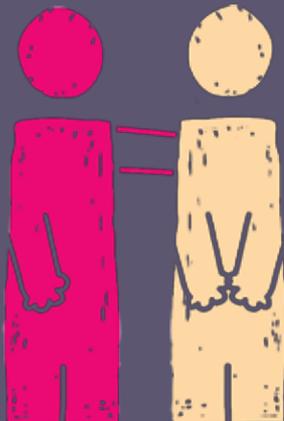
“I had one consultant who made me feel respected, cared for and opinions valued”

“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”

Other types of positive experiences relating to the recovery approach were reported but by fewer participants. For example, some described how the HSE MHSs had been instrumental in enabling them to access social inclusion supports and the positive impact this had for them, e.g. supports relating to housing, employment and welfare. Some participants reported that the MHSs had saved their life.

“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 alluded to the empowerment they felt simply by having the opportunity to voice their opinions..



3.9: The Complaints Process

Participants were asked whether anyone in the HSE MHSs let them know how to make a complaint about the MHSs. Three-quarters of participants (75.7%) reported that no one in the HSE MHSs let them know how to make a complaint about the MHSs, while approximately one in every eight (13.1%) reported that they sought and found the information themselves. Taken together, almost nine in every ten (88.8%) participants reported that no one in HSE MHSs had let them know how to complain about the MHSs. Some 5.9% reported that someone in the MHSs had let them know how to complain about the MHSs ‘more than once’, while 5.2% reported that someone in MHSs had let them know ‘once’.

Participants were presented with a series of statements relating to the complaints process and asked to indicate which of the statements best represented their experience. A third of all participants (34.0%) reported that they had ‘never wanted to complain about the mental health services’. However, more than half (53.0%) reported that they ‘wanted to complain but did not’ make a complaint, while approximately one in every eight participants (13.1%) reported that they ‘wanted to complain and did’ lodge a complaint.

Those who ‘wanted to complain but did not’ (n=619) were presented with potential reasons why they did not complain and were asked to indicate which applied to them.⁹³ The most common reason for not complaining was that they didn’t think it would make a difference (55.1%); however, a considerable proportion also reported that they were worried that it would affect the quality of service they received (35.2%). Other reasons for not complaining included that they were not well enough to do so (34.6%), that they didn’t know how (28.1%) or that they were scared to complain (21.6%). Table 3.3 summarises the responses.

Table 3.3: Participant reasons for not complaining.

Reasons for not complaining:	%
Didn’t think it would make a difference	55.1
Worried that it would affect the quality of service they receive	35.2
Not well enough to do so	34.6
Didn’t know how	28.1
Scared to complain	21.6
Haven’t got around to it yet	7.8

As noted, one in eight (13.1% or n=153) reported that they ‘wanted to complain and did’. Of these, 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 the quality of service had suffered as a result.

⁹³ This was a ‘tick all that apply’ question, therefore the proportions listed in table 3.3 do not sum to 100%.



3.10: GP/Primary Care

Although GP/primary care is not part of the specialist MHSs in Ireland, it is nevertheless often the first port of call for those seeking help for a mental health difficulty and addresses 90% of all mental health need.⁹⁴ All mental health service users should be registered with a GP to maintain their overall health care, and many people who have accessed MHSs will have been discharged to their GP. Therefore, participants who reported seeking mental health specific treatment from a GP were presented with a number of questions relating to their experiences of and satisfaction with the treatment and care they received. Approximately four in every five participants (81.9% or n=973) reported that they had sought mental health specific treatment from a GP in the last two years.

These participants were asked to indicate, on a scale ranging from 0 (very dissatisfied) to 10 (very satisfied), how satisfied they were with the mental health care received from their GP. Almost half (49.0%) reported high levels of satisfaction (scores from seven to 10), while approximately one in four reported moderate (27.2%; scores between four and six) and low (23.8%; scores between zero and three) levels of satisfaction (see figure 3.13). On average, participants were moderately satisfied with the mental health care received from their GP (M=5.99; SD=3.03).⁹⁵

Figure 3.13: Satisfaction with mental health specific care received from a GP.



SATISFACTION WITH MENTAL HEALTH SPECIFIC CARE RECEIVED FROM GP



Participants were asked to indicate the extent to which they agreed with the following statement: 'My GP gave me enough time to speak about my mental health difficulty and listened to what I had to say'. Two-thirds (65.8%) agreed, approximately one in six (15.6%) neither agreed nor disagreed, and less than one in five (18.7%) disagreed with the statement (see figure 3.14). On average, participants agreed that their GP gave them enough time to speak about their mental health difficulty and listened to what they had to say (M=4.00; SD=1.25).⁹⁶

⁹⁴ Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office.

⁹⁵ The M and SD are based on an 11-point rating scale ranging from zero (very dissatisfied) to 10 (very satisfied).

⁹⁶ This M and SD are based on a five-point rating scale ranging from one (strongly disagree) to five (strongly agree).



Figure 3.14: Agreement that GP gave enough time to speak about a mental health difficulty and listened.



MY GP GAVE ME ENOUGH TIME TO SPEAK ABOUT MY MENTAL HEALTH DIFFICULTY AND LISTENED TO WHAT I HAD TO SAY



Participants were presented with a list of mental health supports and were asked to indicate which, if any, they had received or been referred to by the GP. Participants could tick any that applied. The most common support received by participants from their GP was medication, with 79.4% of participants having received a prescription for their mental health difficulty. The next most common supports were referral to a psychiatrist (73.3%) and referral to an ED (68.8%). The least common support was referral to a voluntary group or service, with 19.8% of participants indicating that their GP referred them to a voluntary group or service. Table 3.4 summarises participant responses.

Table 3.4: Participant experiences as a result of seeking mental health care from a GP.

Experience	Yes	No
Prescribed medication for the mental health difficulty	79.4%	20.6%
Referred to a psychiatrist	73.3%	26.7%
Referred to an emergency department	68.8%	31.2%
Referred to a community mental health team	56.9%	43.1%
Given information or a referral to counselling/psychotherapy services	55.6%	44.4%
Referred to a psychologist	31.0%	69.0%
Referred to a local voluntary group or service	19.8%	80.2%

Valid percentages are reported in this table. Note that missing responses for these questions ranged from 4.1% (prescribes medication) to 16.2% (referred to an ED).

Finally, participants who had sought mental health care from a GP were asked whether their GP had assessed their physical health in the last two years, (e.g. blood pressure, weight). Three-quarters (75.7%) reported that their GP had assessed their physical health, while one in five (20.6%) reported that they had not (don't know/can't remember: 3.7%).

Related Qualitative Feedback:

The above findings were reflected in the qualitative data that arose from the open-ended questions included in the survey. When asked what kind of positive experiences they had of HSE MHSs, some participants wrote positively about the capacity of their GP to care for and treat individuals experiencing a mental health difficulty. Others described the knowledge that some GPs have about mental health, including information about particular mental health difficulties.

“SOME GPs are incredibly knowledgeable about mental health. This needs to be more widespread”

Others wrote positively about how quickly their GP referred them to mental health supports and/or the continuity of support they received from their GP.

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

“My GP. Utterly invested in my recovery. 7 years in she is delighted with my progress and remains supportive”

Positive views and experiences of GPs was not universal. As noted, more than one in four participants (28.0%) reported low levels of satisfaction, while more than one in six (17.5%) disagreed that their GP gave them enough time to speak and listened to what they had to say.

This too was reflected in the qualitative data. Some participants criticised what they perceived as a lack of knowledge of mental health among GPs, particularly in such an important role.

“I spoke to another woman doctor that was not clued into mental health at all, this completely deterred me from trying to get help again ... GPs are the gatekeepers to nearly every specialised medical service and the majority of them are ignorant towards mental health issues”

Others wrote negatively about what they perceived as an excessive focus on medication when they had sought mental health care from their GP.

“GP services and support vary greatly and is very much medication orientated”

3.11: Additional Qualitative Findings

As previously noted, the open-ended questions gave participants the opportunity to express their views and answer in greater detail than did the closed-ended questions on the survey. Many participants responded to the open-ended questions with feedback that was not specific to the questions. Instead, many chose to share negative experiences they had had or to raise what they perceived as important issues relating to the provision of MHSs in Ireland. This section describes the most widely reported issues that have not been described in previous sections.

Related Qualitative Feedback:

Continuity of Care: Many participants alluded to a lack of and/or poor quality continuity of care. These participants most often conveyed frustration at the level/frequency of staff rotation in the MHSs. Echoing quantitative findings outlined in section 3.4, many described how their psychiatrist changed regularly (often every 3-6 months) 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, while others described how difficult it can be to develop trust and/or a relationship with staff when they keep changing.

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

"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"

"I was thrown from support to support growing up as everything had a time limit. People going through mental health issues, especially young people, need stability and security. I hated having to share my life story and open up years of pain again to someone new. I hated learning to trust someone and having them tell me after 8 weeks or a few months that they were no longer going to help me"

Others wrote negatively about the lack of follow-up services and how this could lead to feelings of isolation and even the deterioration of their mental health.

"There are many times now though, I wish I had follow up care. I do not have a way to access any follow up care"

"I was left in limbo being told to speak to my gp who referred me to MHS and vice versa with little to no follow up"

MHS System: Responses in this section relate to the shortcomings of the HSE mental health system, as perceived by participants. Some participants raised issues of staff shortages or a lack of/poor quality MHS facilities, often attributing these shortages to a lack of resources or funding for the MHSs.

"Most of the staff were very nice and respectful. They are understaffed and under pressure so they are working under difficult circumstances and doing their best (many courses like the anxiety group were cancelled because lack of staff)"

"Building & facilities badly needed updating but the care and attention of the nurses and their compassion will stay with me forever, Fabulous women"

“I would be dead now except I had money. to pay for private therapy. Service is crisis driven. Whoefully underfunded so only most desperate get crisis care for a short period...need to be holisititic psychotherapy/ medication/community team managing each case”

“I have seen heartening changes in language and policy documents. As well as learned of grass roots things in my community. I think the problem is that although the change is being championed by people at grassroot and top level, it’s just not meeting in the middle - where services are overburdened and where changes need to be actually implemented”

It should be noted that, when raising these issues, many participants also wrote positively about the care, dedication and professionalism of frontline MHS staff, despite the shortcomings in the system.

“Mental health nurses excellent. most doctors also. Dept. of Health/ HSE/useless”

“I think there are plenty of good psychiatrists and psychiatric nurses but the system itself does not seem to work effectively”

“Staff are helpful and try there best even thou they are severely under pressure due to lack of funding”

When writing about this issue, some participants wrote of what they perceived as a lack of accountability in the mental health system. Some echoed the quantitative findings related to the complaints process (see section 3.9) and indicated that they felt that making a complaint about the MHSs would make no difference.

“I work for HSE in mental health - my positive experiences are gleaned from my colleagues. I have no positive experience from my perspective as a service user. My needs were not met, and still aren’t. But I appreciate how the organisational structure does not facilitate recovery oriented care, and hence why I haven’t complained, feels fruitless”

Accessibility Issues: In their responses, many participants described difficulties accessing key services they required. These access issues were often attributed to perceived shortcomings in the MHSs, as outlined above. For example, for many of these participants, staff shortages, long waiting lists (often attributed to staff shortages) and gaps in local service provision led to difficulties accessing services.

Related Qualitative Feedback:

“I need DBT but it’s not available in my area. My Mental health team does not have a psychologist so my psychiatrist gave me a referral to a private one which I must pay for twice a week. Thankfully it’s on a sliding scale but it’s still 80 euro week which I can’t afford but I need the support so I have to find the money from somewhere”

A number of participants found it difficult to access private MHSs due a lack of financial resources. These participants expressed frustration about being unable to afford private services and expressed that ‘excessive waiting times’ for HSE MHSs made them feel as though private MHSs were their only option.

“I had to attend a psychologist privately but it proved to costly so I couldn’t continue”

“I was in a very bad way and had no access to counselling services, the waiting lists were very long and I was in crisis ... The assumption is you can just pay for private counselling. It was recommended I have weekly sessions which amounted to 350 euro a month, which was a financial worry when I was in extreme distress. It was a horrible time”



..participants expressed frustration about being unable to afford private services and expressed that ‘excessive waiting times’ for HSE MHSs made them feel as though private MHSs were their only option..

DISCUSSION





4. DISCUSSION

In this chapter, a discussion of the findings is presented in the context of mental health policy. In doing so, findings relating to the following will be summarised and discussed: participants' overall experience of HSE MHSs and the factors associated with their overall experiences; CMHSs; the role of psychiatrists; inpatient MHSs; treatments and supports; a multidisciplinary approach to mental health care; recovery orientated mental health care; the complaints process; and mental health in primary care. This section will conclude with a discussion of the methodological strengths and limitations of this research.

4.1: Overall Experience of HSE MHSs

Participants were asked to indicate how satisfied they were with their overall experience of the HSE MHSs. The largest proportion of participants, more than four in every ten, indicated that they had a poor experience of the services and less than one in three reported having a good experience.

Several factors were found to be significantly associated with participants' overall experience of HSE MHSs. For example, age was found to be a significant predictor of participants' overall experience. Older people were significantly more likely to report a good overall experience than were younger participants. Having the contact details of a key worker and reporting having a recovery/care plan were both found to be significant predictors of overall experience. Participants who had the contact details of a key worker and participants who reported having a recovery/care plan were both found to be more than twice as likely to report a good overall experience of HSE MHSs. Similarly,

participants who reported that they were involved as much as they would like in decisions about the medications they take were two and a half times more likely to report a good overall experience of HSE MHSs. Finally, highlighting the importance of continuity of care, participants who had not had a change of psychiatrist in the last two years were over one and a half 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.

