

MY VOICE MATTERS |

My Voice Matters Launch

Mansion House, Dublin 2
13th March 2019

#MyVoiceMatters



@MHReform



Agenda

- 11:00 Welcome**
Dr. Shari McDaid, Executive Director, Mental Health Reform
- 11:05 Presentation of Research Findings**
Kate Mitchell, Senior Policy & Research Officer, Mental Health Reform
Dr. Pádraig Ó Féich, Research Officer, Mental Health Reform
- 11:45 Q&A**
- 12:00 Official Launch**
John Farrelly, Chief Executive, Mental Health Commission
- 12:15 Service User and Family Member Response**
Dr. Mike Watts, Independent Researcher, Mental Health Expert by Experience
- 12:30 HSE Response**
Jim Ryan, Assistant National Director for Mental Health Operations, HSE





An Overview

Presentation by Kate Mitchell (Senior Policy and Research Officer) and Dr Pádraig Ó Féich (Research Officer)



Background

- MHR regional consultations
- MHR identified the need for a national, large-scale consultation
- HSE funding secured
- Consultation with service users (SUs) and family, friends and carers/supporters (FFCSs)
- Involvement of SUs and FFCSs in the research process
- Partnership/ collaborative approach



Aims

- ***My Voice Matters:*** A national consultation project funded by the Health Service Executive (HSE) and conducted independently by Mental Health Reform (MHR).
- **Aim:** to explore the views of people who have used secondary and tertiary mental health services (MHSs) in the last two years and the views of family, friends and carers/supporters (FFCSs) supporting those accessing these services.
- **Aim of Presentation:** to give an overview of the key findings from the national consultation surveys.



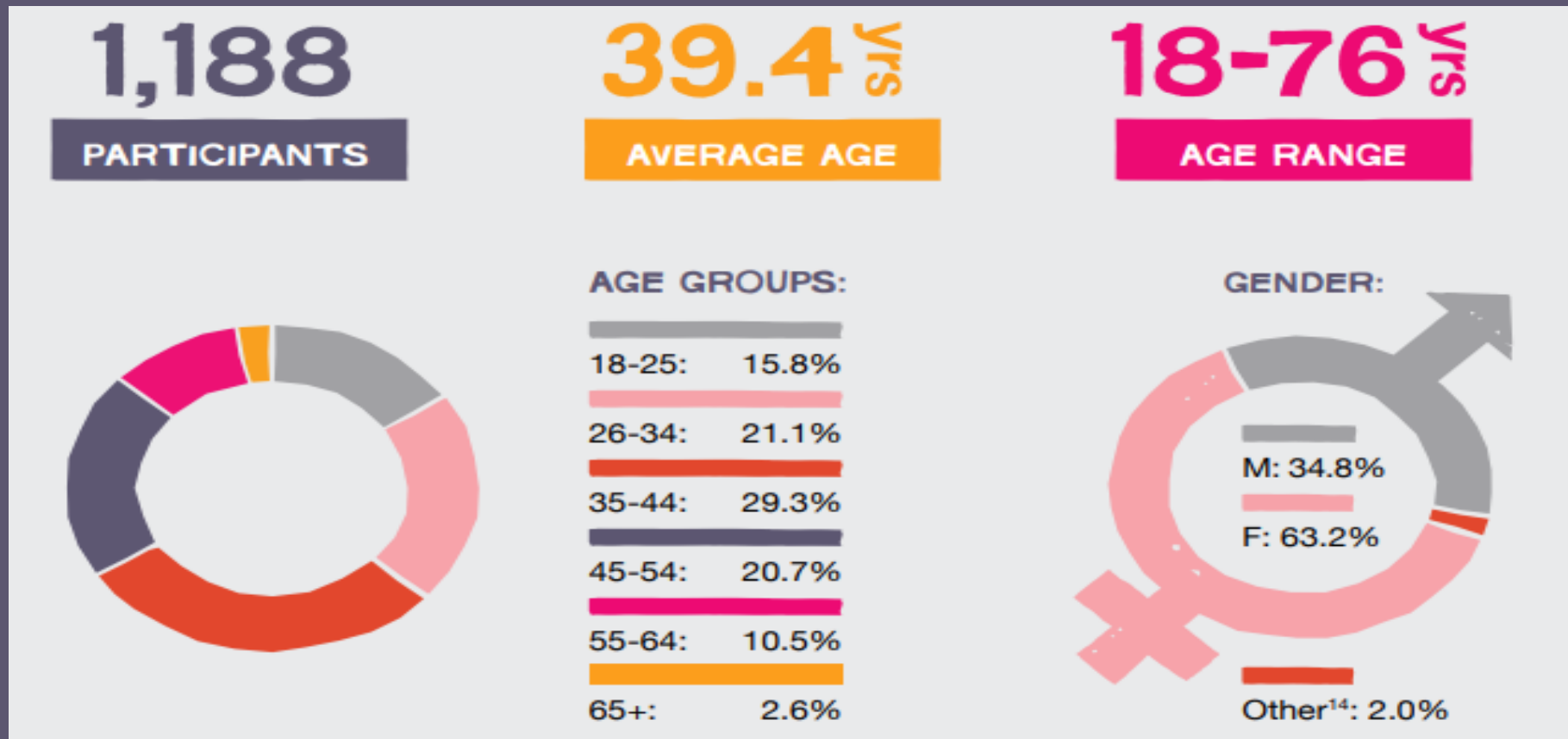
What did we do?

- In consultation with key stakeholders, MHR carried out two national surveys:
 - Service User Survey
 - Family, Friends & Carers/Supporter (FFCS) Survey
- **Survey Design:** A phased process resulting in robust surveys.
 - Literature review and previous MHR consultations;
 - Working draft were developed in consultation with the Project Steering Group;
 - Cognitive Interviews and Focus Groups;
 - Reviewed by researchers with Survey Design Expertise
- **Recruitment:** Snowball Sampling in conjunction with radio ads and an extensive social media campaign.
- **Data Collection:** online and paper surveys.



Service User Survey: Who took part?

