

# Mental Health Reform

Promoting Improved Mental Health Services

## Family, Friends and Carers Survey

### Information & 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 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 Mental Health Reform.**

\* 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.

## Introduction

**This survey aims to capture the views of individuals supporting people with mental health difficulties on public mental health services.**

**This survey asks about:**

- 1) the person that you are supporting, and their experiences of the services**
- 2) how your support needs were addressed**

**This survey can also be completed by people who have recent experience supporting people with mental health difficulties, but are no longer providing that support.**

**There are many different ways that people identify with their role in supporting people with mental health difficulties, and there is yet to be a single word to describe it. For the purposes of the survey, we use the words 'support' and 'care' to describe this role.**

## Screening question

**This is just a question to see if this survey is relevant to you.**

***If the person you support has no contact with mental health specific services in the last 2 years, the questions aren't relevant to your experience, please do not continue with the survey.***

\* 2. Has the person you support had contact with the following mental health services in the last two years?

Please tick all that apply.

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

## Section A. About the person you support

**In this section, questions are about the person you support. Please answer the questions in relation to that person.**

**These questions are important to get an idea of the breadth of experiences that family, friends, and carers have when supporting people with mental health difficulties. For example, different ages, diagnoses, or levels of contact with the HSE mental health services may change the experiences of people in a supporting role.**

3. Who is the person you support?

- |   |                                      |
|---|--------------------------------------|
| <input type="radio"/> Spouse/Partner                | <input type="radio"/> Other relative |
| <input type="radio"/> Parent                        | <input type="radio"/> Friend         |
| <input type="radio"/> Child (including adult child) | <input type="radio"/> Other          |
| <input type="radio"/> Sibling                       |                                      |

4. What is the age of the person you support?

5. Overall, how long have they been in contact with HSE mental health services?

- |  |   |
|--|---|
| <input type="radio"/> Less than 1 year | <input type="radio"/> More than 10 years  |
| <input type="radio"/> 1 to 5 years     | <input type="radio"/> They are no longer in contact with HSE mental health services |
| <input type="radio"/> 6 to 10 years    | <input type="radio"/> Don't know / can't remember                                   |

6. Do they have a...

Tick all that apply.

- Medical card
- GP access card
- Over 70s card
- Drugs Payment Scheme card
- None of the above

7. Are you living with the person you support?

- Yes
- Some of the time
- No

8. 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.

If the person you support has a diagnosis for their mental health difficulty, please select the closest to their 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 |

9. Does the person you support also have a long term physical health diagnosis as well as a mental health diagnosis?

- Yes
- No

10. Does the person you support use or have access to private care?

This means services that they 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
A private psychiatrist	<input type="radio"/>	<input type="radio"/>
Private therapist/counsellor	<input type="radio"/>	<input type="radio"/>
Access to private community services	<input type="radio"/>	<input type="radio"/>
Private inpatient care	<input type="radio"/>	<input type="radio"/>

## Section B. Primary care

**This section relates to the person you support. Please answer the questions in relation to them.**

\* 11. Has the person you support sought mental health specific treatment from the GP?

- Yes -> go to Q12
- No -> go to section C

## Primary care

This section relates to the person you support. Please answer the questions in relation to them.

\* 12. The GP...

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

	Yes	No	Don't know
Prescribed them medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred them to a psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred them to A&E	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred them to a psychologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gave them information or referral to counselling/psychotherapy services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Referred them to the HSE community mental health team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Informed or referred them to a local voluntary group or service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Section C. Your support needs

This section is about you, and your support needs.

\* 13. My caring role impacts me financially.

- Strongly agree  Disagree  
 Agree  Strongly disagree  
 Neutral

14. Please describe your role in relation to the person with mental health difficulties

- Carer  
 Supporter  
 Other (please specify)

15. Please indicate if you have used any of the following advocacy services.

Tick all that apply.