Taken together, these findings not only highlight the need to improve service users' experiences of HSE MHSs, but also indicate some ways that this may be achieved. In accordance with *A Vision for Change*⁹⁷ and the MHC's Quality Framework⁹⁸, the findings indicate that the provision of accessible support (a contactable key worker), an individualised recovery/care plan, promoting the involvement of service users in decisions about their treatment, and improving the continuity of care received by service users may be key factors in improving service users' experiences of the MHSs in Ireland.



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

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



..there is a need for a shift in MHS delivery, from the paternalistic approach to one that is rooted in principles of recovery and human rights..

4.2: Community (Outpatient) Mental Health Services (CMHSs)

Although not directly asked whether they were satisfied with their CMHT, a proxy indicator of satisfaction was included on the extent to which individuals felt they were treated with dignity and respect by the CMHSs. Just over one-third of participants reported that they felt they were ‘always’ treated with dignity and respect by the CMHSs, while a majority of almost six in every 10 felt that they were, at best, only sometimes treated with dignity and respect by their CMHSs. In comparison, in a similar survey in the UK, almost three-quarters of participants said that overall, in the last 12 months, they felt that they were ‘always’ treated with dignity and respect by National Health Service (NHS) MHSs.⁹⁹

The importance of being treated with dignity and respect was reflected in the qualitative data for the *My Voice Matters* survey. When asked about their positive experiences of HSE MHSs, many participants described feeling listened to, supported and treated with dignity and respect by HSE MHS staff and the positive impact this had on their recovery. Participants also described the need for better communication between staff and service users and the importance of being listened to and understood. Clearly there is considerable scope for improvement in communication between staff and service users. The qualitative feedback points to ways that the concepts of dignity and respect can be operationalised through listening and empathy skills.

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

Good quality CMHSs are the focal point for recovery of those with severe and/or enduring mental health difficulties, and a cornerstone of the community-based care envisaged in national mental health policy since 1984.¹⁰⁰ More recently, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) affirms the right of all people with disabilities to the required supports to live in the community. The State has an obligation to fulfil the UNCRPD’s principles, including “respect for the inherent dignity, individual autonomy, and freedom to make one’s own choices, and independence” of all people who experience a mental health difficulty.¹⁰¹ Notwithstanding the lack of independent regulation and inspection of community based (outpatient) MHSs, the MHC’s Quality Framework for MHSs provides a basis for quality improvement and standardisation across the MHSs. Specifically, the Framework sets a standard for ensuring “respectful, empathetic relationships between people using the MHSs and those providing them”.¹⁰²

There is a general consensus that there is a need for a shift in MHS delivery, from the paternalistic approach to one that is rooted in principles of recovery and human rights. Of serious concern, the responses from the *My Voice Matters* survey participants indicate that many service users are not consistently being treated with dignity and respect on the ground. A minority of people who took part in this survey reported always being treated with dignity and respect by the CMHSs, while many in the sample

100 Department of Health and Children. (1984). *Planning for the future*. Dublin: The Stationery Office.

101 United Nations General Assembly. (2007). *Convention on the rights of persons with disabilities (A/RES/61/106)*. Retrieved from <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>, p.5.

102 Mental Health Commission. (2007). *Quality framework: Mental health services in Ireland*. Dublin: MHC, p. 26.

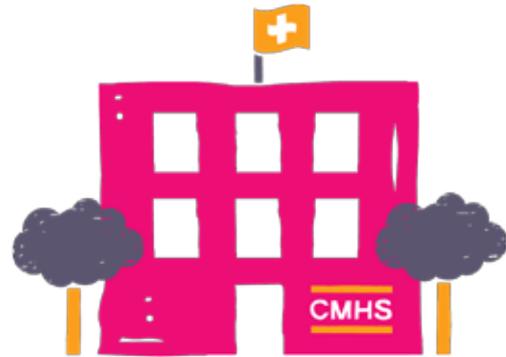


experienced a health service that has failed to promote even the most basic of human rights. This finding suggests that the impact of the HSE's recovery orientated culture change programme has not yet been embedded in the day-to-day service delivery to individuals across the country. The HSE should focus its next efforts on culture change to ensure consistency in the delivery of the recovery orientated approach by all staff.

A majority of survey participants reported that they did not have contact details of a key worker. Importantly, of those who had the contact details of a key worker, more than three quarters felt that they were well supported, either in full or in part. As noted above, participants who had a contactable key worker were more than twice as likely to report a good overall experience of HSE MHSs than were participants who did not have a contactable key worker. The desire for a key worker featured strongly in the qualitative data, with many participants expressing the need for and potential benefits of such a resource.

One of the core components of CMHS delivery is the ongoing development of an individual recovery/care plan, to be co-ordinated by a designated member of the multidisciplinary team, i.e. a key worker, as set out in the MHC's Quality Framework.¹⁰³ Findings highlighting the high proportion of survey participants with no contact details of a key worker and no written recovery/care plan developed with a member of the multidisciplinary team, indicate a lack of compliance with national standards. Of note, of those who had contact details of a key worker, the majority felt well supported. It could be argued that the appointment of key workers is likely to be effective in supporting the needs of service users and should be extended to ensure that all service users benefit from the availability of this role.

¹⁰³ Mental Health Commission. (2007). *Quality framework: Mental health services in Ireland*. Dublin: MHC.



4.3: Role of Psychiatrists

Of those who indicated that they currently had a psychiatrist, more than half felt that they were 'always' or 'mostly' well supported and listened to by their current psychiatrist. While such findings are encouraging, it must be recognised that over four in every 10 reported that they were only 'sometimes' or 'never' well supported or listened to by their current psychiatrist. Similarly, when asked about their experiences of the MHSs more generally, through open-ended survey questions, findings relating to experiences with staff were again mixed. A number of participants reported positive experiences with staff, including among them, psychiatrists. However, many others expressed strong dissatisfaction with the care provided by their psychiatrist, raising what they perceived as a lack of effective communication, engagement and continuity of care.

Findings relating to continuity of care were particularly stark. While over one-third of participants reported never having had a change in psychiatrist in the last two years, more than half reported having had a change of psychiatrist at least once in the last two years and a considerable minority of one in six reported having had a change of psychiatrist 'more than four times' in the last two years. The frequency of change was negatively related to the perceived impact of this change, indicating that the more often a person had a change of psychiatrist, the more negative the perceived impact of this change on their treatment and care. Further highlighting the importance of continuity of care, participants who had 'never' had a change of psychiatrist



..excessive staff rotation, particularly among psychiatrists, had a detrimental effect on (their) mental health and treatment..

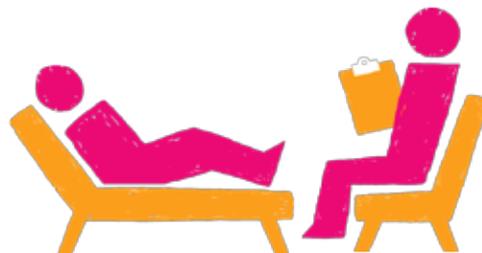
in the last two years were significantly more likely to report a good overall experience of HSE MHSs than were those who had a change of psychiatrist three or more times in the last two years. As noted, frustration with the lack of continuity of care from mental health professionals, particularly psychiatrists, also featured prominently in participant responses to open-ended questions. In fact, participants described how excessive staff rotation, particularly among psychiatrists, had a detrimental effect on their mental health and treatment, and inhibited the development of trust between psychiatrists and service users.

The national mental health policy *A Vision for Change* includes specific recommendations on the governance of CMHTs (inpatient and outpatient). It states that “a lead clinician will articulate the collective vision of the team and ensure clinical probity. In keeping with current legislation [i.e. Mental Health Act, 2001]¹⁰⁴ and contractual arrangements, this role would be the remit of the consultant psychiatrist or psychiatrists attached to the team”.¹⁰⁵ No doubt psychiatrists, as the clinical lead responsible for service user treatment, play a powerful role in making decisions about the person’s care and treatment regime. Most, if not all, service users will see a psychiatrist upon accessing the MHSs. If MHSs are to effectively embed the recovery ethos, psychiatrists must routinely convey that they are listening to service users. This is a basic demand of MHS users and a prerequisite for their involvement as equals in planning their treatment.

The traditional approach of MHS delivery fostered a culture whereby service users were often disempowered as passive recipients of professional expertise, rather than active participants in their own care and treatment. The introduction of the recovery approach and a recognition of the importance of human rights in underpinning MHS provision has led to a move towards a partnership approach between those who use and those who work in the MHSs. This survey has highlighted a very positive finding in that a majority of the sample reported that they felt they were always or mostly listened to by their psychiatrist. It could be argued that this is indicative of the services undergoing some degree of change in terms of implementing aspects of the recovery ethos.

Notwithstanding the positive findings, there was a sizeable minority of survey participants who reported only sometimes or never having felt listened to by their psychiatrist. The HSE and the College of Psychiatrists should consider whether there are particular groups of individuals who are having a more negative experience in terms of having their voice heard and how this can be addressed. Also, 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.

104 Part 6, section 71 of the Mental Health Act, 2001 states that the governing body of each approved centre shall appoint in writing a consultant psychiatrist to be the clinical director of the centre.
105 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p.80.





4.4: Inpatient MHSs

Participants with experience of acute care were asked to rate their satisfaction with numerous aspects of inpatient service provision. In relation to experiences of 'diet/nutrition', 'use of medication' and 'enforcement of daily routine, e.g. bedtime', considerably more participants reported that they were satisfied than dissatisfied. However, in relation to the 'range of recreational activities' and 'therapeutic supports' provided, considerably more participants reported that they were dissatisfied than satisfied.

The Mental Health Act¹⁰⁶ provides, through the MHC and the Inspector for MHSs, for the inspection and regulation of inpatient mental health units to protect the rights of people with mental health difficulties. There are a number of regulations that inpatient MHSs must comply with, such as, providing an adequate supply of food and nutrition, providing access to appropriate recreational activities and a range of therapeutic services and programmes.

Of concern is the level of dissatisfaction with two key components of MHS delivery in inpatient services: the range of recreational activities and therapeutic supports. The Inspector for MHSs has repeatedly found inadequate provision of therapeutic programmes in some inpatient settings for many years. Similar concerns were reported in the MHC's most recent annual report, specifically, "the continuing inability of some services to put in place an individualised care plan and therapeutic programme, which are the cornerstone of a recovery focused, person centred service as per national policy".¹⁰⁷ The HSE and all service providers must ensure that individuals in inpatient settings can receive a variety of high quality, therapeutic programmes tailored to the service users' recovery/care plans.

106 Government of Ireland. (2001). *Mental Health Act*. Dublin: Stationery Office.

107 Mental Health Commission. (2018). *Mental Health Commission annual report including report of the inspector of Mental Health Services, 2017*. Dublin: MHC, p. 4.

When asked about the use of seclusion, restraint and sedation, the proportions of inpatient service users reporting satisfaction and dissatisfaction were almost equal. However, the question was not restricted to those who had experienced such restrictive practices themselves, so this finding must be interpreted with caution.

In the MHC's study on the effects of the Mental Health Act¹⁰⁸ from the perspectives of service users, the researchers found that there was a lack of association between attitudes to care and being subject to coercive measures.¹⁰⁹ In fact, the research found that it is the level of perceived coercion experienced by individuals which is associated with attitudes towards their care and treatment, rather than the experience of actual documented coercive measures. The MacArthur Coercion study found that where individuals felt they had a "voice" in the admission process and were treated by others with respect, that levels of perceived coercion experienced were less.¹¹⁰ The findings from the current survey do not illuminate further individuals' experience of seclusion and restraint. In a re-run of this survey, questions should be focused on those who have received restrictive practices.

The Regulation on Privacy, as set out under the Mental Health Act¹¹¹ expressly states that a resident's privacy and dignity be respected at all times. Of concern, just one in four participants felt as though they were 'always' treated with dignity and respect by the MHSs during their inpatient experience.

Although not directly comparable, due to population differences and response options, a similar question in the MHC's survey on people's experiences of inpatient

108 Government of Ireland. (2001). *Mental Health Act*. Dublin: Stationery Office.

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

110 MacArthur Research Network on Mental Health and the Law. (2004). *The MacArthur Coercion Study: May 2004 update of the executive summary*. Retrieved from <http://www.macarthur.virginia.edu/coercion.html>

111 Government of Ireland. (2001). *Mental Health Act*. Dublin: Stationery Office.



..The Inspector for MHSs has repeatedly found inadequate provision of therapeutic programmes in some inpatient settings for many years..

services in 2011 found that more than 8 in 10 people agreed that they were always treated with dignity and respect by the MHSs. In comparison, about 6 in 10 participants to this current study reported that they were 'always' or 'mostly' treated with dignity and respect. The low number of participants reporting that they were always treated with dignity and respect in inpatient settings (approximately one in four) calls for concerted action on the part of inpatient service providers and again shows the need for a programme to improve the quality of interaction between service users and staff at the one-to-one level. The potential that inadequate permanent staffing resources for inpatient units may be impacting on individuals' experience of being treated with dignity and respect should also be considered.

4.5: Treatment and Supports

A majority of six in every ten participants reported a high focus on medication in their treatment, while almost one in five indicated that their treatment was totally focused on medication. Furthermore, a large proportion of participants indicated that they were not involved as much as they would like in decisions about the medication they take; of those who stated they were not involved, four in five expressed that they would like to be involved. Participants who reported that they were involved in decisions about the medications that they take were two and a half times more likely to report a good overall experience of HSE MHSs than were those who were not involved. This suggests that promoting the involvement of service users in decisions about their treatment and care may help to improve their experiences of HSE MHSs.

The qualitative data showed that for some participants, medication was a helpful resource which supported them through their recovery. However, for others, there was a perceived over reliance on medication, often in the absence of other therapeutic supports and programmes.