Eligibility Criteria: aged 18 years or older with experience of the MHSs in Ireland in the last two years



Service User Survey

- **Data Analysis:**

- Descriptive Analysis
- Qualitative Content Analysis of responses to open-ended questions:
 - *'Is there any service that was not available to you that you believe you would have benefitted from?'*
 - *'What kind of positive experiences have you experienced from HSE mental health services (MHS)?'*
- Examined predictors of Overall Experience: Ordinal logistic regression analysis.



Community Mental Health Services (CMHSs)

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



CMHSs Cont'd: Key Worker

DO YOU HAVE THE CONTACT DETAILS OF A KEY WORKER, AND IF SO, DO YOU FEEL WELL SUPPORTED BY YOUR KEY WORKER?



Inpatient Mental Health Services

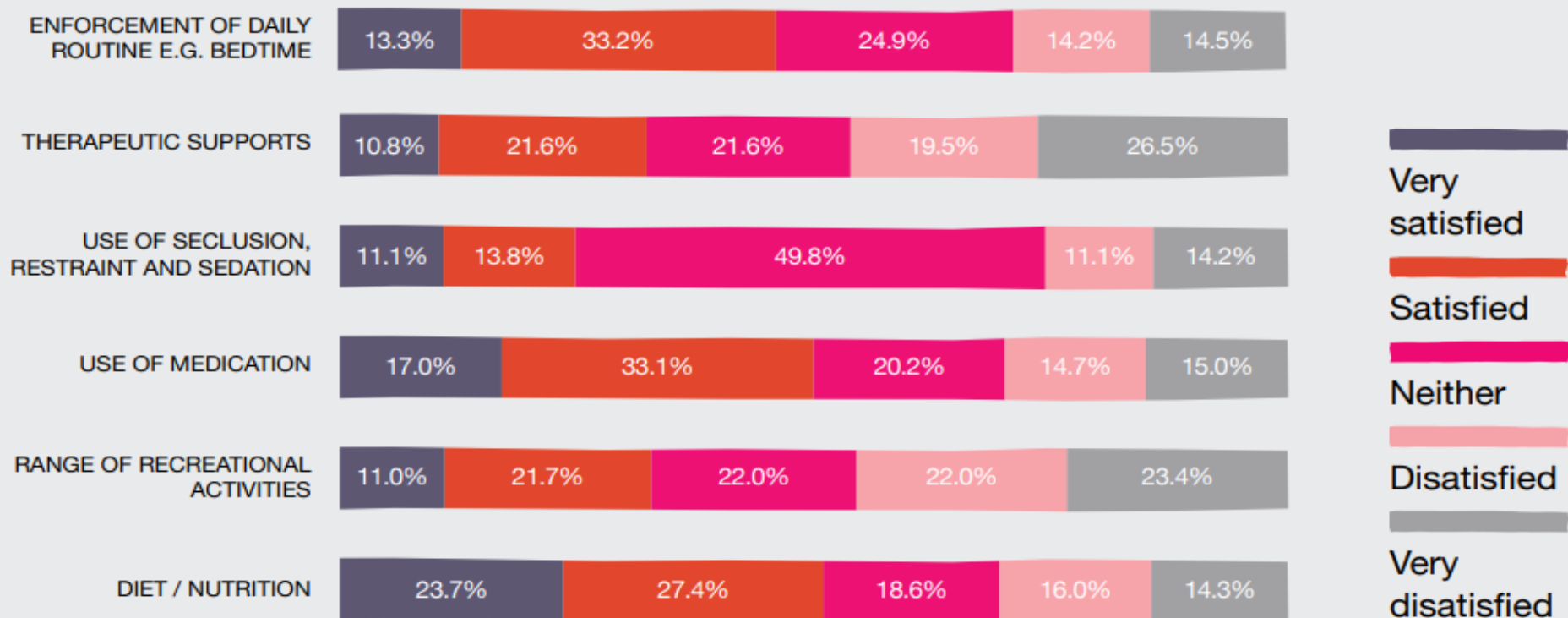


THROUGHOUT YOUR INPATIENT EXPERIENCE, HOW OFTEN DID YOU
FEEL YOU WERE TREATED WITH DIGNITY AND RESPECT BY MHSs?