- Citizens Information Centre
- Irish Advocacy Network
- Money Advice & Budgeting Service (MABS)
- National Advocacy Service for People with Disabilities
- None of the above
- Other (please specify)

16. Have you accessed any of the following in relation to your support role in the last 2 years?

Tick all that apply.

- Peer support groups
- Individual counselling
- Family therapy/counselling
- Advocacy service
- Family mental health education
- Listening service over the phone or helpline
- Online support (including counselling, listening service)
- No support accessed, though it was available
- No support available
- I was not aware of available support

17. Please indicate whether the HSE has assessed or addressed your needs for each of the following options.

When we say assessed we mean have the mental health service staff asked you what your needs as a supporter are in terms of your wellbeing and coping skills.

When we say addressed we mean that mental health services have provided supports to you based on their assessment of your needs as a supporter.

	Assessed	Addressed	Neither
Your physical wellbeing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your emotional wellbeing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your coping skills	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Section D. Information and advice given to you by HSE mental health services

\* 18. Are you satisfied with the information and advice you received by the HSE Mental Health Services when the person you support first came into contact with the services?

- Very satisfied
- Satisfied
- Neutral
- Dissatisfied
- Very dissatisfied
- I wasn't supporting them when they first came into contact with the services

19. How satisfied are you with the information given about mental health services on the HSE website?

- Very satisfied
- Satisfied
- Neutral
- Dissatisfied
- Very dissatisfied
- I have not accessed the HSE's website

20. The HSE mental health services explained to me how to support the person in the long term.

- Strongly agree
- Agree
- Neutral
- Disagree
- Strongly disagree
- Not involved by my choice
- Not involved by choice of the person I support

21. 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

22. Do you have the contact details of a designated mental health professional (key worker) in the HSE mental health services to provide you with support?

- Yes
- No
- In the process of getting details
- Not involved by my choice
- Not involved by choice of the person I support

23. Did the HSE mental health services give you information about a support group in the community to support your needs?

- Yes, but only at my request -> go to Q24
- Yes, without prompt -> go to Q24
- No, but I would have liked to receive this information -> go to section E
- No, but I wouldn't have wanted this information -> go to section E
- Not involved by my choice -> go to section E
- Not involved by choice of the person I support -> go to section E



24. Only if you received information, was this information useful?

- The information was useful
- The information wasn't very useful

## Section E. Supporting in-patient care

**When we say inpatient care, we mean staying in a mental health ward in a hospital, or in a psychiatric hospital.**

25. Has the person you support been a voluntary or involuntary inpatient in the last 2 years?

- Yes, a voluntary patient -> go to Q26
- Yes, an involuntary patient -> go to Q26
- Yes, both voluntary and involuntary patient -> go to Q26
- No inpatient experience. -> go to section F

## Section E. Supporting in-patient care

26. The last time the person was in hospital...

Please provide an answer for each.

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	I was not involved
I felt listened to by the hospital staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt the hospital expected me to be responsible for the recovery of the individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt the hospital valued my knowledge and experience of supporting the individual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt the hospital considered the role that I play in supporting the individual's recovery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Supporting in-patient care

**These questions relate to the last time the individual was in hospital.**

\* 27. Did the mental health services involve you in the discharge planning for the person you support?

- Yes -> go to Q28
- No -> go to section F
- I was not involved by my choice -> go to section F
- I was not involved by choice of the person I support -> go to section F

## Supporting in-patient care

**These questions relate to the last time the individual was in hospital.**

28. Were your views and concerns incorporated into the discharge plan for the person you support?

- All of my views and concerns were taken into account
- Most of my views and concerns were taken into account
- Some of my views and concerns were taken into account
- None of my views or concerns were taken into account

29. Before discharge were your support needs identified by the mental health team?

(support needs as a friend/family member/carer)

- Yes
- No
- Sometimes

30. Before discharge were you given information about how to access any of the following:

Please tick all that apply.