The Expert Group on *A Vision for Change* highlighted the perceived over reliance on medication in dealing with mental health difficulties and the need to provide a range of therapeutic supports across the mental health system. The importance of medication for some individuals should be recognised; however, national policy also holds that all people who come into contact with MHSs be provided choice in terms of their treatment and have equivalent access to non-pharmacological as to pharmacological supports: "The range of specific interventions will vary from individual to individual but all





three interventions (medical, psychological and social) should have equal importance in the lives of service users".¹¹² It must also be acknowledged that the principles of recovery, including choice and partnership, which underpin national policy, relate to all aspects of MHS delivery, including the administration of medication.

On a more practical note, the Expert Group specifically recommended that service users be provided with "individualised" information about their medication in an accessible format.¹¹³

The provision of information on medication to service users and carers/supporters' is affirmed in the MHC's Quality Framework¹¹⁴ and in the HSE's Best Practice Guidance for MHSs.¹¹⁵

The Expert Group on the review of the Mental Health Act, 2001, further recommends that where medication is being proposed, the views of the service user should be recorded, and if appropriate the views of the family and/or advocate.¹¹⁶

In order to fulfil its commitments under national policy, Government must invest in the development of a range of therapeutic supports for service users. Moreover,

there is a fundamental need for system-wide organisational change to ensure nationwide services whereby staff empower service users to make decisions about their own care and treatment. The findings above show a worryingly low level of involvement among the survey sample in decisions about the medication they take. Of greater concern is that this perceived lack of involvement is not by choice of many of the sample service users, a large majority of whom would like to be involved. Despite efforts in recent years to move away from the medical model, the survey findings indicate a continued over reliance on the administration of medication. A recovery orientated approach to medication is required, which allows for an open discussion with service users about the risks and benefits of taking medication, respecting the person's values and choices about medication and taking account of the individual's personal goals and the potential impact of medication on such goals.

The survey findings also showed that just over half of participants had been referred to a talking therapy, while more than one in four had not. While such findings indicate that a sizeable proportion of the participants had been referred to psychotherapeutic supports, a considerable minority were not. There was considerable variation in waiting times to access talking therapy, with many waiting excessively long periods of time. Of those who were referred for a talking therapy, over one in four reported waiting between three and 12 months and almost one in five reported waiting more than a year to avail of a talking therapy. Talk therapy services were most commonly reported by participants when asked whether there were any services that were unavailable to them that they believe they would have benefitted from. Some participants also wrote about the long waiting times to get access to talk therapies, the lack of specific types of talk therapy and the time limited nature of such supports, which often had a negative impact on their mental health and recovery. National mental health policy sets out that every CMHT should "include a range of psychological

112 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p. 235.

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

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

115 The HSE's Best Practice Guidance recommends

- 1) Each service user, family and carer is advised, as appropriate, about the side effects of prescribed medicines and is given access to information leaflets and where necessary training, regarding medication.
- 2) The views of service users, and the history of previous treatment, is considered and documented prior to administration of new medication and/or other technologies.
- 3) Medication information sheets, as well as verbal information, are provided in a format that is appropriate to the service user's needs. See: HSE Mental Health Services. (2017). *Best practice guidance for mental health services: Supporting you to meet regulatory requirements and towards continuous quality improvement*. Dublin: HSE MHS.

116 Expert Group. (2015). *Report of the expert group on the review of the Mental Health Act, 2001*. Dublin: Department of Health.



..The HSE must ensure that shortfalls in the availability of allied health and social care services are rectified so that service users can avail of a multidisciplinary care approach that effectively meets all of their needs..

therapy expertise to offer individual and group psychotherapies in line with best practice”.¹¹⁷ The MHC’s Quality Framework echoes this sentiment¹¹⁸ and the Expert Group on the review of the Mental Health Act recognised that “while traditionally the focus of treatment was on the administration of medication”, treatment should include a range of psychological and other remedies.¹¹⁹

Unfortunately, due to a lack of data collection in HSE MHSs, there is no information on the total number of service users who are offered and/or avail of talk therapies.

There is extensive research on the effectiveness of talk therapy^{120,121} and this is reflected by qualitative responses from this survey which further highlight the benefits of such therapies. Direct access to a range of therapeutic supports, including talk therapies, should be standardised across the MHSs, in line with national policy.



4.6: Multidisciplinary Approach

When asked about access to a range of different disciplines on the CMHT, the majority of participants reported access to a psychiatrist, followed by access to a community psychiatric nurse. Participants reported, to a much lesser extent, access to non-medical professionals, including psychologists, psychotherapists or counsellors, social workers, and occupational therapists. In response to the open ended questions, many participants expressed frustration at how difficult they found it to access different types of mental health professionals. This was perceived by many participants as being a result of staff shortages, leading to gaps in service provision.

Not all service users will require input from each type of mental health professional, and the descriptive findings reported do not provide enough information to make an assessment on the balance of professionals involved in care. It appears that service users had more engagement with medical professionals than other members of the multidisciplinary team; however, further comparative analysis may shed greater light on the nature of multidisciplinary input that individual service users are receiving. Peer support workers, family therapists and advocates were among the least common professionals that individuals reported having come in contact with, indicating clearly that for participants these types of workers have played a limited role. Through open-ended questions, some participants recommended increased access to peer supports for service users and others wrote about the benefits of such supports.

117 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p. 98.

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

119 Expert Group. (2015). *Report of the expert group on the review of the Mental Health Act, 2001*. Dublin: Department of Health, p.18.

120 Department of Health. (2012). *IAPT Three year report: The first million patients*. London: Department of Health.

121 Carr, A. (2007). *The effectiveness of psychotherapy: A review of research prepared for the Irish Council of Psychotherapy*. Dublin: Irish Council of Psychotherapy.



Planning for the Future proposed a new model of mental health care, one which would be centred on a multidisciplinary approach to service delivery.¹²² *A Vision for Change* retained this core principle and set out that the cornerstone of community based MHS delivery should be an enhanced multidisciplinary team, with skilled professionals, to combine their unique expertise and provide integrated care to service users in the context of their local community.¹²³ The importance of a multidisciplinary approach in supporting the mental health needs of service users was later reflected in the MHC's Quality Framework which recommends the "provision of a holistic, seamless service and the full continuum of care provided by a multidisciplinary team".¹²⁴ The framework states that multidisciplinary teams be comprised of core members from psychiatry, clinical psychology, nursing, social work and occupational therapy and that additional members that reflect the service user's needs are also available. Both national policy and the MHC's Quality Framework highlight the importance of multidisciplinary teams in providing the appropriate skill mix and expertise to address the range of mental health needs presenting at both individual and local level.

The HSE must ensure that shortfalls in the availability of allied health and social care services are rectified so that service users can avail of a multidisciplinary care approach that effectively meets all of their needs. The findings from both the descriptive and qualitative data indicates that there is a need to increase the level of input from peer support workers and advocates in MHS delivery. The need for advocacy supports has been shown in one local area through Mental Health Reform's previous research¹²⁵ and is an issue

that is consistently raised in mental health inspection reports. It may also be beneficial to increase access to family therapy as it appears people have had little exposure to this type of therapeutic support, to date.

Survey participants were also asked if CMHSs had linked them in with a range of different supports, including those external to the specialist MHSs. Approximately one-third of participants reported that they had not been linked to any supports by the HSE MHSs. Similarly, approximately one-third reported that they found out about the supports themselves. The qualitative data shows the importance of community and voluntary groups for service users in providing ongoing mental health supports in their local communities, with many participants writing about the benefits of accessing such services.

A Vision for Change recognised the need for "formalised links between specialised MHSs, primary care and mainstream community agencies to support the care and integration of individuals within their local communities".¹²⁶ The policy acknowledged the 'community', the first of three layers in mental health support, as a valuable resource in dealing with mental health difficulties.¹²⁷

More specifically, the Expert Group on *A Vision For Change* referred to the value of services that use the support of families and communities to improve outcomes in mental health.¹²⁸ The evidence suggests that this policy recommendation is yet to be fully implemented. A clear framework should therefore be developed to ensure effective collaboration and referral to community and voluntary sector supports.

122 Department of Health and Children. (1984).

Planning for the future. Dublin: The Stationery Office.

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

124 Mental Health Commission. (2007). *Quality framework: Mental health services in Ireland*. Dublin: MHC, p. 20.

125 Mental Health Reform. (2017). *The advocacy needs of mental health service users living in the community: A pilot study*. Dublin: Mental Health Reform.

126 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p. 13.

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

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



..services should operate from a hopeful orientation that supports recovery, listen to and work in partnership with people who use services, offer choice and the opportunity for individuals to exercise their autonomy..

4.7: Recovery Orientated MHSs

As previously noted, being aware of one's own recovery/care plan was found to be significantly associated with participants' overall experience of HSE MHSs, such that those who reported having a recovery/care plan were more than twice as likely to report a good overall experience than were those without a recovery/care plan. Of concern, just over one in five participants reported having a written recovery/care plan developed with their mental health team, while almost two-thirds reported that they had no recovery/care plan. This was the case despite national policy, guidance and regulations which specify the requirement for each service user to have an individual recovery/care plan. The MHC's regulations for approved inpatient services place an obligation on each unit to ensure that every service user has an individual care and treatment plan that describes the levels of support and treatment required in line with his/her needs. Furthermore, the MHC's Quality Framework¹²⁹ includes the same standard, which is applicable to all MHSs, including community outpatient services. Additionally, less than one-third of participants agreed that someone on their mental health team frequently talked to them about recovery as part of their treatment. Similarly, only one in six reported that their multidisciplinary team 'definitely' talked to them about their strengths as a core part of their recovery/care plan, while just under half stated that this was not the case. More than one in four reported that their diagnosis had not been explained to them in a way they understood. Finally, almost one third of participants felt that their CMHT did not take account of how their mental health

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

difficulty affects other areas of their life, with only a minority reporting this as part of their care. These findings suggest that a majority of the survey sample are not experiencing fundamental aspects of a recovery orientated MHS.

In contrast, when asked about their positive experiences of the MHSs, some participants highlighted the positive role of their CMHT in supporting their recovery. These participants identified numerous measures taken by the services, including the provision of recovery education, the promotion of service user involvement in decisions about their care and treatment, and the empowerment of service users to voice their opinions and be listened to. These findings suggest that some service users are experiencing a welcome change through recovery orientated initiatives.

A Vision for Change emphasises the importance of a recovery approach, stating that it "should inform every level of service provision".¹³⁰ The associated components of Mental Health Reform's recovery approach recognise that services should operate from a hopeful orientation that supports recovery, listen to and work in partnership with people who use services, offer choice and the opportunity for individuals to exercise their autonomy, and support the social inclusion of people with mental health difficulties. The recovery ethos is further endorsed by the MHC in its Quality Framework for MHSs¹³¹ and in its report on a recovery approach within Irish MHSs.¹³²

130 Department of Health. (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy*. Dublin: The Stationery Office, p.5.

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

132 Mental Health Commission, (2008). *The Recovery Journey: A Recovery Approach Within the Irish Mental Health Service*. Dublin: MHC.



The HSE's recent publication of the National Framework for Recovery in Mental Health¹³³ defines the core principles of a recovery orientated service, and provides guidance to MHSs in delivering a quality, recovery focused service. The recovery principles, as set out in this framework, include 1) the centrality of the service user's lived experience 2) the co-production of recovery-promoting services, between all stakeholders 3) an organisational commitment to the development of recovery orientated MHSs and 4) supporting recovery orientated learning and practice across all stakeholders.

Notwithstanding the introduction of recovery programmes at national and local levels, the findings show that a substantial proportion of the survey sample are not experiencing a recovery orientated MHS. It appears that there are ongoing challenges in effectively implementing the recovery approach, and the commitments as set down in national policy to implement a modern, recovery orientated MHS are not being fully translated in practice. As previously noted, there is a need for a cultural shift across the mental health system, which places the recovery ethos at the heart of service delivery.

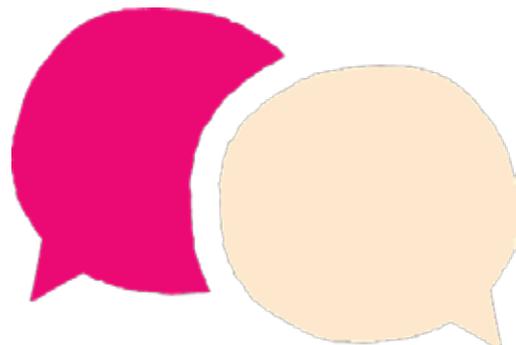
4.8: The Complaints Process

Over three-quarters of service users surveyed reported that no one in the HSE MHSs let them know how to make a complaint about the MHSs, while just over one in ten agreed that someone in the HSE MHSs had let them know how to make a complaint. However, lack of knowledge about how to complain did not appear to be the biggest hindrance to people making a complaint. While over half of participants reported that they 'wanted to complain but did not', just over a quarter of this group

cited not knowing how to do so as the reason. The most common reason for not complaining was that the participant didn't think it would make a difference, and more than a third reported that they were worried that it would affect the quality of service they receive.

These findings provide cause for serious concern. Receiving and responding to complaints is an important way for MHSs to identify areas for improvement. The low level of confidence that survey participants have expressed in knowing how to and making complaints is likely to be hindering the ongoing improvement of the MHSs. An independent complaints mechanism to receive, investigate and resolve complaints about MHS delivery should be established to provide a direct route for service users to complain without fear of reprisal. In order that services can garner the feedback that will help them to be more responsive to service users, it is important that mental health staff communicate a welcoming and responsive attitude to complaints.

Furthermore, the provision of independent advocacy services to support the making of complaints should be ensured, as has previously been called for by Mental Health Reform in the context of the review of the Mental Health Act, 2001. This would likely benefit both service providers and service users by facilitating complaints by service users, allowing them to give voice to their concerns, while providing service providers with crucial information about how services can be improved going forward.