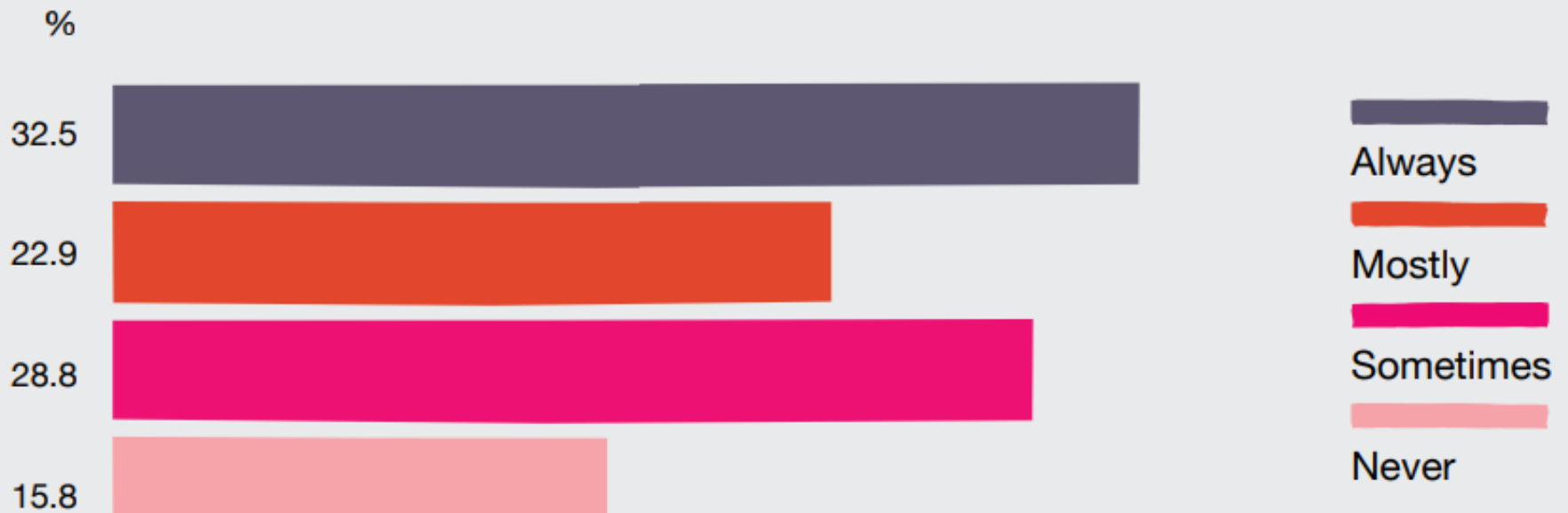
Inpatient MHSs Cont'd

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



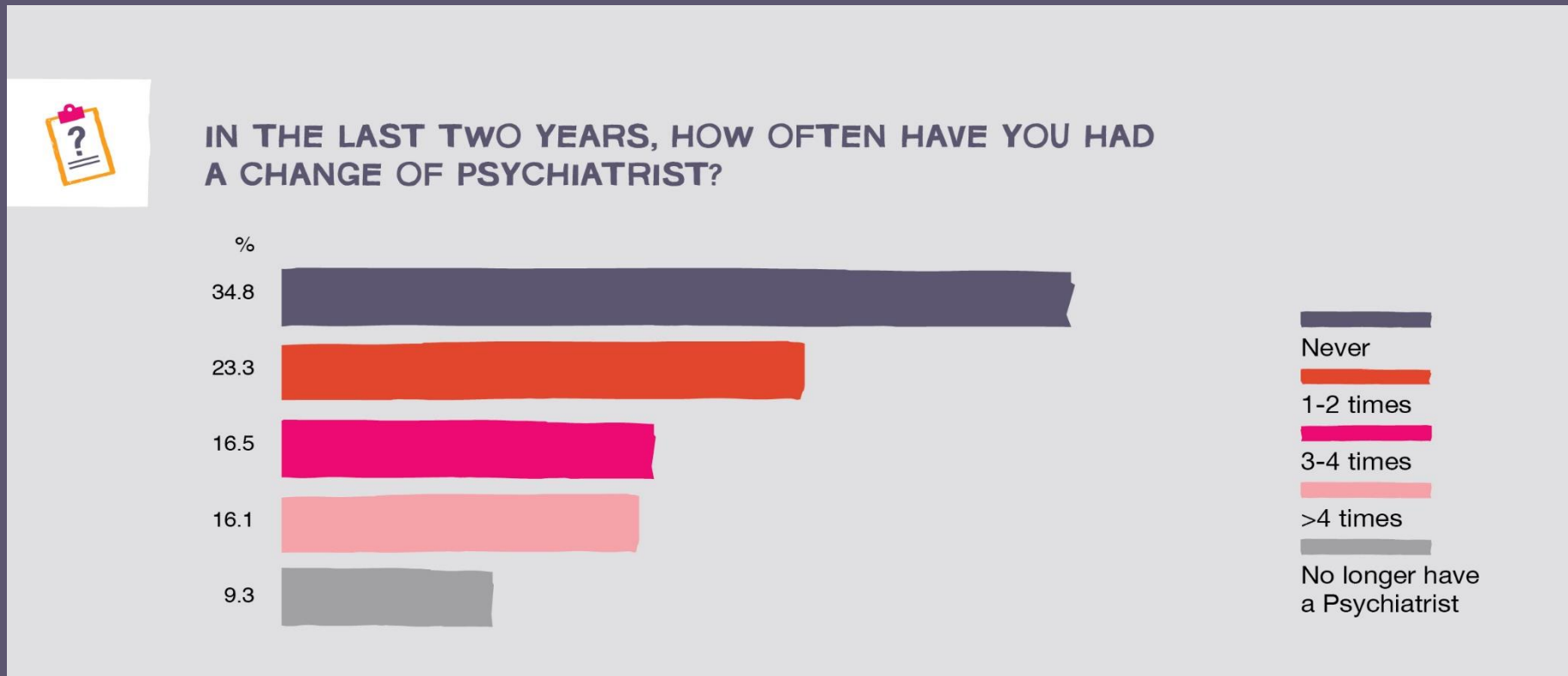
Experiences of Psychiatrists

DO YOU FEEL WELL SUPPORTED AND LISTENED TO BY YOUR CURRENT PSYCHIATRIST?