- Community mental health services
- Advocacy services
- Relevant voluntary organizations
- Relevant community groups
- Supported employment for the individual
- Crisis point of contact
- I was not given any information

31. Were you given a minimum of 2 days notice before the person you support was discharged from the mental health inpatient unit?

- Yes
- No
- Sometimes

32. Before the individual's discharge, was the person you support notified of the date for follow up appointment?

- Yes
- No
- Sometimes
- Don't know

## Section F. Child and Adolescent Mental Health Services (CAMHS)

\* 33. Has the person you support accessed Child and Adolescent Mental Health Services (CAMHS)?

- Yes -> go to Q34
- No -> go to section G

## Discharge from CAMHS

34. Has the person you support been discharged from CAMHS?

- Yes -> go to Q35
- No -> go to section G

## Transition from CAMHS to Adult Mental Health Services

35. Upon discharge from CAMHS, did you experience any of the following issues?

Please tick all that apply

- |  |  |
|--|--|
| <input type="checkbox"/> There was no follow-on key worker identified for the child/young adult  | <input type="checkbox"/> There was a gap in the support available after discharge from CAMHS   |
| <input type="checkbox"/> The person I support had to re-enter the system as an adult and required reassessment   | <input type="checkbox"/> There was a big change in environment between CAMHS and Adult Mental Health Services that did not suit the person I support |
| <input type="checkbox"/> There was no referral, or there was an issue with the referral that meant they couldn't access follow-on mental health services | <input type="checkbox"/> I experienced a lack of support from HSE mental health services for me as a family carer                                    |
| <input type="checkbox"/> The person I support continued using CAMHS because Adult Mental Health Services were not suited to their needs                  | <input type="checkbox"/> None of the above   |

## Section G. Crisis care

**A crisis is when a person with a mental health difficulty needs urgent help because their mental or emotional state is getting worse very quickly.**

36. Were you given information about what to do in the case of a crisis?

- Yes, and it was useful
- Yes, but it wasn't useful
- No, but I would have liked to receive this information
- No, but I wouldn't have liked to receive this information.

37. In the last 2 years, if you tried to contact community mental health services during a crisis did the person you support get the help they needed for their mental health difficulty?

- I have not contacted community mental health services during a crisis
- I tried to contact the community mental health services but the person I support didn't receive the help they needed/no answer
- I contacted them and received some help/advice
- I contacted them and the person I support got the help they needed

## Section H. Emergency department

\* 38. In the last 2 years, did the person you support need to go to an Emergency Department for their mental health difficulty?

- Yes -> go to Q39
- No -> go to Section I
- Don't know -> go toSection I

## Emergency department

39. In the last 2 years, when the person you support sought help for their mental health difficulty in an Emergency Department, they received support that adequately addressed their needs.

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

40. In the last two years when the person you support went to an Emergency Department for a mental health crisis, what is the longest they waited to be seen by 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 hours
- 20+ hours
- Never saw a mental health professional

## Section I. Overall Feedback

\* 41. Overall, are you satisfied that HSE mental health services have considered your support needs?

- Very satisfied
- Satisfied
- Neutral
- Dissatisfied
- Very Dissatisfied

42. Are your views incorporated into the individual's recovery/care plan?

- All of my views and suggestions were taken into account     None of my views or suggestions were taken into account
- Most of my views and suggestions were taken into account     Not involved by my choice
- Some of my views and suggestions were taken into account     Not involved by choice of the person I support

43. Has confidentiality between the mental health team and the person you support ever been a barrier to your views being taken into account by the mental health services?

- Never
- Once
- Sometimes
- Always

44. In the last 2 years, I have had an opportunity to provide feedback to the mental health services to inform service improvement.

NOTE: By feedback, we do not mean complaints.

- Strongly agree     Disagree
- Agree     Strongly disagree
- Neutral

45. Overall, how satisfied are you that the person you support has received a good quality service from 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

46. Overall, how satisfied are you that the HSE mental health services has provided the individual with supports that adequately target their needs?

