

# Mental Health Reform

Promoting Improved Mental Health Services

## 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"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Range of recreational activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use of medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Use of seclusion, restraint, and sedation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Therapeutic supports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enforcement of daily routine, e.g. bedtime	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<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.

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

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?

- |                                   |  |
|-----------------------------------|--|
| <input type="radio"/> 0-2 hours   | <input type="radio"/> 12-14 hours                            |
| <input type="radio"/> 2-4 hours   | <input type="radio"/> 14-16 hours                            |
| <input type="radio"/> 4-6 hours   | <input type="radio"/> 16-18 hours                            |
| <input type="radio"/> 6-8 hours   | <input type="radio"/> 18-20                                  |
| <input type="radio"/> 8-10 hours  | <input type="radio"/> 20+ hours                              |
| <input type="radio"/> 10-12 hours | <input type="radio"/> 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.

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

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.

- |   |  |
|---|--|
| <input type="checkbox"/> I was worried that complaining would affect my quality of healthcare | <input type="checkbox"/> I didn't know how                         |
| <input type="checkbox"/> I was not well enough to do so                                       | <input type="checkbox"/> I didn't think it would make a difference |
| <input type="checkbox"/> I haven't got around to it yet                                       | <input type="checkbox"/> 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?

- |                                   |                                     |
|-----------------------------------|-------------------------------------|
| <input type="radio"/> Very likely | <input type="radio"/> Unlikely      |
| <input type="radio"/> Likely      | <input type="radio"/> Very unlikely |
| <input type="radio"/> 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.

- |                         |                          |
|-------------------------|--------------------------|
| <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 |                          |

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

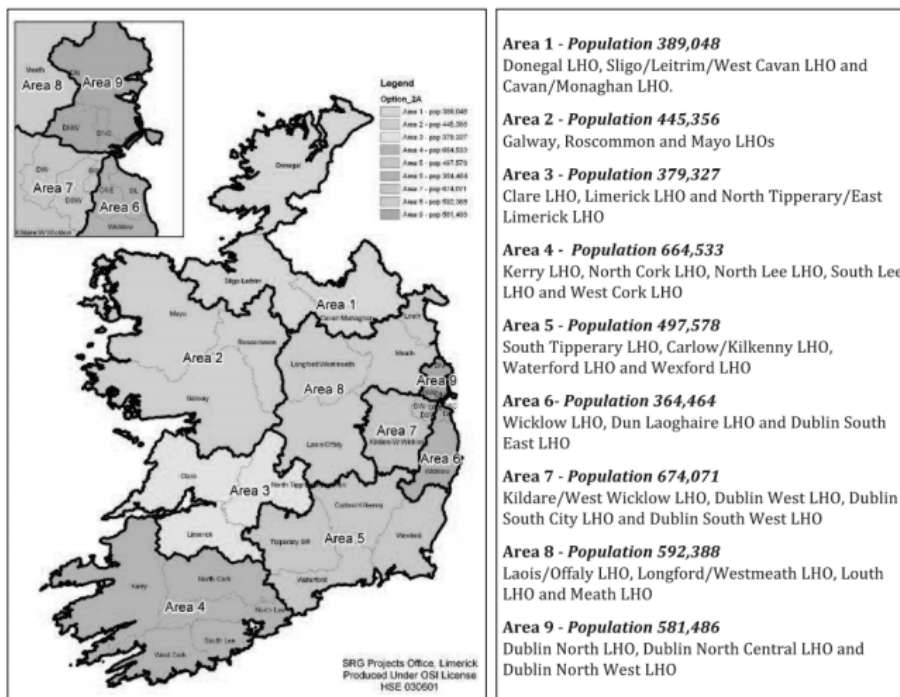
44. What kind of positive experiences have you experienced from HSE mental health services?

## 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 (Laois/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.

- |                                      |  |
|--------------------------------------|--|
| <input type="radio"/> Medical card   | <input type="radio"/> Drugs Payment Scheme card      |
| <input type="radio"/> GP access card | <input type="radio"/> I do not have any of the above |
| <input type="radio"/> Over 70s card  |  |

47. What is your marital status?

- |                                 |  |
|---------------------------------|--|
| <input type="radio"/> Single    | <input type="radio"/> Cohabiting                   |
| <input type="radio"/> Married   | <input type="radio"/> Divorced                     |
| <input type="radio"/> Separated | <input type="radio"/> Civil partnership            |
| <input type="radio"/> Widowed   | <input type="radio"/> Other/Prefer not to classify |
| <input type="radio"/> Remarried |  |

48. 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"/> Any other ethnic group (please specify)        |   |

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?

- |   |  |
|---|--|
| <input type="radio"/> Paid employment, full time or part time | <input type="radio"/> Student  |
| <input type="radio"/> Looking after home or family            | <input type="radio"/> Unable to work due to permanent sickness or disability |
| <input type="radio"/> Unemployed                              | <input type="radio"/> Retired from employment                                |
| <input type="radio"/> Other (please specify)                  |  |

55. What is your main source of income?

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

56. What is your highest educational attainment level?

- |   |   |
|---|---|
| <input type="radio"/> No formal education/Primary school only | <input type="radio"/> Third level non degree      |
| <input type="radio"/> Lower secondary                         | <input type="radio"/> Third level degree          |
| <input type="radio"/> Upper secondary                         | <input type="radio"/> 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](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.**