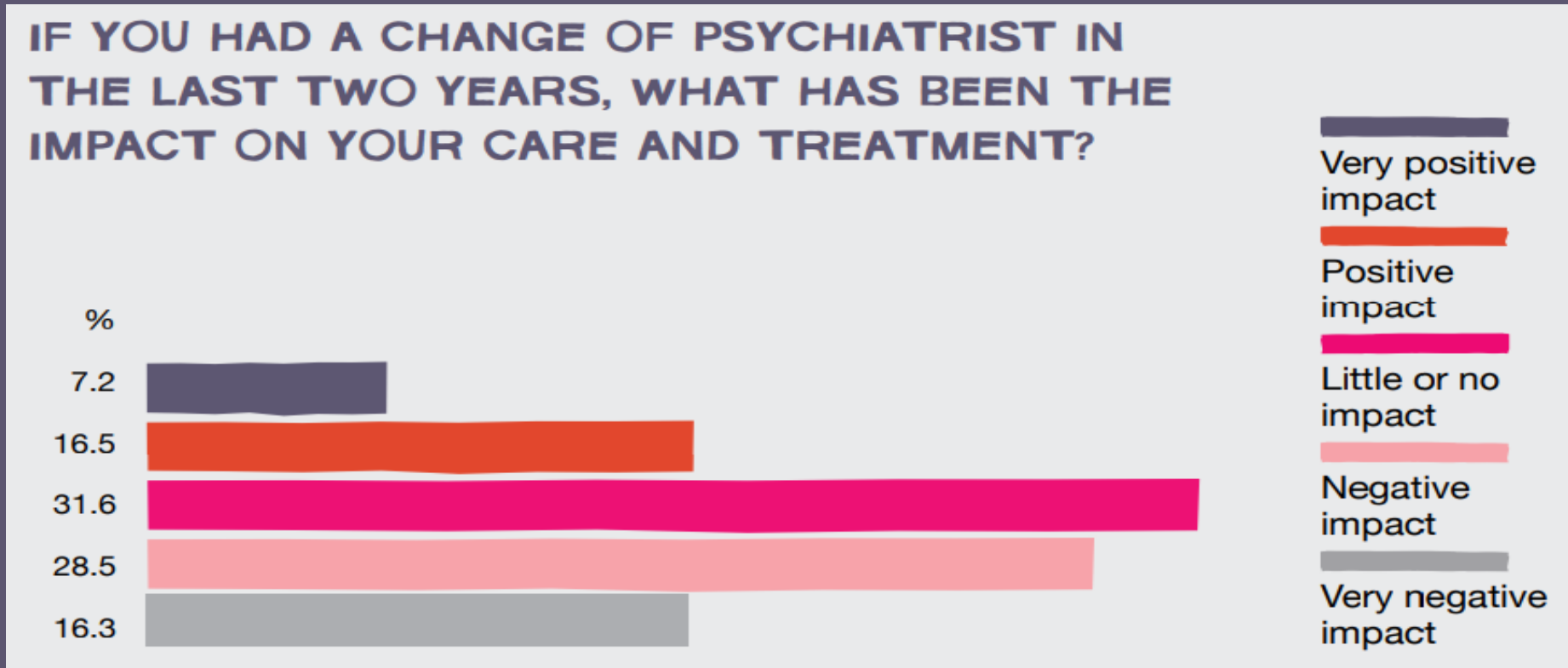
Experiences of Psychiatrists Cont'd

- 55.9% reported having had a change of psychiatrist at least once in the last two years.



Experiences of Psychiatrists Cont'd

- Significant negative correlation between the frequency of changed and the impact of said change, $S_{rho} = -.36$, $p < .001$.



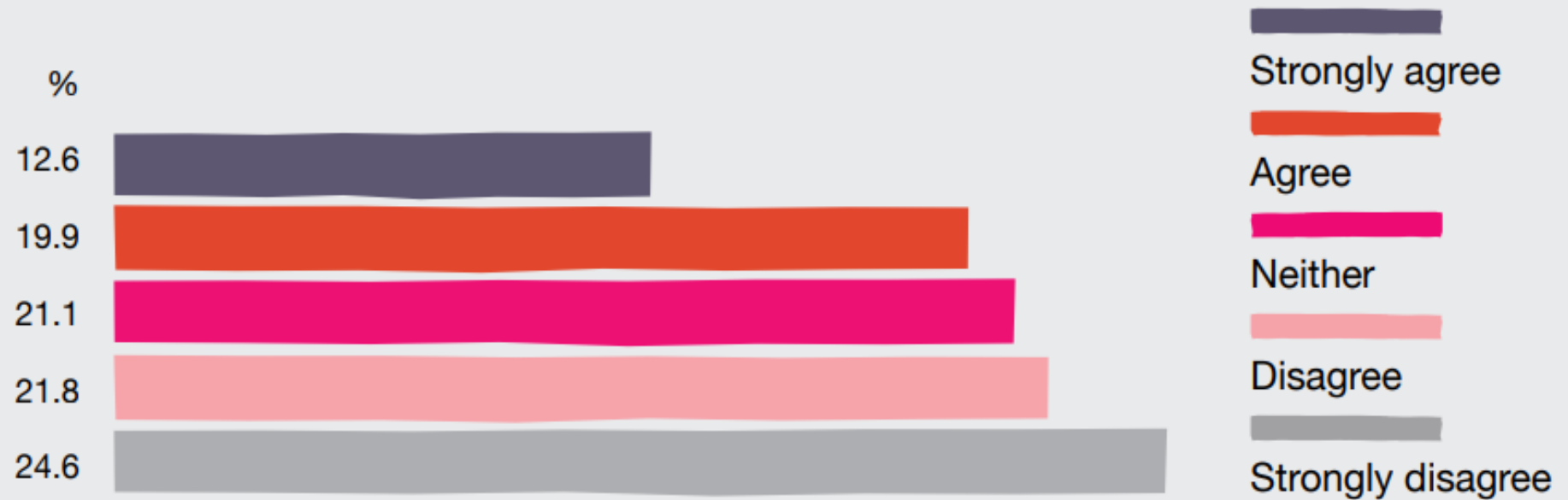
Recovery

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



Recovery Cont'd

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



Recovery Cont'd



DID YOUR CMHT TAKE INTO ACCOUNT HOW YOUR MENTAL HEALTH DIFFICULTY AFFECTS OTHER AREAS OF YOUR LIFE (E.G. HOUSING, EMPLOYMENT, EDUCATION)?



Medication

- **Involvement in decisions about Medication:** 24.6% “definitely”, 33.5% “to some extent” and 38.8% “no” (DK/can’t remember: 3.1%).

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



Talking Therapy



REFERRED TALKING THERAPY BY CMHS



- **Reported waiting times:** 31.2% waiting a month, 23.7% waiting 1 to 3 months, 27.5% waiting 3 to 12 months, and 17.6% waiting more than a year.



Qualitative Findings

- *‘Is there any service that was not available to you that you would have benefitted from?’*

- Talking Therapy Services
- Access to Specific Disciplines on the CMHT
- Alternative Recreational and/or Therapeutic Services
- Difficulty Accessing Specific Support Services
- Out of Hours/Crisis Services
- Peer Support Services
- Social Inclusion Support Services
- Information and Education Services
- No Additional Services Required

- *‘What kind of positive experiences have you experienced from HSE MHSs?’*

- Positive Experiences of Staff
- Therapies and Facilities
- Recovery and Discovery
- Treated with Dignity and Respect
- Crisis and Outreach MHSs
- Direct access to services
- Community and voluntary groups
- Empowerment and involvement
- Primary/GP care



Additional Qualitative Findings

- ***Waiting times***: e.g. dissatisfaction with long waiting times and resulting delays in treatment and care.
- ***Issues with MHS staff***: e.g. poor communication between staff and service users and a perceived lack of time for service users.
- ***HSE MHS system***: Frustration at the shortcomings in the HSE MHS system, e.g. staff shortages, a lack of funding, a lack of accountability in the system, or gaps in provision in certain areas.
- ***Continuity of Care***: e.g. frustration at perceived excessive staff rotation (particularly among psychiatrists) and the strain this places on service users.