¹³³ 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.



..the majority of participants are satisfied with the mental health care received from their GP..

4.9: Mental Health in Primary Care

Although the focus of this report is on HSE MHSs, it was important to ask survey participants a small number of questions about their experiences of mental health in primary care, given the sector's role in the mental health system as a whole.

On average, findings in relation to GP/primary care were more positive than findings in relation to psychiatrists, CMHSs and acute inpatient care. Almost two thirds of those who sought mental health specific treatment from a GP felt that 1) they had been given enough time to speak about their mental health difficulty and 2) they were listened to by their GP. Overall, more participants reported high rather than low satisfaction with the mental health care they received from their GP. Such positive experiences were also reflected in responses gathered from open-ended questions, with many survey participants highlighting the capacity of their GP to care for and treat mental health difficulties.

In contrast, there were a number of participants who were not satisfied with the mental health care received from their GP and who raised serious concerns about the over prescribing of medication for mental health difficulties and a lack of knowledge among GPs in regard to mental health.



The Expert Group on *A Vision for Change* recognised that the primary care sector holds responsibility for the delivery of 90% of mental health care and that most people who experience a mental health difficulty will have their needs met at this level. Similarly, *A Vision for Change* clearly recommended the need to prioritise the full range of mental health supports from primary to specialist (outpatient and inpatient) MHSs. Sláintecare,¹³⁴ the ten-year vision to transform Ireland's health and social care services, recommends providing mental health care at the lowest level of complexity possible, from integrating it within the primary care domain.¹³⁵

The above finding that the majority of participants are satisfied with the mental health care received from their GP is very encouraging. The survey sample reported positive aspects of care in terms of being listened to and being afforded enough time to speak about their mental health difficulty, which are core components of a modern, recovery orientated model and should be replicated across all levels of the system. While it was not within the scope of this project to identify the specific factors related to satisfaction levels, it could be inferred from other research¹³⁶ that continuity of care and the ongoing relationship between the GP and the individual at the primary care level enhances quality of care and, in effect, satisfaction levels.

134 Houses of the Oireachtas Committee on the Future of Healthcare. (2017). *Sláintecare Report*. Retrieved from https://data.oireachtas.ie/ie/oireachtas/committee/dail/32/committee_on_the_future_of_healthcare/reports/2017/2017-05-30_slaintecare-report_en.pdf.

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

136 World Health Organisation. (2008). *Integrating mental health into primary care: A global perspective*. Geneva: WHO Press.



The positive findings also support current policy direction of providing the bulk of mental health care in the primary care setting. This will, of course, require significant investment to enhance the capacity of primary care services and professionals to provide high quality care. Despite the positive findings on people's experiences of GPs, there is a considerable minority who reported low satisfaction levels with the mental health care they received. There may be a need for further research to identify the characteristics of dissatisfaction with GP mental healthcare as well as a need to ensure continued monitoring of people's experiences of mental health in primary care.

4.10: Methodological Strengths and Limitations

This national consultation of MHS users is the first in depth national survey of its kind conducted in Ireland.¹³⁷ As such, although this research had its strengths, it was not without limitations. This section will outline these methodological strengths and limitations.

4.10.1: Survey Design:

Considerable efforts were made to design a robust and accessible survey instrument. As noted in section 2.2, the survey was designed in a phased manner, which was an important strength of this research. As far as possible, survey questions were initially sourced from similar empirical research carried out in Ireland¹³⁸ and abroad.¹³⁹ Importantly, questions were also designed based on Mental Health Reform's

previous consultations examining people's experiences of the MHSs, carried out across Ireland between 2011 and 2015. This helped to ensure the survey questions were meaningful and relevant to issues that were important to service users. When designing the survey, researchers were aware that low literacy levels and/or language barriers may inhibit participation. Therefore, multiple in depth consultations¹⁴⁰ with service users were carried out to ensure that the survey was as accessible as possible. However, the language barrier may have remained an issue for those with low levels of English. This may partially explain the low levels of participation among ethnic minority groups where English is not the first language. However, previous research examining participation and response rates in the NHS patient survey programme has shown that certain groups, including minority ethnic groups, are less likely to participate and/or respond.^{141,142,143}

Experts both in survey design and in the field of mental health were also consulted during the design of the survey, which served to further strengthen the survey instrument, while the inclusion of open-ended questions afforded participants the opportunity to express their views and share their experiences in much greater detail. This in turn provided greater insight into the lived experiences of these service users and should be considered an important strength of this research.

¹³⁷ Limited previous research has explored the views of service users in relation to aspects of the MHSs in Ireland, e.g. see: Mental Health Commission. (2011). *Your views of mental health inpatient services*. Dublin: Mental Health Commission.

¹³⁸ Mental Health Commission. (2011). *Your views of mental health inpatient services*. Dublin: Mental Health Commission.

¹³⁹ UK Care Quality Commission. (2017). *Community mental health survey: Quality and methodology report*. London: UK Care Quality Commission.

¹⁴⁰ Three focus groups and 10 cognitive interviews with service users were carried out and changes were made to the survey based on feedback from these processes.

¹⁴¹ Sheldon, H. (2007). *Increasing response rates amongst black and minority ethnic and seldom heard groups: Report of a consultation with stakeholders on increasing response rates to the national inpatients survey*. Oxford: Picker Institute.

¹⁴² Sheldon, H., Graham, C., Potheary, N., & Rasul, F. (2007). *Increasing response rates amongst black and minority ethnic and seldom heard groups: A review of literature relevant to the national acute patients' survey*. Oxford: Picker Institute.

¹⁴³ UK Care Quality Commission. (2017). *Community mental health survey: Quality and methodology report*. London: UK Care Quality Commission.



..This consultation is the first national, large-scale survey in recent years to provide in depth and up-to-date feedback of service users' experiences..

The above procedures resulted in a robust and accessible survey instrument which could serve to provide a valuable baseline against which to compare the results of future national consultations of this kind. However, this is not to say that the survey could not be further strengthened by addressing certain limitations.

The survey did not include a question to distinguish between those accessing HSE MHSs and those accessing private MHSs only. Participants were asked whether they had access to private MHSs of various kinds. However, indicating access to private services did not mean that participants were not also accessing public MHSs of some kind. This meant that a comparison of private and public MHSs was not possible. It is also possible that some participants who had not accessed HSE MHSs in the last two years answered questions relating specifically to HSE MHSs. However, as survey questions that made specific reference to HSE MHSs were easily identifiable, this risk was modest and the number of cases where someone without relevant experience of HSE MHSs answered questions relating specifically to HSE MHSs was likely small. Even so, including a question designed to identify private only service users would avoid this issue in future consultations and facilitate a useful comparison of the views and experiences of private only and public only MHS users.

There were a small number of minor discrepancies between the online and paper versions of the survey. For example, participants were asked to indicate how satisfied they were with their overall experience of HSE MHSs on a scale ranging from one to ten. On the online

version the opposing poles were labelled 'I had a very poor experience' (one) and 'I had a very good experience' (ten) but on the paper version these poles were labelled 'very dissatisfied' (one) and 'very satisfied' (ten). Although the vast majority of participants completed the survey online, there were likely a small number of cases who responded using the latter scale. However, the number of paper returns were not tracked. It was therefore not possible to identify these cases post data entry. Future consultations should strive to eliminate such discrepancies and should track online and paper returns so that issues like this could be more easily addressed.

The survey covered a variety of issues that may have been perceived as sensitive by participants. Therefore, some participants may have been uncomfortable or unwilling to answer these questions. For example, when asked to share their main diagnosis, some answered that they would 'prefer not to say'. However, the use of online surveys and assurances regarding confidentiality and anonymity likely served to reduce non-response rates for certain questions.

A small number of survey questions had missing responses exceeding five percent of the sample, perhaps indicating issues with these questions. These items should be examined and, if deemed necessary, changed to avoid similar issues in future consultations. Finally, although not inherently a limitation, the inclusion of validated scales and the use of multiple-item measures of satisfaction could strengthen the survey instrument for future consultations.



4.10.2: Data Collection and Recruitment:

Although every participant had the option of requesting a paper version of the survey, the vast majority of participants completed the survey online. Research has found that online surveys have a number of inherent advantages over paper surveys, which were particularly relevant to, and served to strengthen, the present research. These include the following: online surveys can reach more potential participants quickly; they can reduce bias and measurement error as a result of questions relating to stigmatised topics (like mental health); and they can enhance participation of stigmatised populations (like those experiencing mental health difficulties).^{144,145,146,147} Research has also found that the quality of the data gathered via online surveys is at least as good as traditional survey methods.^{148,149,150} Online data collection was therefore an appropriate and effective method of data collection in this context, which facilitated the recruitment of an often stigmatised and therefore difficult to access population.

- 144 McCabe. (2004). Comparison of web and mail surveys in collecting illicit drug use data: A randomized experiment. *Journal of Drug Education*, 34(1), 61-73. doi:10.2190/4HEY-VWXL-DVR3-HAKV.
- 145 McCabe et al. (2002). Mode effects for collecting alcohol and other drug use data: Web and U.S. mail. *Journal of Studies on Alcohol*, 63, 755-762. doi:10.15288/jsa.2002.63.755.
- 146 Rhodes, S. D., Bowie, D. A., & Hergenrather, K. C. (2003). Collecting behavioural data using the World-Wide Web: Considerations for researchers. *Journal of Epidemiology and Community Health*, 57, 68-73.
- 147 Trau, R. N., Härtel, C. E., & Härtel, G. F. (2013). Reaching and hearing the invisible: Organizational research on invisible stigmatized groups via web surveys. *British Journal of Management*, 24(4), 532-541. doi:10.1111/j.1467-8551.2012.00826.x
- 148 Gosling et al. (2004). Should we trust web-based studies? A comparative analysis of six preconceptions about Internet questionnaires. *American Psychologist*, 59, 93-104. doi: 10.1037/0003-066X.59.2.93.
- 149 Trau, R. N., Härtel, C. E., & Härtel, G. F. (2013). Reaching and hearing the invisible: Organizational research on invisible stigmatized groups via web surveys. *British Journal of Management*, 24(4), 532-541. doi:10.1111/j.1467-8551.2012.00826.x.
- 150 Whitehead. (2011). Methodological issues in Internet-mediated research: a randomized comparison of internet versus mailed questionnaires. *Journal of medical Internet research*, 13(4). doi: 10.2196/jmir.1593

As noted above, research examining participation and response rates in the NHS patient survey programme has shown that certain groups are less likely to participate and/or respond. Those experiencing a mental health difficulty were one such group.^{151,152,153} Although the use of online surveys helped to recruit participants in this difficult to access group, additional steps were taken to increase awareness of and participation in this research. Through its advocacy work, Mental Health Reform has developed a network of organisations, academic institutions and individuals who work directly with service users. Using snowball sampling methods, Mental Health Reform was able to draw on this extensive and well-established network to publicise this project and facilitate recruitment. National radio advertisements with a potential reach of 1.5 million people and an extensive social media campaign ensured that the survey was brought to the attention of as wide a group as possible. The above, in conjunction with the use of online surveys, resulted in a large and diverse sample of service users and should be considered a strength of this research.

Participants from all CHO areas, age groups and backgrounds, with a wide variety of main diagnoses, participated in this research (see section 2.3). However, there were issues with the sample. For example, there was a female to male gender imbalance of approximately two to one, the proportion of service users aged 65 years or older was low¹⁵⁴, and the proportion of participants who reported high

- 151 Sheldon, H. (2007). *Increasing response rates amongst black and minority ethnic and seldom heard groups: Report of a consultation with stakeholders on increasing response rates to the national inpatients survey*. Oxford: Picker Institute.
- 152 Sheldon, H., Graham, C., Potheary, N., & Rasul, F. (2007). *Increasing response rates amongst black and minority ethnic and seldom heard groups: A review of literature relevant to the national acute patients' survey*. Oxford: Picker Institute.
- 153 UK Care Quality Commission. (2017). *Community mental health survey: Quality and methodology report*. London: UK Care Quality Commission.
- 154 2.5% of participants were aged 65 years or older.



..research examining participation and response rates in the NHS patient survey programme has shown that certain groups are less likely to participate and/or respond. Those experiencing a mental health difficulty were one such group..

educational attainment was high.¹⁵⁵ Indeed, the sample of participants for this survey was not a representative sample of the target population. Rather, this was a self-selecting sample subject to non-response bias, wherein those who chose to take part may be different to those who didn't. For example, participants may have been those who were most motivated to contribute and/or those most engaged with services. This means that the findings cannot be generalised to the population of MHS users in Ireland as a whole. However, it is important to recognise how difficult it would be to recruit a representative sample of MHS users when so little reliable data about this population is available. For example, there is limited information about the prevalence rates of specific diagnoses. Similarly, although all CHO areas are roughly equivalent in terms of population, the number of service users per CHO area is not available. This and similar information, e.g. a breakdown of service users by age group or gender, would be invaluable to future consultations as it may facilitate the recruitment of a more representative sample. HSE Mental Health should consider recording such data at both CHO and national level.

Steps were taken to examine whether it would be appropriate to group the peer-research assisted (PRA) subsample from CHO3 with the remaining sample. As noted, analysis highlighted consistent and often statistically significant differences between the PRA and non-PRA samples (see appendix B). In line with expectations consistent with the presence of acquiescence bias, the responses of the PRA sample were significantly more positive/favourable compared to the non-PRA sample. Based on these results, it was deemed inappropriate to group the PRA and non-PRA samples. Had these samples been grouped and reported as one, the results would likely have been positively skewed.