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 |                          |

47. Is there any service that was not available which would have benefited the person receiving support?

48. Is there any service that was not available which you would have benefited from?

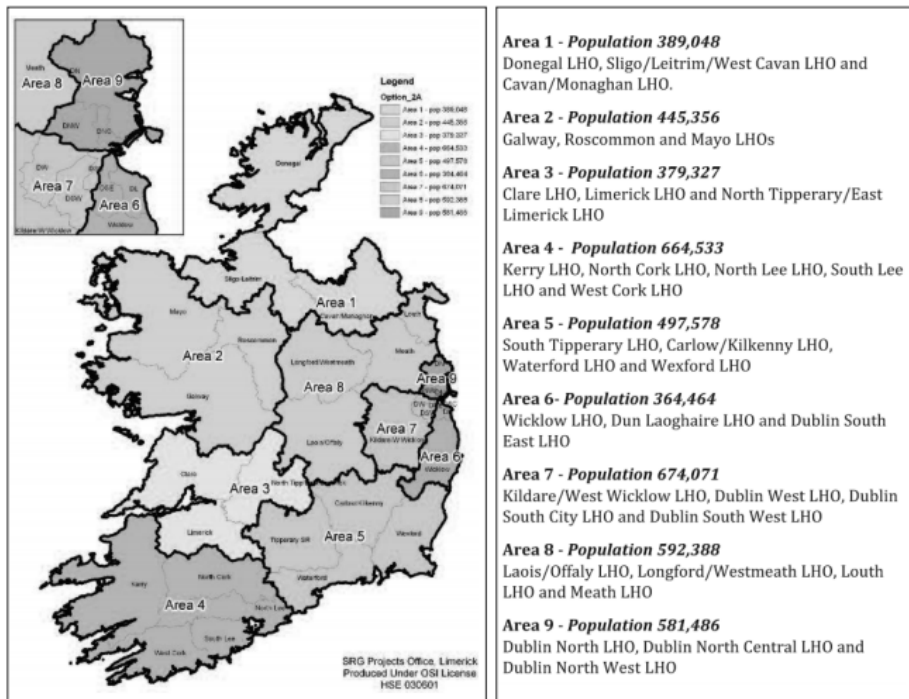
49. What positive experiences have you experienced of HSE mental health care?

## 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.**

\* 50. 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 (Laois/Offaly, Longford/Westmeath, Louth/Meath)
- CHO Area 9 (Dublin North, Dublin North Central, Dublin North West)

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

Tick all that apply.

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



52. 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)

53. 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)

54. 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

55. What is your age in years?

56. Are you

- Male
- Female
- Other

57. Are you...

Tick all that apply.

- Straight/heterosexual
- Transgender
- Gay/Lesbian
- Intersex
- Bisexual
- Other

58. What is your ethnic or cultural background

- |  |   |
|--|---|
| <input type="radio"/> Irish  | <input type="radio"/> Bangladeshi                                   |
| <input type="radio"/> Irish Traveller                                | <input type="radio"/> Chinese                                       |
| <input type="radio"/> English/Welsh/Scottish/Northern Irish/British  | <input type="radio"/> Any other Asian background                    |
| <input type="radio"/> Any other White background                     | <input type="radio"/> White and Black Caribbean                     |
| <input type="radio"/> African  | <input type="radio"/> White and Black African                       |
| <input type="radio"/> Caribbean                                      | <input type="radio"/> White and Asian                               |
| <input type="radio"/> Any other Black, African, Caribbean background | <input type="radio"/> Any other mixed or multiple ethnic background |
| <input type="radio"/> Indian   | <input type="radio"/> Arab  |
| <input type="radio"/> Pakistani                                      |   |
| <input type="radio"/> Other (please specify)                         |   |

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](mailto:info@mentalhealthreform.ie)**

**Website: [www.mentalhealthreform.ie](http://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:**

**Oscar James,  
Mental Health Reform,  
Coleraine House,  
Coleraine St,  
Dublin 7.**