Overall Experiences of HSE MHS

OVERALL EXPERIENCE WITH THE HSE MHSs



Predicting Overall Experience

- **Age:** For every one-year increase in age, the odds of reporting a good overall experience of HSE MHS increased by 1.8%.
- ***Contact Details for a Key Worker:*** Those with contact details for a key worker were found to be 2.3 times more likely to report a good overall experience.
- ***Provision of a Written Recovery/Care Plan:*** Those with a written recovery/care plan were 2.2 times more likely to report a good overall experience.



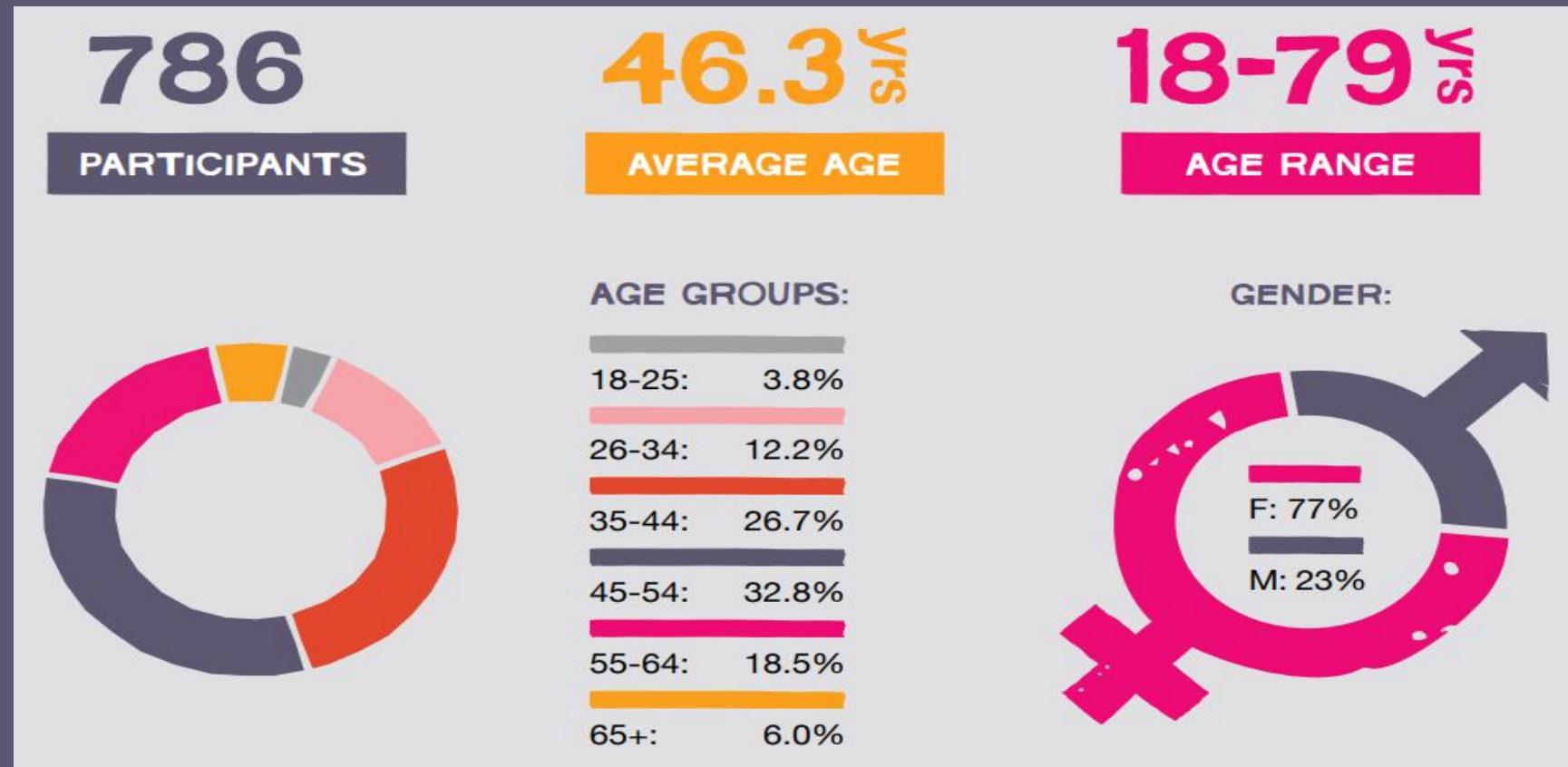
Predicting Overall Experience

- ***Involvement in Decisions about Medication:*** Those who reported that they were involved as much as they would like in decisions about the medication that they take were 2.5 times more likely to report a good overall experience.
- ***Continuity of Care:*** Those who reported never having had a change of psychiatrist in the last two years were 1.6 times more likely to report a good overall experience of HSE MHS than were those who had a change of psychiatrist three or more times.
- **Non-significant predictors:** Referral to Talking Therapy by CMHSs & Gender.



FFCS Survey: Who took part?

Eligibility Criteria: aged 18 years or older with experience of supporting a mental health service user in Ireland in the last two years