Finally, it was not possible to identify and exclude repeat participants. Although there are methods to help reduce the likelihood of repeat participants, e.g. ensuring that a single IP address can only access the survey once, these do not guarantee that repeat responses will not occur and often involve collecting potentially identifiable information. To ensure confidentiality and anonymity, and to ensure that the survey could be completed multiple times from the same computer (particularly where service users were using a computer located within a day or residential service or training centre), these methods were not deemed appropriate. The potential exclusion of service users wishing to share their views and experiences by completing the survey was considered inappropriate.

¹⁵⁵ 38.7% reported their highest level of educational attainment as 'third-level degree' or higher.



As noted, this was the first national consultation of its kind carried out in Ireland. In many ways, this could be considered a pilot study for an ongoing and regular consultation process with MHS users and their carers/supporters. Every effort should be made to address the limitations of this research in the future to further strengthen any subsequent consultations. However, as evidenced by the methodological strengths outlined above, this research has provided a solid baseline against which to compare similar research in the future. This research has also provided significant insight into the views and experiences of MHS users in Ireland and invaluable first-hand feedback on the quality of MHS provision. Going forward, Mental Health Reform will continue to draw on the wealth of information gathered as part of this national consultation to inform our advocacy work going forward and by considering how best this consultation process can be carried out in the future.



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CONCLUSION AND RECOMMENDATIONS





5. CONCLUSION

In his most recent report, the 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.¹⁵⁶ 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.¹⁵⁷

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 psychiatric, 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. However, many are not experiencing a modern, recovery orientated MHS as envisaged in *A Vision for Change* more than a decade ago.¹⁵⁸

156 United Nations General Assembly. (2017). *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (A/HRC/35/21)*. Retrieved from https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session29/Documents/A_HRC_29_33_ENG.DOCX

157 United Nations General Assembly. (2017). *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. (A/HRC/35/21)*. Retrieved from https://www.ohchr.org/EN/HRBodies/HRC/RegularSessions/Session29/Documents/A_HRC_29_33_ENG.DOCX

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

The survey findings indicate that some service users are experiencing MHS provision that reflects recovery orientated practices and the implementation of national 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; and being offered talking therapies by the MHSs.

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 CMHTs. Mental Health Reform is of the view that there is a fundamental requirement for



..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..

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 Voice 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 publish its report in early 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.

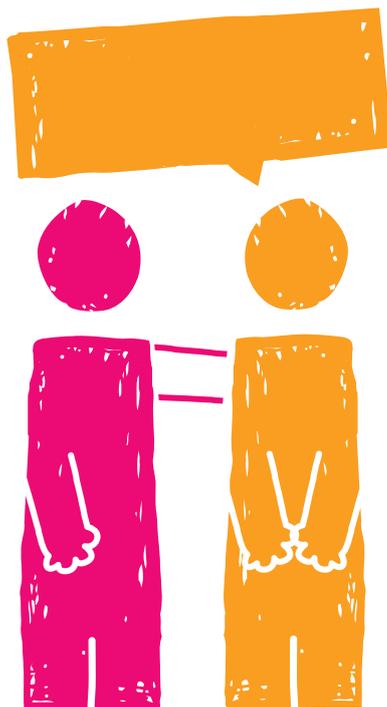


RECOMMENDATIONS

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 must 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 attending 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.



..This consultation on people's experiences of the mental health services 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..



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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.¹⁵⁹ 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.

¹⁵⁹ Members of the Forum are nominated by MHR member organisations and participate as nominees of their organisation. Currently, there are approximately 15 active members.

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.

..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 services 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.



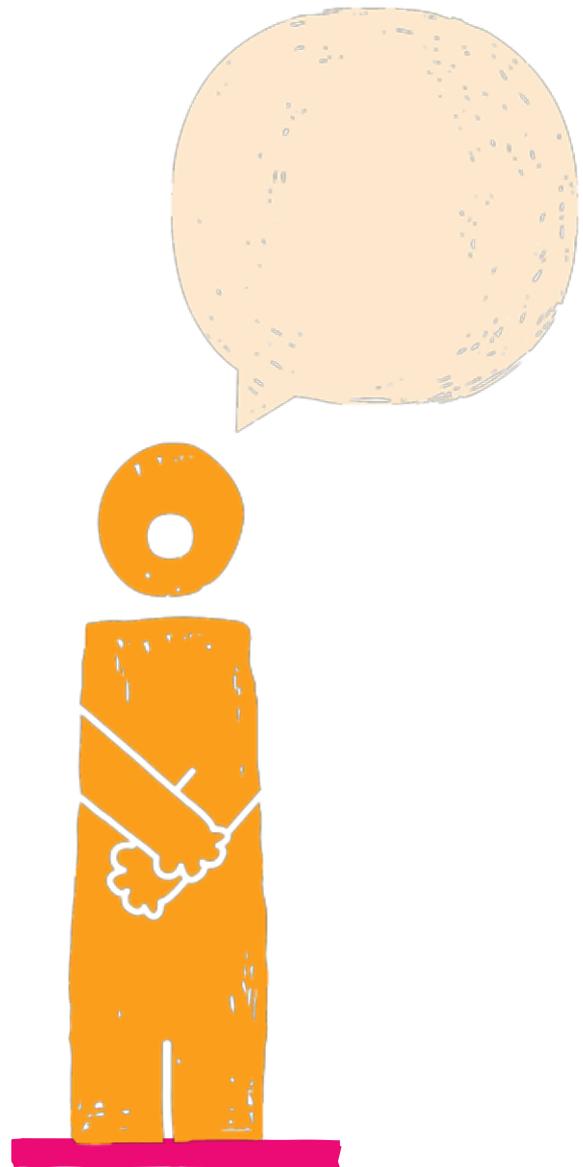
..it is crucial that mental health staff are empathetic, friendly and welcoming to all individuals coming into contact with their services..



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.



..This national consultation was important in giving voice to the views of people who use the mental health services in Ireland...

APPENDICES



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APPENDIX A: INFORMATION AND CONSENT SHEET

My Voice Matters National Consultation on Mental Health Services

Please read the following information below before deciding on whether to participate in the survey.

What is this research for?

My Voice Matters is a national consultation that will gather feedback through two surveys, one for people who use mental health services and one for their family members, friends and carers. The surveys will look at three main issues:

- What services are available
- Experience of services provided
- How services could be improved

This information will help Mental Health Reform identify gaps in the mental health services and, in turn, campaign for improvements in these areas.

The survey is focused on people who have used mental health services within the last two years so that Mental Health Reform can gather up-to-date information on the services based on people's most recent experiences.

This survey will take approximately 15-20 minutes to complete.

Who is Mental Health Reform (MHR)?

Mental Health Reform is the national coalition driving reform of Ireland's mental health services and the social inclusion of people with mental health difficulties. Our vision is of an Ireland where people with mental health difficulties can recover their wellbeing and live a full life in the community. With 62 member organisations¹⁶⁰ and 15,000 individual supporters, MHR provides an independent, coordinated voice to Government, its agencies, the Oireachtas and the general public on mental health issues. This research is being funded by the HSE but the HSE will have no editorial control over the findings or final report.

Where does the information go?

- No names or contact information will be collected and therefore you cannot be identified
- All information collected is confidential and will be stored securely
- Your answers will be archived - again you cannot be identified through this process
- Your answers will be collated and analysed for inclusion in a Mental Health Reform report that will be published

Where can I get further information?

If you need any further information, would like clarification on any of the above, or would like to be kept informed about the survey, you can contact Oscar James, Research Assistant at 01-874-9468. You can also find out more about Mental Health Reform by going to our website at <https://www.mentalhealthreform.ie>.

¹⁶⁰ The number of member organisations stated here was accurate when data collection began in November 2017. When this report was published, Mental Health Reform's membership had grown to 73 member organisations.



If you would like support to fill in the survey, contact Oscar James at 01-874-9468.

Consent

Your participation is entirely voluntary. It is your decision whether you would like to take part or not.

1. I confirm I have read the information about this national consultation and have had the appropriate information and contact information to ask questions.
2. I understand my participation is voluntary and I have the right to withdraw at any time. I accept that once the survey is completed, I cannot withdraw due to the anonymous nature of the survey.
3. I have the right to confidentiality. All information obtained is strictly confidential and is stored securely at the offices of Mental Health Reform and on a secure cloud server.
4. I understand that once the study is over, the data will be archived in the Irish Social Science Data Archive (ISSDA), and used in future research.
5. I have the right to be kept informed about the progress of the project and to be provided with a copy of the final report.

If you have any questions about the survey, please do not hesitate to contact Mental Health Reform.

Please tick the box to indicate your consent to participate in the research.
If you do not consent, please do not complete the survey.



APPENDIX B: PRA AND NON-PRA SAMPLES COMPARED

As noted in section 2.3, targeted sampling was used to recruit people accessing outpatient CMHSs in a single CHO (CHO3). These participants were approached and recruited by Peer Research Assistants (PRAs). PRAs were individuals with lived experience of mental health difficulties that were hired by Mental Health Reform to assist in carrying out this research. All PRAs completed training in basic research skills and received training manuals to prepare them for their role. Training days took place on four separate occasions between September and November 2017. The training covered the following: background information on Mental Health Reform and the research project; the role and importance of peer research; self-care during the process of peer facilitation; principles of research; ethical and practical considerations; and role-play sessions to practice introducing, explaining and facilitating the research and survey.

In total, 274 participants were recruited by PRAs across three sites in CHO3. These service users completed the survey on their own or with the assistance of a PRA on a site where they accessed MHSs. On site assisted survey completion likely increased the possibility of the following: that these individuals may have been influenced by their surroundings, the person administering the survey and/or by acquiescence bias, i.e. where survey participants respond more favourably or positively either because they do not feel comfortable criticising a service or because they believe that they are expected to respond favourably.^{161,162}

Vulnerability to this form of bias can be even more pronounced among ‘patients’ as they are often reluctant to criticise their health care.¹⁶³ For example, in a study of patient satisfaction surveys in paediatric orthopaedics, the responses of those who took the survey on the site where they received care were consistently more positive than the responses of those who completed the survey by post.¹⁶⁴ Therefore, PRA assisted participants who completed the survey on a site where they access MHSs were likely particularly vulnerable to acquiescence bias, resulting in more favourable responses relative to the majority of participants who completed the survey online at a time and place that was convenient for them.

When considered in conjunction with the fact that all PRA assisted service user surveys came from a single CHO (and were therefore likely to be unrepresentative of the views of service users accessing outpatient CMHSs in other CHO areas) and that this subsample was large enough to potentially skew the results, not only in CHO3 but in the sample as a whole, the decision was taken to compare the PRA sample with the non-PRA sample, in an effort to establish whether the responses of these groups were significantly different.

PRA and non-PRA samples were compared with regard to five indicators/proxy indicators of service user satisfaction at different levels of the MHSs (see table one). If the responses of the PRA sample were subject to acquiescence bias, then one could expect that their responses would be significantly more positive/favourable than the responses of the non-PRA sample, both in CHO3 specifically and overall. Owing to the directional nature of this expectation, findings were only considered statistically significant at the $p < .025$ level.

161 Hinz, A., Michalski, D., Schwarz, R., & Herzberg, P. Y. (2007). The acquiescence effect in responding to a questionnaire. *GMS Psycho-Social Medicine*, 4, 1-9.

162 Kaldenberg, D. (2000). Better or worse? Patient's perceptions of hospital services. *Press Ganey Satisfaction Report*, Vol. 4. South Bend, IN: Press Ganey.

163 Carey, R. (1999). How to Choose a Patient Survey System. *Joint Commission Journal on Quality Improvement*, 25(1), 20-25.

164 Segal, N. A., Glass, N. A., Teran-Yengle, P., Singh, B., Wallace, R. B., & Yack, H. J. (2015). Intensive gait training for older adults with symptomatic knee osteoarthritis. *American Journal of Physical Medicine & Rehabilitation/Association of Academic Physiatrists*, 94(10 0 1), 848-858. doi:10.1097/PHM.000000000000264



Table 1: Indicators on which the PRA and non-PRA samples were compared.

Indicators/proxy indicators of satisfaction:	Response Options/Scoring:
'Overall, how satisfied are you with your experience of the HSE mental health services?'	Scale: 0 (I had a very poor experience) to 10 (I had a very good experience)
'Overall, how satisfied are you with the mental health care you received from your GP?'	Scale: 0 (very dissatisfied) to 10 (very satisfied)
'Overall, did you feel that you were treated with dignity and respect by CMHSs?'	Scale: 1 (never) to 3 (always)
'Do you feel well supported and listened to by your current psychiatrist?'	Scale: 1 (never) to 4 (always)
Inpatient Experience	7 item measure

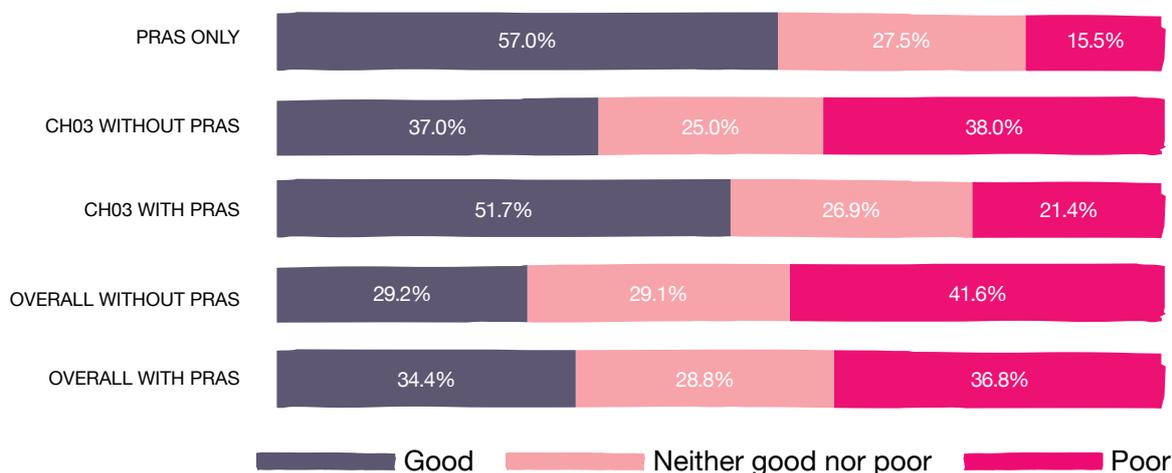
Overall Experience:

On a scale ranging from 0 (very poor experience) to 10 (very good experience), participants were asked to indicate the nature of their overall experience of HSE MHSs in the last two years. Figure one shows the proportions of participants who reported a good (scores between seven and 10), neither good nor poor (scores between four and six) and poor experience (scores between zero and three). This graph clearly shows not only the contrast between the responses of the PRA and non-PRA samples, but also the potential influence inclusion of the PRA sample may have on the finding, both in CHO3 and overall. For example, almost six in ten of the PRA sample (57.0%) reported a good experience, while less than three in ten (29.2%) reported the same in the non-PRA sample as a whole. Similarly, when the PRA sample is included in CHO3, over half (51.7%) the participants reported a good experience of HSE MHSs in the last two years. However, when the PRA sample is excluded from CHO3, this falls to just over a third (37.0%).

Figure 1: Overall experience compared.



OVERALL, HOW SATISFIED ARE YOU WITH YOUR EXPERIENCE OF HSE MHSs IN THE LAST TWO YEARS?





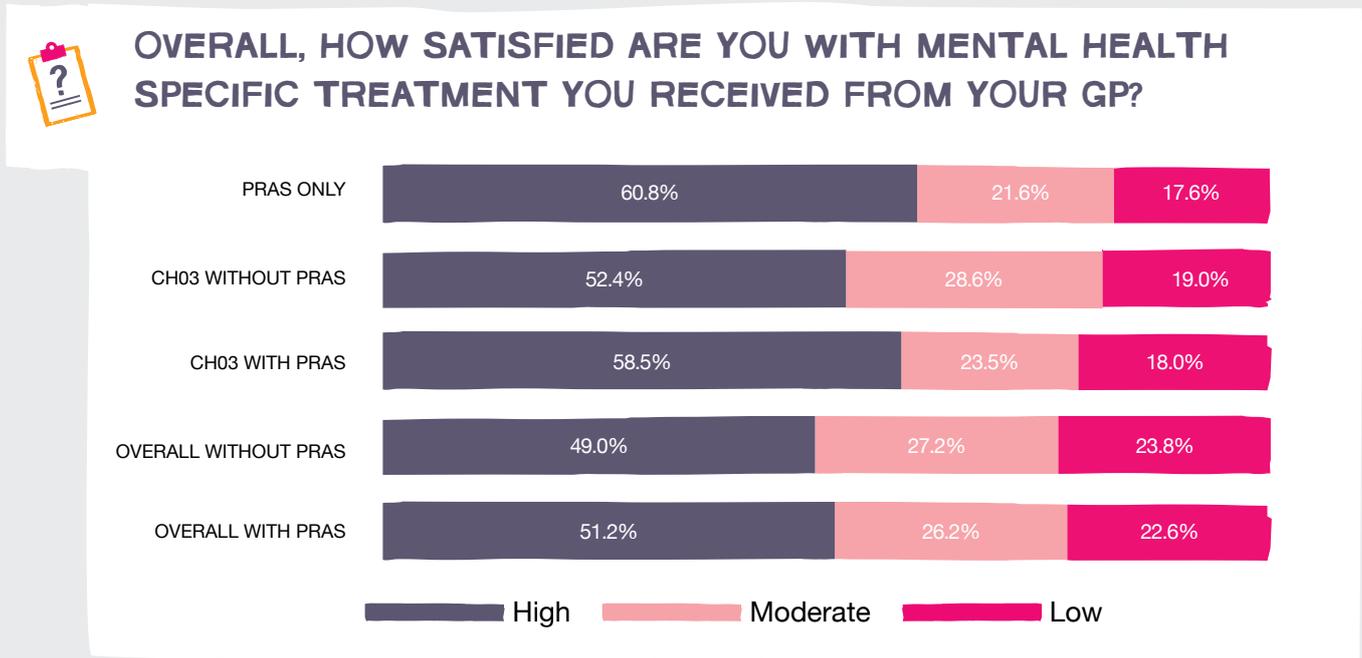
The PRA sample (n=258) was compared to both the total non-PRA sample (n=1039) and the non-PRA sample in CHO3 alone (n=92) using two Mann-Whitney U tests. Results showed that the PRA sample (Mdn=7.00) reported having a significantly more positive experience of HSE MHSs in the last two years than did the total non-PRA sample (Mdn=5.00), U=84860; z=-10.68, p<.001, r=-.29. Similarly, the PRA sample (Mdn=7.00) reported having a significantly more positive experience of HSE MHSs in the last two years than did the non-PRA sample from CHO3 (Mdn=5.00), U=8104.5; z=-4.55, p<.001, r=-.24.

GP/primary care:

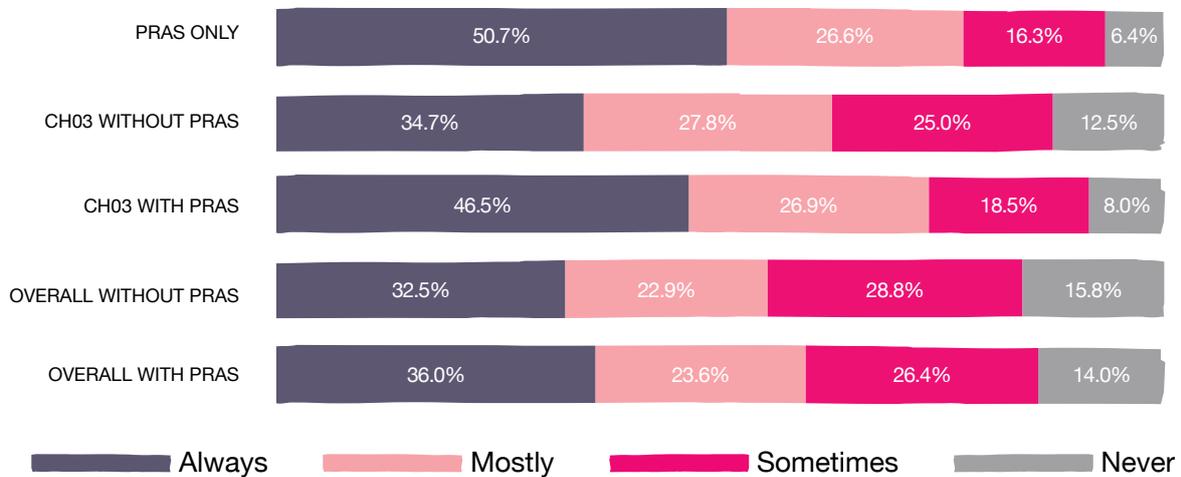
Those who reported that they had sought mental health specific treatment from a GP in the last two years were asked to indicate, on a scale ranging from 0 (very dissatisfied) to 10 (very satisfied), how satisfied they were with the mental health care received from their GP. Note that only participants who reported having sought mental health specific treatment from a GP in the last two years were included in this analysis.

Figure two shows the proportions of participants who reported high (scores of seven or higher), moderate (scores of four to six) and low (scores of three or lower) levels of satisfaction with the mental health specific treatment received from a GP. Although the contrasts are perhaps less clear cut than in figure one, 60.8% of the PRA sample reported high levels of satisfaction in this regard, while the equivalent in the non-PRA sample as a whole was just over half (49.0%).

Figure 2: GP satisfaction compared.



Once again, the PRA sample (n=222) was compared to both the total non-PRA sample (n=967) and the non-PRA sample in CHO3 alone (n=84) using two Mann-Whitney U tests. Results showed that the PRA sample (Mdn=7.00) reported significantly higher levels of satisfaction with the mental health specific treatment received from a GP than did the total non-PRA sample (Mdn=6.00), U=92572.5; z=-3.22, p<.01, r=-.23. However, there was no statistically significant difference between the PRA sample (Mdn=7.00) and the non-PRA sample from CHO3 (Mdn=7.00) in this regard, U=8275.0; z=-1.53, p>.025.

**Figure 3: Feeling well supported and listened to by current psychiatrists compared.****DO YOU FEEL WELL SUPPORTED AND LISTENED TO BY YOUR CURRENT PSYCHIATRIST?****Psychiatrist Care:**

On a scale ranging from one (never) to four (always), participants were asked to indicate the extent to which they felt well supported and listened to by their current psychiatrist. Figure three (above) shows the breakdown of responses in each of the subgroups being examined. Note that only the responses of participants who indicated that they currently had a psychiatrist were included in this analysis.

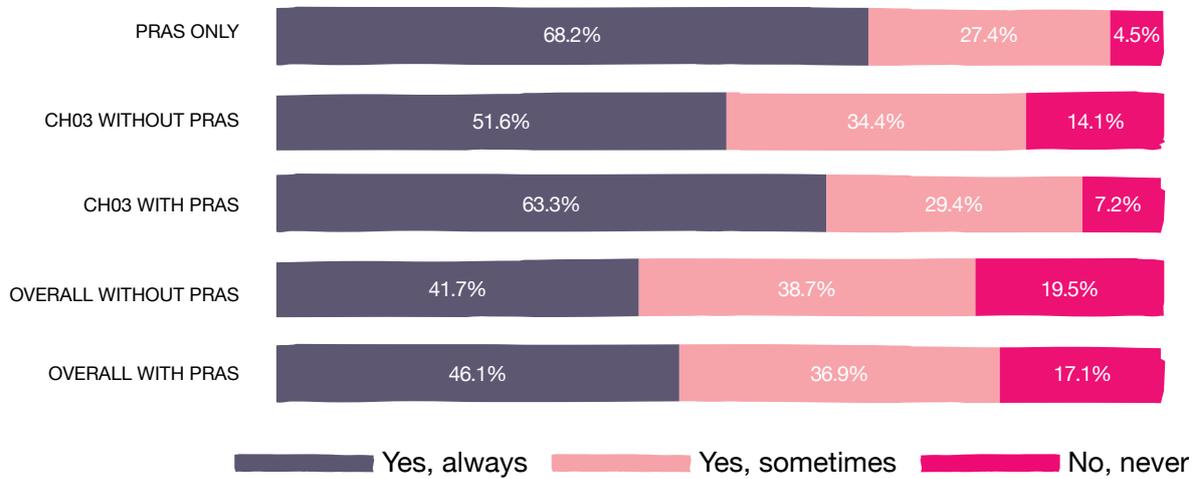
Once again, the contrast between the PRA and non-PRA samples appears clear. For example, over half of the PRA sample (50.7%) reported always feeling well supported and listened to by their current psychiatrist, while less than one-third of the non-PRA sample (32.5%) reported the same. Similar if less pronounced contrasts are evident between the CHO3 samples including and excluding PRA participants and in the sample as a whole including and excluding PRA participants (see figure three).

Again, the PRA sample (n=203) was compared to both the total non-PRA sample (n=865) and the non-PRA sample in CHO3 alone (n=72) using two Mann-Whitney U tests. Results showed the extent to which the PRA sample felt well supported and listened to by their current psychiatrist (Mdn=4.00) was significantly greater than in the non-PRA sample (Mdn=3.00), $U=65261.5$; $z=-5.94$, $p<.001$, $r=-.18$. Similarly, the extent to which the PRA sample felt well supported and listened to by their current psychiatrist (Mdn=4.00) was significantly greater than in the non-PRA sample from CHO3 specifically (Mdn=3.00), $U=5837.0$; $z=-2.716$, $p<.01$, $r=-.16$.

CMHSs:

On a scale ranging from one (always) to three (never), participants who had accessed CMHSs in the last two years were asked to indicate the extent to which they were treated with dignity and respect by CMHSs.¹⁶⁵ Figure four shows the breakdown of responses in each of the subgroups being examined. Note that only the responses of participants who indicated having accessed CMHSs in the last two years were included in this analysis.

¹⁶⁵ Note that higher scores on this question indicate more negative feelings, while lower scores are indicative of more positive feelings.

**Figure 4: Feeling treated with dignity and respect by CMHSs compared.****IN THE LAST TWO YEARS, DID YOU FEEL THAT YOU WERE TREATED WITH DIGNITY AND RESPECT BY CMHSs?**

Again, there appears a clear contrast between the responses of the PRA and non-PRA samples, with almost two-thirds (63.3%) of the PRA sample reporting that they always felt that they were treated with dignity and respect by CMHSs, while just over four in ten (41.7%) of the non-PRA sample reported the same (see figure four). Similarly, when PRA participants are included, 63.3% of participants in CHO3 felt that they were always treated with dignity and respect but this falls by over 10% to 51.6% when PRA participants are excluded.

The PRA sample (n=157) was compared to both the total non-PRA sample (n=798) and the non-PRA sample in CHO3 alone (n=64) using two Mann-Whitney U tests. Results showed the extent to which the PRA sample felt that they were treated with dignity and respect by their CMHSs (Mdn=1.00) was significantly greater than in the total non-PRA sample (Mdn=2.00), $U=43818.0$; $z=-6.47$, $p<.001$, $r=-.21$. Similarly, the extent to which the PRA sample felt that they were treated with dignity and respect by their CMHSs (Mdn=1.00) was significantly greater than in the non-PRA sample from CHO3 (Mdn=1.00), $U=4074.0$; $z=-2.597$, $p<.01$, $r=-.17$.