FFCSs Survey

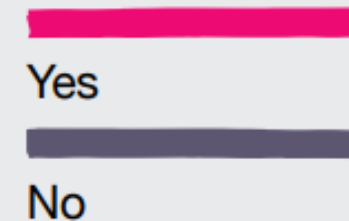
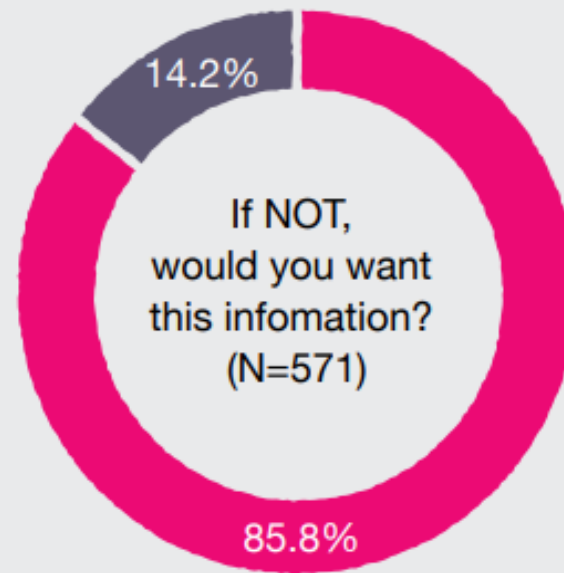
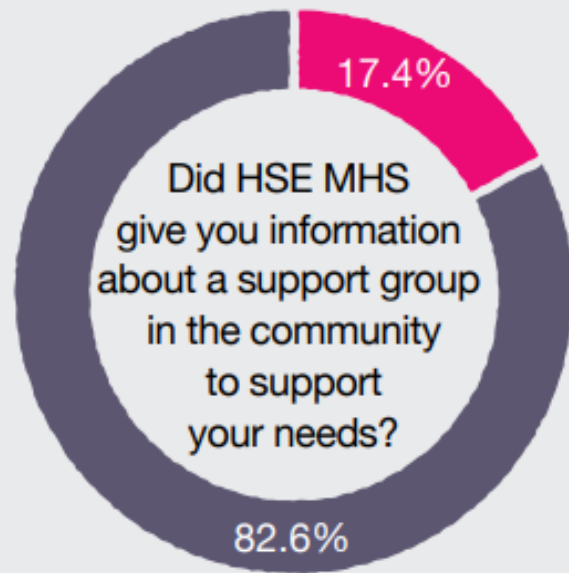
- **Data Analysis:**

- Descriptive Analysis
- Qualitative Content Analysis of responses to open-ended questions:
 - *‘Is there any service that was not available to you that you believe you would have benefitted from?’*
 - *‘What kind of positive experiences have you experienced from HSE mental health services (MHS)?’*



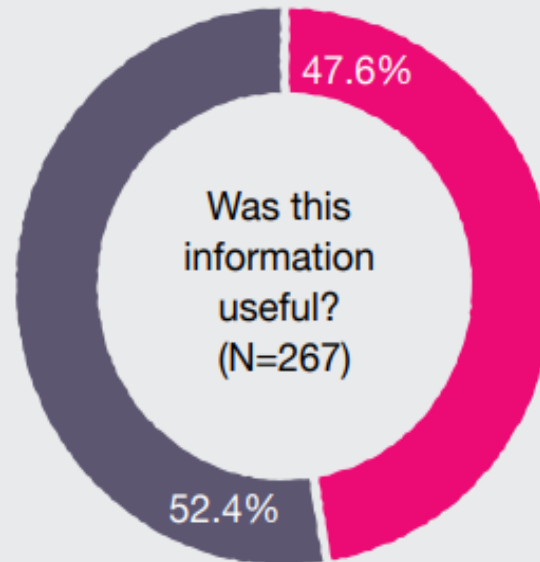
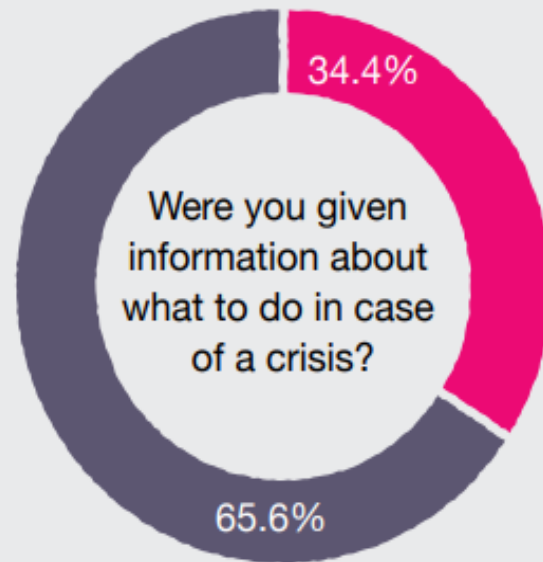
Information and Advice

DID HSE MHS GIVE YOU INFORMATION ABOUT A SUPPORT GROUP IN THE COMMUNITY TO SUPPORT YOUR NEEDS, AND IF NOT, WOULD YOU WANT THIS INFORMATION?



Information and Advice Cont'd

WERE YOU GIVEN INFORMATION ABOUT WHAT TO DO
IN CASE OF A CRISIS AND, IF SO, WAS IT USEFUL?