Inpatient Care:

Seven questions relating to inpatient care¹⁶⁶ were combined to create a measure of inpatient experience. An exploratory factor analysis was conducted on the seven items. The Kaiser-Meyer-Olkin measure verified that the sample size was adequate, $KMO=.87$, and all KMO values for the individual items were $\geq .80$, which is well above the acceptable limit of .5. Bartlett's test of sphericity indicated that correlations between the items were sufficiently large, $\chi^2(21) = 1142.64$, $p<.001$. One component had an eigenvalue above Kaiser's criterion of one and explained 60.72% of the variance. The scree plot showed an inflexion point that would justify retaining one component. Taken together, this suggested that all seven items were measuring the same factor. Factor loading scores ranged between 0.71 and 0.85. The resulting scale demonstrated high internal reliability with a Cronbach's α of .89. Possible scores on this scale ranged from seven to 34. The average for all service users with inpatient experience in the last two years was 20.76 (SD=6.79).

¹⁶⁶ The six questions relating to different aspects of inpatient care (see figure 3.5) and the following question: 'throughout your inpatient experience, how often did you feel that you were treated with dignity and respect by the mental health services?'



Scores of the PRA sample (n=46) on this inpatient experience measure were compared to the equivalent scores in both the total non-PRA sample (n=318) and the non-PRA sample in CHO3 alone (n=19) using two Mann-Whitney U tests. Note that only participant who indicated that they had inpatient experience in the last two years were included in this analysis, resulting in smaller sample sizes, particularly in the non-PRA sample from CHO3. Results showed that the PRA sample (Mdn=24.50) reported significantly more positive inpatient experiences than did the total non-PRA sample (Mdn=20.00), $U=5534.5$; $z=-2.671$, $p<.01$, $r=-.14$. However, there was no statistically significant difference between the PRA sample (Mdn=24.5) and the non-PRA sample from CHO3 (Mdn=23.00) in this regard, $U=8275.0$; $z=-1.53$, $p>.025$.

Summary:

The analysis above highlighted considerable and often statistically significant differences between the PRA and non-PRA samples in both CHO3 and in the sample as a whole. In line with expectations consistent with the presence of acquiescence bias, the responses of the PRA sample were significantly more positive/favourable on all five indicators when compared to the non-PRA sample. When compared to the non-PRA sample in CHO3 specifically, the responses from the PRA sample were significantly more positive/favourable in three of the five cases¹⁶⁷, despite both groups being based in the same CHO area. Note that the non-PRA sample from CHO3 did not differ significantly from the total non-PRA sample (excluding those from CHO3) in relation to any of the above.¹⁶⁸ When considered in conjunction with the significant differences evident between the PRA and the non-PRA samples from CHO3, this indicated that the evident differences could not be attributed to CHO area. Based on these results, it was deemed inappropriate to include the PRA sample in the main analysis outlined in chapter three.

167 Satisfaction with the mental health specific treatment from a GP was an exception. On average, levels of satisfaction in this regard were higher among the PRA sample (M=6.67; SD=3.01) than among non-PRA sample (M=6.19; SD=2.91). However, this difference was not significant at the $p=.025$ level. The other exception was scores on the measure of inpatient experience. Once again, the PRA sample reported more positive experiences than did the PRA sample. However, this difference was not statistically significant.

168 A comparison of the non-PRA sample from CHO3 and non-PRA sample as a whole (excluding those from CHO3): Overall experience of HSE MHS: $U=24936.5$; $z=-1.561$, $p>.05$; Satisfaction with GP: $U=35402.5$; $z=-.576$, $p>.05$; Treated with dignity and respect by CMHSs: $U=20089.0$; $z=-1.847$, $p>.05$; Well supported and listened to by current psychiatrist: $U=26011.0$; $z=-1.093$, $p>.05$; Scores on the inpatient experience measure: $U=2697.5$; $z=-.907$, $p>.05$



APPENDIX C: STATISTICAL INFORMATION FOR THE ORDINAL LOGISTIC REGRESSION ANALYSIS

Table 1: Predictors of overall experience.

Predictors	Estimate (SE)	Wald test statistic	Sig.	Exp(β)	95% C.I. Exp(β)	
				Odds Ratio	Lower	Upper
Age	.017 (.008)	4.825	.028	1.018	1.002	1.034
Gender	.061 (.202)	0.092	.761	1.063	0.715	1.581
Contact details of key worker	-.823 (.202)	16.660	.000	0.439 (2.28*)	0.296	0.652
Provision of written recovery/ care plan	-.782 (.221)	12.519	.000	0.439 (2.18*)	0.297	0.706
Involved in decisions re. medication	-.914 (.201)	20.761	.000	0.401 (2.49*)	0.270	0.594
Continuity of Care: Never had a change of psychiatrist	.472 (.224)	4.455	.035	1.603	1.034	2.484
Continuity of Care: 1-2 changes of psychiatrist	-.050 (.241)	0.044	.834	0.951	0.593	1.524
Choice of treatment	.011 (.200)	0.003	.957	1.011	0.683	1.497

*These are the inverted odds ratios which will be used for interpretation purposes.

NOTE: $R^2 = .23$ (Nagelkerke); Model fit: $\chi^2(8) = 94.08$; $p < .001$; Goodness of fit: $\chi^2(742) = 756.47$; $p > .05$ (Pearson), $\chi^2(742) = 755.18$; $p > .05$ (deviance); Assumption of proportional odds: $\chi^2(8) = 20.80$; $p < .01$.



APPENDIX D: MEDIANS AND MODES FOR LIKERT SCALE SURVEY QUESTIONS

Table 1: Medians and modes for Likert scale survey questions.

Question	Response Options/ Scoring	Median	Mode
<i>'Overall, how satisfied are you with your experience of the HSE mental health services?'</i>	Scale: 0 (I had a very poor experience) to 10 (I had a very good experience)	5.0	0
<i>'In the last 12 months if I needed support during a crisis, I got the help I needed from my community mental health team'</i>	Scale: 1 (strongly disagree) to 5 (strongly agree)	5.0	5
<i>'When I went to an emergency department in the last two years to seek support for my mental health difficulties, I got the support I needed'</i>	Scale: 1 (strongly disagree) to 5 (strongly agree)	4.0	5
<i>'How likely are you to use online support or apps as a part of your therapy if it was available'</i>	Scale: 1 (very unlikely) to 5 (very likely)	4.0	5
<i>'Please indicate the extent that medication has been the and focus of your care and treatment plan'</i>	Scale: 0 (no focus on medication) to 10 (total focus on medication)	7.0	10
<i>'Someone on my mental health team frequently talks to me about recovery as part of my treatment'</i>	Scale: 1 (strongly disagree) to 5 (strongly agree)	3.0	1
<i>'Overall, how satisfied are you with the mental health care you received from your GP?'</i>	Scale: 0 (very dissatisfied) to 10 (very satisfied)	6.0	10
<i>'My GP gave me enough time to speak about my mental health difficulty and listened to what I had to say'</i>	Scale: 1 (strongly disagree) to 5 (strongly agree)	4.0	5

NOTE: The median is the score in a set of responses where all responses are equally likely to fall above or below this score. The mode is the value that most often appears in a set of responses.



APPENDIX E: SERVICE USER SURVEY



Service Users Survey Paper Version

Information and Consent

***My Voice Matters* National Consultation on Mental Health Services**

Please read the following information below before deciding whether to participate in the survey.

What is this research for?

My Voice Matters is a national consultation that will gather feedback through two surveys, one for people who use mental health services and one for their family members, friends and carers. The surveys will look at three main issues:

- What services are available
- Experience of services provided
- How services could be improved

This information will help Mental Health Reform identify gaps in the mental health health services and, in turn, campaign for improvements in these areas.

The survey is focused on people who have used mental health services within the last two years so that MHR can gather up-to-date information on the services based on people's most recent experiences.

This survey will take approximately 15-20 minutes to complete.

Who is Mental Health Reform (MHR)?



Mental Health Reform is the national coalition driving reform of Ireland's mental health services and the social inclusion of people with mental health difficulties. Our vision is of an Ireland where people with mental health difficulties can recover their wellbeing and live a full life in the community. With 62 member organisations and 15,000 individual supporters, MHR provides an independent, coordinated voice to Government, its agencies, the Oireachtas and the general public on mental health issues. This research is being funded by the HSE but the HSE will have no editorial control over the findings or final report.

Where does the information go?

- No names or contact information will be collected and therefore you cannot be identified
- All information collected is confidential and will be stored securely
- Your answers will be archived - again you cannot be identified through this process
- Your answers will be collated and analysed for inclusion in a Mental Health Reform report that will be published

Where can I get further information?

If you need any further information, would like clarification on any of the above, or would like to be kept informed about the survey, you can contact Oscar James, Research Assistant at 01-874-9468. You can also find out more about Mental Health Reform by going to our website at <https://www.mentalhealthreform.ie>.

If you would like support to fill in the survey, contact Oscar James at 083 0520 491.

Consent

Your participation is entirely voluntary. It is your decision whether you would like to take part or not.

1. I confirm I have read the information about this national consultation and have had the appropriate information and contact information to ask questions.
2. I understand my participation is voluntary and I have the right to withdraw at any time. I accept that once the survey is completed, I cannot withdraw due to the anonymous nature of the survey.
3. I have the right to confidentiality. All information obtained is strictly confidential and is stored securely at the offices of Mental Health Reform and on a secure cloud server.
4. I understand that once the study is over, the data will be archived in the Irish Social Science Data Archive (ISSDA), and used in future research.
5. I have the right to be kept informed about the progress of the project and to be provided with a copy of the final report.



If you have any questions about the survey, please do not hesitate to contact MHR.

* 1. Please tick the box to indicate your consent to participate in the research. If you do not consent, please do not complete the survey.

I agree to take part in the above study.

Screening Questions

This question is to make sure the survey is relevant to you.

* 2. Have you had contact with the following services in relation to your mental health in the last two years?

Please tick all that apply.

If you have not had contact with a psychiatrist, community mental health services, or inpatient services in the last two years, please do not complete the survey, as most of the questions will not be relevant to your experience.

- Psychiatrist
- Community Mental Health Services
- Inpatient Mental Health Services
- None of these

A few quick questions

3. Do you use or have access to private care?

This means services that you paid for personally or with private health insurance, without support from the HSE, and includes any type of talking therapy, treatment by a psychiatrist, private inpatient care and/or private community mental health service.

Please tick yes or no to each of the below answer options.

	Yes	No
Private psychiatrist	<input type="radio"/>	<input type="radio"/>
Private therapist/counsellor	<input type="radio"/>	<input type="radio"/>
Access to private community mental health services	<input type="radio"/>	<input type="radio"/>
Private inpatient mental health care	<input type="radio"/>	<input type="radio"/>



4. Overall, how long have you been in contact with HSE mental health services?

- Less than 1 year
- 1 to 5 years
- 6 to 10 years
- More than 10 years
- I am no longer in contact with HSE mental health services
- Don't know / can't remember

Section A. Primary care

This is an initial question to see if this section is relevant to you.

* 5. Have you sought mental health specific treatment from a GP?

- Yes -> go to Q6
- No -> go to section B

Primary Care

* 6. My GP...

Please tick yes or no to each of the answer options.

	Yes	No
Prescribed me medication for my mental health difficulty	<input type="radio"/>	<input type="radio"/>
Referred me to a psychiatrist	<input type="radio"/>	<input type="radio"/>
Referred me to the emergency department	<input type="radio"/>	<input type="radio"/>
Referred me to a psychologist	<input type="radio"/>	<input type="radio"/>
Gave me information or referral to counselling/psychotherapy services	<input type="radio"/>	<input type="radio"/>
Referred me to a HSE community mental health team	<input type="radio"/>	<input type="radio"/>
Referred me to a local voluntary group or service	<input type="radio"/>	<input type="radio"/>



7. Overall how satisfied are you with the mental health care you received from your GP?

Please tick a number to indicate your answer, where 0 means very dissatisfied, and 10 means very satisfied.

- | | |
|-------------------------|--------------------------|
| <input type="radio"/> 0 | <input type="radio"/> 6 |
| <input type="radio"/> 1 | <input type="radio"/> 7 |
| <input type="radio"/> 2 | <input type="radio"/> 8 |
| <input type="radio"/> 3 | <input type="radio"/> 9 |
| <input type="radio"/> 4 | <input type="radio"/> 10 |
| <input type="radio"/> 5 | |

8. My GP gave me enough time to speak about my mental health difficulty, and listened to what I had to say.

- | | |
|--------------------------------------|---|
| <input type="radio"/> Strongly agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly disagree |
| <input type="radio"/> Neutral | |

9. Did your GP assess your physical health in the last 2 years? (e.g. blood pressure, weight)

- Yes
- No
- Can't Remember/Don't Know

Section B. Diagnosis and your Psychiatrist

We understand that not everybody agrees with the mental health diagnosis they have been given, or with the bio-medical approach to mental health, however we want to identify if people's diagnosis affects the care and treatment they receive in mental health services.