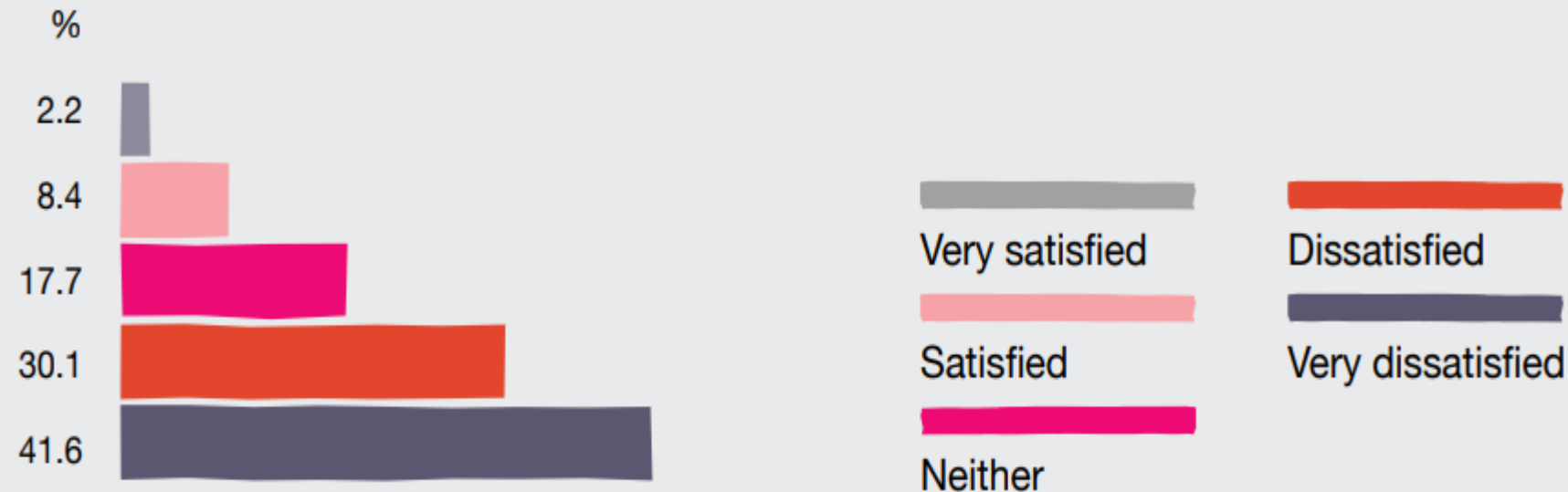


Yes
No



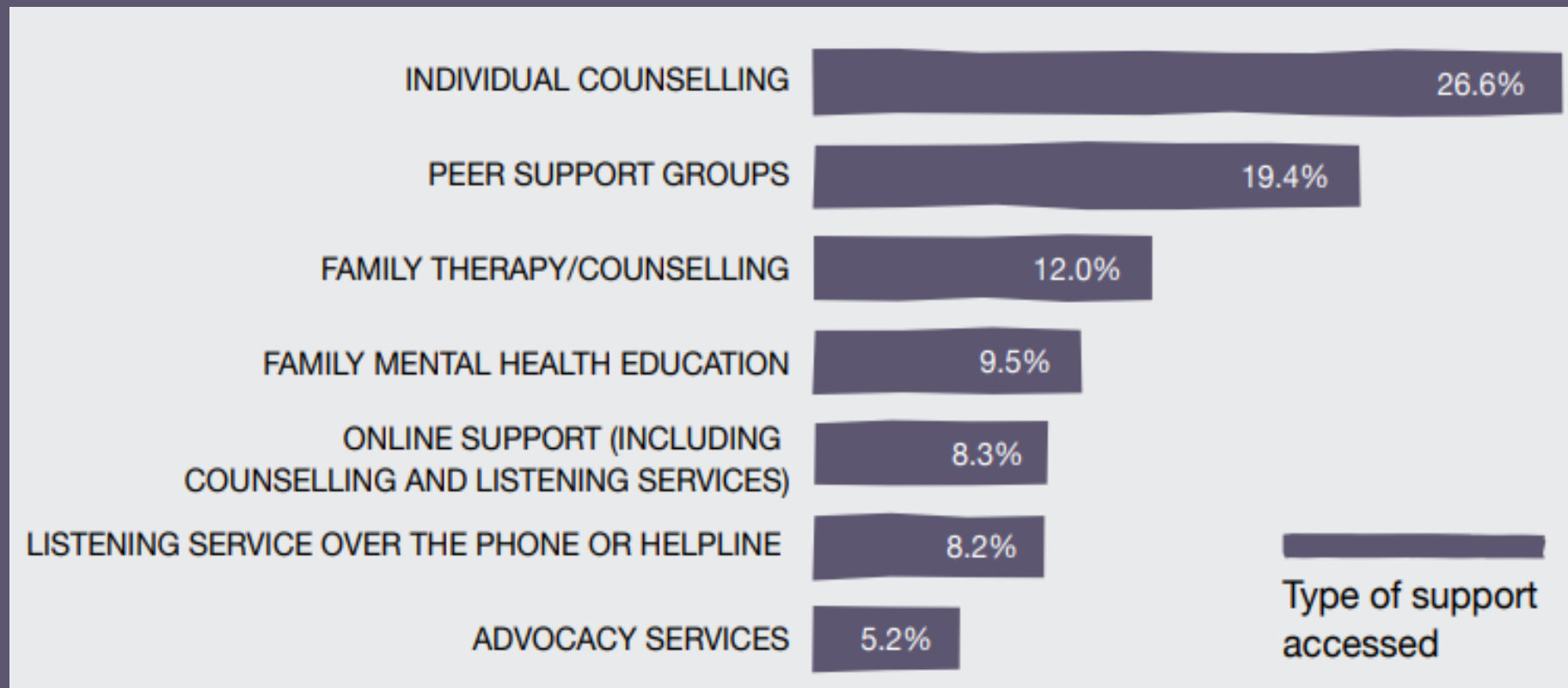
Support Needs of FFCs

OVERALL, ARE YOU SATISFIED THAT HSE MENTAL HEALTH SERVICES HAVE CONSIDERED YOUR SUPPORT NEEDS?



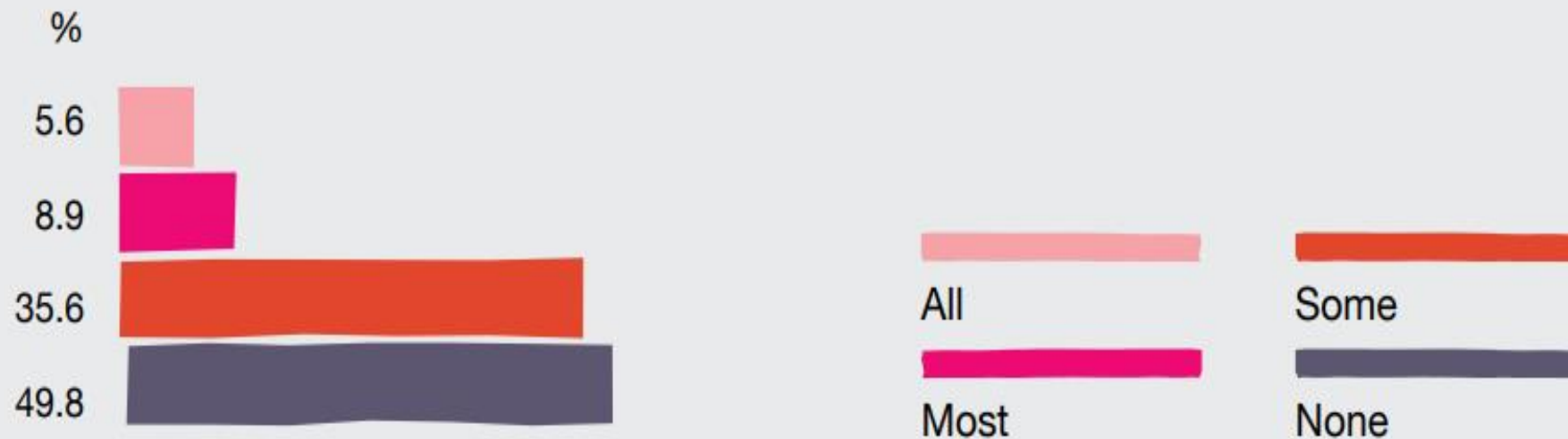
FFCS Support Needs Cont'd

- Supports being Accessed: 51.2% accessing some form of support.