10. If your mental health difficulty has been given a diagnosis, please select the closest to your main diagnosis:

- | | |
|---|--|
| <input type="radio"/> Schizophrenia (includes schizoaffective disorder) | <input type="radio"/> Eating disorder |
| <input type="radio"/> Depression | <input type="radio"/> Post-Traumatic Stress Disorder |
| <input type="radio"/> Anxiety disorder | <input type="radio"/> Other |
| <input type="radio"/> Bi-polar disorder | <input type="radio"/> Have not been given a diagnosis |
| <input type="radio"/> Personality disorder | <input type="radio"/> Prefer not to answer this question |

Diagnosis and your psychiatrist



11. Did you feel your diagnosis was explained to you in a way you understood?

- Yes, definitely
- Yes, to some extent
- No
- Can't remember/don't know

12. In the last 2 years, how often have you had a change of psychiatrist?

- Never -> go to Q14
- Once
- Twice
- 2-4 times
- More than 4 times
- I used to have a psychiatrist, but I don't have one any longer
- Never had a psychiatrist -> go to Q14

13. If you had a change of psychiatrist during the last 2 years, what has been the impact on your care and treatment?

- Very positive impact
- Positive impact
- No impact
- Little impact
- Negative impact
- Very negative impact

14. Do you feel well supported and listened to by your current psychiatrist?

- Always -> go to section C
- Mostly
- Sometimes
- Never

15. If you chose 'Mostly', 'Sometimes' or 'Never', please tell us why you don't feel supported and listened to by your psychiatrist.

Section C. Community Mental Health Services

HSE community based mental health care involves provision of mental health care for people with severe or complex difficulties in your local area. Community mental health teams should include staff from a range of different disciplines including psychiatrists, psychologists, occupational therapists, social workers, peer support workers, and mental health nurses.



* 16. What kind of mental health service support have you received from the HSE community mental health services?

Tick all that apply.

- | | |
|--|--|
| <input type="checkbox"/> A Psychiatrist | <input type="checkbox"/> A speech and language therapist |
| <input type="checkbox"/> CPN (Community Psychiatric Nurse) | <input type="checkbox"/> Family therapist |
| <input type="checkbox"/> A counsellor or psychotherapist | <input type="checkbox"/> A Peer support worker |
| <input type="checkbox"/> A psychologist | <input type="checkbox"/> An Advocate |
| <input type="checkbox"/> A social worker | <input type="checkbox"/> Other |
| <input type="checkbox"/> An occupational therapist | <input type="checkbox"/> None -> go to section D |

Community Mental Health Services

17. Do you have the contact details of a designated mental health professional in your community mental health team (a key worker) to provide you with support?

- Yes
- No -> go to Q19
- In the process of getting details -> go to Q19

18. If you have details of a key worker, do you feel well supported by your key worker?

- Yes, definitely
- Yes, to some extent
- No

19. Did your community mental health team take into account how your mental health difficulty affects other areas of your life (e.g. housing, employment, education, community life)?

- Yes, definitely
- Yes, to some extent
- No
- Can't remember/Don't know



20. Have you heard of any of the following advocacy services?

- Citizens Information Centre
- Irish Advocacy Network
- Money Advice & Budgeting Service (MABS)
- National Advocacy Service for People with Disabilities
- Other (please specify)

21. A crisis is if you need urgent help because your mental or emotional state is getting worse very quickly.

Do you have someone in the community mental health services who you can contact out of office hours if you have a crisis?

- Yes
- No -> go to Q23
- Not sure -> go to Q23

22. In the last twelve months if I needed support during a crisis, I got the help I needed from my community mental health team

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree



23. As part of your recovery/care plan in the last 2 years, did the HSE community mental health services link you in with any of the following supports?

Tick all that apply

- Employment supports
- Housing supports
- Social welfare entitlements
- Online mental health supports
- Educational programmes
- Peer support
- Recovery programmes e.g. WRAP
- Voluntary organisations e.g. GROW, Aware, Suicide or Survive
- I found out about supports by myself
- I was not linked to any community supports by the mental health services
- Don't know / can't remember

24. If you were referred for talking therapy by HSE community mental health services, how long was the waiting time before accessing this support?

- No waiting time
- 1-2 weeks
- 2-4 weeks
- Between one and three months
- Longer than 3 months
- Longer than 6 months
- 12 -18 months
- 18 months or longer
- Never offered talking therapy from mental health services
- Don't know/can't remember

25. Overall in the last 2 years, did you feel that you were treated with respect and dignity by community mental health services?

- Yes, always
- Yes, sometimes
- No

Section D. In-patient Experience

When we say in-patient care, we mean a mental health ward in a hospital or psychiatric hospital.



26. Have you been a voluntary or involuntary inpatient in the last 2 years?

- Yes, a voluntary inpatient -> go to Q27
- Yes, an involuntary inpatient -> go to Q27
- Yes, both voluntary and involuntary inpatient -> go to Q27
- No inpatient experience -> go to section E

In-patient Experience

27. How satisfied were you on the following aspects of your inpatient experience?

	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied
Diet/nutrition	<input type="radio"/>				
Range of recreational activities	<input type="radio"/>				
Use of medication	<input type="radio"/>				
Use of seclusion, restraint, and sedation	<input type="radio"/>				
Therapeutic supports	<input type="radio"/>				
Enforcement of daily routine, e.g. bedtime	<input type="radio"/>				

28. Throughout your inpatient experience, how often did you feel that you were treated with respect and dignity by the mental health services?

- Always
- Most of the time
- Sometimes
- Never

Section E. Experience with Emergency Department

* 29. In the last 2 years, have you gone to an Emergency Department to seek support for your mental health difficulties?

- Yes -> go to Q30
- No -> go to section F

Experience with Emergency Department



30. When I went to an Emergency Department in the last 2 years to seek support for my mental health difficulties I got the support I needed.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree

31. During the last two years when you went to an Emergency Department for a mental health crisis, what is the longest you waited to see a mental health professional?

- 0-2 hours
- 2-4 hours
- 4-6 hours
- 6-8 hours
- 8-10 hours
- 10-12 hours
- 12-14 hours
- 14-16 hours
- 16-18 hours
- 18-20
- 20+ hours
- Never saw a mental health professional

Section F. Continuity of Recovery/Care Plans

When we discuss recovery, we are talking about staff and services having hopeful attitudes about your recovery, listening to you, and valuing your views about your care and treatment. It also means that you have choices and are given the opportunity to be an equal partner in decisions relating to your care/treatment, and that services and staff support your inclusion within the community.

32. Do you have a written recovery/care plan developed with your mental health team?

- Yes
- No, but I would like to
- No, but I'm not interested anyway
- Don't know/can't remember

33. Someone on my mental health team frequently talks to me about recovery as a part of my treatment.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree



34. Has a member of your mental health team talked to you about your strengths as a core part of your recovery/care plan?

- Yes, definitely
- Yes, to some extent
- No, but I would have liked that
- Don't know / can't remember

35. Have you been involved as much as you would like in decisions about the medicines you take

- Yes, definitely
- Yes, to some extent
- No, but I wanted to be
- No, but I did not want to be
- Don't know / can't remember

36. Please indicate the extent that medication has been the main focus of your care, and treatment plan by the HSE mental health services?

Please give your answer using a number between 0-100 where 0 means no focus on medication, and 100 means total focus on medication.

Section G: Complaints

* 37. Did anyone from the HSE mental health services let you know how to make a complaint about the mental health services?

- Yes, on more than one occasion
- Yes, once
- I found the information displayed in their facilities (clinic, website, leaflets)
- No

38. Which of the following statements best represents your experience?

- I have never wanted to complain about the mental health services -> go to section H
- I have wanted to complain but did not -> go to Q39
- I have wanted to complain and I did -> go to Q40

If you wanted to complain but didn't...



39. If you wanted to complain but did not, why didn't you?

Tick all that apply.

- I was worried that complaining would affect my quality of healthcare
- I didn't know how
- I was not well enough to do so
- I didn't think it would make a difference
- I haven't got around to it yet
- I was scared to

If you filed a complaint...

40. If you filed a complaint, what happened?

- The issue was resolved satisfactorily
- Nothing was done about it
- I received an apology
- My quality of service suffered as a result

Section H. Overall Feedback Section

* 41. How likely are you to use online support or apps as a part of your therapy if it was available?

- Very likely
- Unlikely
- Likely
- Very unlikely
- Neutral

42. Overall, how satisfied are you with your experience of the HSE mental health services?

Please tick a number to indicate your answer, where 0 means very dissatisfied, and 10 means very satisfied.

- 0
- 6
- 1
- 7
- 2
- 8
- 3
- 9
- 4
- 10
- 5



43. Is there any service that was not available to you that you would have benefitted from?

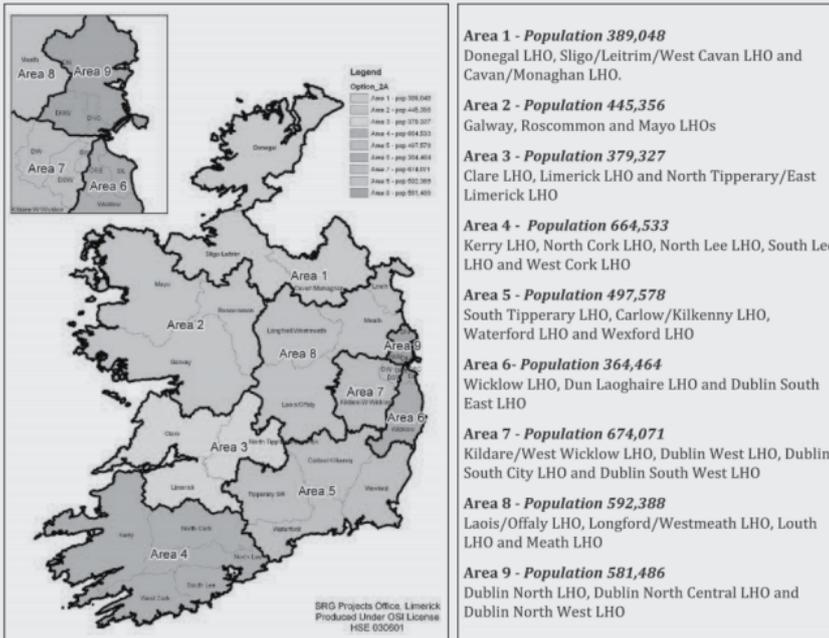
44. What kind of positive experiences have you experienced from HSE mental health services?

About You

Now we want to ask you some questions about yourself and your background. We use this information to identify who is having a better or worse experience of the HSE mental health services, e.g. depending on your location. This information cannot be used to identify you, because we will not be recording any names or contact details.

* 45. What is your Community Healthcare Organisation catchment area?

The nine Community Healthcare Organisations are outlined below:



- CHO Area 1 (Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan)
- CHO Area 2 (Galway, Roscommon, Mayo)
- CHO Area 3 (Clare, Limerick, North Tipperary/East Limerick)
- CHO Area 4 (Kerry, North Cork, North Lee, South Lee, West Cork)
- CHO Area 5 (South Tipperary, Carlow/Kilkenny, Waterford, Wexford)
- CHO Area 6 (Wicklow, Dun Laoghaire, Dublin South East)
- CHO Area 7 (Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West)
- CHO Area 8 (Laos/Offaly, Longford/Westmeath, Louth/Meath)
- CHO Area 9 (Dublin North, Dublin North Central, Dublin North West)



46. Do you have a...

Tick all that apply.

- Medical card
- GP access card
- Over 70s card
- Drugs Payment Scheme card
- I do not have any of the above

47. What is your marital status?

- Single
- Married
- Separated
- Widowed
- Remarried
- Cohabiting
- Divorced
- Civil partnership
- Other/Prefer not to classify

48. What is your ethnic or cultural background?

- Irish
- Irish traveller
- English/Welsh/Scottish/Northern Irish/British
- Any other White background
- African
- Caribbean
- Any other Black, African, Caribbean background
- Indian
- Pakistani
- Any other ethnic group (please specify)
- Bangladeshi
- Chinese
- Any other Asian background
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed or multiple ethnic background
- Arab

49. What is your age in years?

50. Are you...

- Male
- Female
- Other



51. Are you...

Tick all that apply.

- Straight/Heterosexual
- Gay/Lesbian
- Bisexual
- Transgender
- Intersex
- Other
- Prefer not to say

52. Do you have any of the following long-lasting conditions or difficulties?

Tick all that apply.

- Blindness or a serious vision impairment
- Deafness or a serious hearing impairment
- A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying
- An intellectual disability
- A difficulty with learning
- Remembering or concentrating
- A speech and language difficulty
- Autism spectrum disorder
- A difficulty with pain, breathing
- Other chronic illness or condition
- None of the above

53. Could you please indicate what type of housing you currently live in?

- Home that you own/pay a mortgage for
- Home that family member owns/pays a mortgage for
- Renting from local authority
- Renting from a voluntary housing association
- Other (please specify)
- Renting from a private landlord
- Renting with support of rent supplement or Housing Assistance Payment
- Live in a community house/hostel
- Live in homeless accommodation



54. How would you describe your current work status?

- Paid employment, full time or part time
- Student
- Looking after home or family
- Unable to work due to permanent sickness or disability
- Unemployed
- Retired from employment
- Other (please specify)

55. What is your main source of income?

- Income from work or self-employment
- Job Seekers Allowance/Benefit
- Occupational or personal pension
- Back to education allowance
- State old age pension
- Disability allowance
- Income from investment or savings
- Informal family support
- Carer's allowance
- Invalidity Pension
- Other (please specify)

56. What is your highest educational attainment level?

- No formal education/Primary school only
- Third level non degree
- Lower secondary
- Third level degree
- Upper secondary
- Post graduate qualification

The end!

Thank you so much for taking part in Mental Health Reform's survey!

Your feedback is extremely important for us. With your feedback, we will write a document that highlights areas for improvement in the HSE mental health services.

If you would like to add your voice to Mental Health Reform's campaign to make mental health a national priority you can sign up to receive our newsletter and/or follow us on any of our social media platforms.

If you have any questions, please do not hesitate to contact us by:

- Email: info@mentalhealthreform.ie
- Website: www.mentalhealthreform.ie
- Phone: 01 874 9468 or 0830520491



Please return completed hard copies with the pages stapled together further privacy to the following address:

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Seirbhís Sláinte
Níos Fearr
á Forbairt

Building a
Better Health
Service

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