Involvement in Mental Health Service Planning

EXTENT TO WHICH THE VIEWS OF PARTICIPANTS WERE INCORPORATED INTO THE RECOVERY/CARE PLAN OF THE PERSON BEING SUPPORTED



Views of Inpatient Care

Almost half of all participants (48.3%) reported that the person they support had experience of inpatient care in the last two years.

I FELT THE HOSPITAL CONSIDERED THE ROLE I PLAY
IN SUPPORTING THE INDIVIDUAL'S RECOVERY (N=345)



I FELT THE HOSPITAL VALUED MY KNOWLEDGE AND
EXPERIENCE OF SUPPORTING THE INDIVIDUAL (N=343)



I FELT THE HOSPITAL EXPECTED ME TO BE RESPONSIBLE
FOR THE RECOVERY OF THE INDIVIDUAL (N=342)



I FELT LISTENED TO BY THE HOSPITAL STAFF (N=345)



Strongly
agree

Agree

Neither

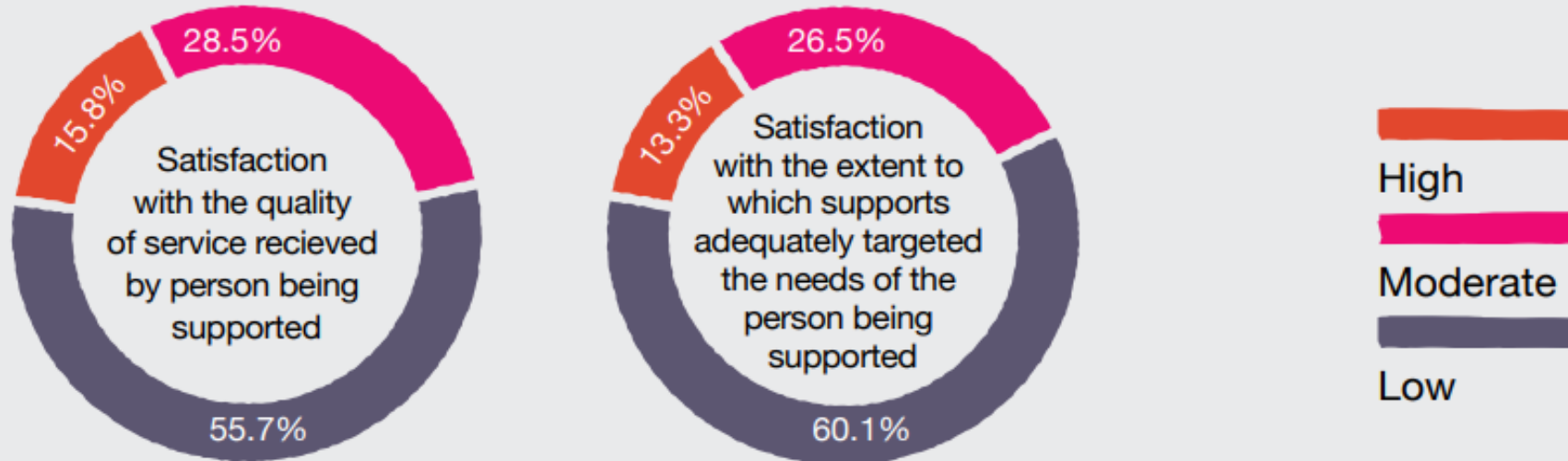
Disagree

Strongly
disagree



Views of Care received by the Person they Support

FFCS VIEW OF CARE RECEIVED BY SERVICE USER



Participants could indicate their level of satisfaction on a scale ranging from 0 (very dissatisfied) to 10 (very satisfied). Scores between 0 and 3 were categorised as low, scores between 4 and 6 were categorised as moderate and scores between 7 and 10 were categorised as high.



Qualitative Findings

- *‘Is there any service that was not available to you that you would have benefitted from?’*

- Additional support services for FFCs
- Information, advice and education services
- Talking therapy for FFCs
- Out of hours/Crisis services
- Services for service users
- Mediator/Communication service
- Peer support services
- Community-based/local support services
- No additional services required

- *‘What kind of positive experiences have you experienced from HSE MHSs?’*

- Positive experiences of staff
- Therapies and facilities
- Direct access to services
- Crisis services
- Support for family members
- Facilitated Recovery
- Involvement of families in the service user’s care
- Follow-up and Outreach MHSs



Additional Qualitative Findings

- **Involvement of FFCs:** some expressed dissatisfaction with the level of their involvement in the treatment and care planning of the person they support.
- **Access issues:** difficulties accessing the services and supports required by themselves and/or the person they support. The most common barrier: **waiting times**.
- **Continuity of care:** e.g. frustration at what they perceived as excessive staff rotation and the potentially detrimental effect this can/did have on the person they support.



Additional Qualitative Findings

- **Issues with MHS staff:** e.g. poor communication between staff and FFCs, a lack of time for both service users and their supporters, and a lack of consideration of the support needs of FFCs.
- **Mental health system:** perceived by some as a '*flawed*', '*broken*' or '*faulty*' system. Others wrote more specifically about an '*under resourced system*' with staff shortages, funding shortages and/or poor facilities.



Conclusion: Service User Experiences Mixed (at best)

- Some are experiencing MHS provision that reflects recovery orientated practices and the implementation of national standards.
- However, the evidence also indicates that many service users are not experiencing these types of services.
- It appears that 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.



Conclusion: FFCs experiences mixed (at best)

- Evidence indicates that some FFCs may be experiencing the quality of service set out in national policy and guidance.
- However, the evidence also indicates that many more are not experiencing the quality of service set out in national policy and guidance.
- It appears that core principles underpinning national mental health policy relating to FFCs have not been uniformly embedded in the day-to-day operation of MHSs across the country.



Service User Recommendations

- 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.
- HSE MHSs must develop and implement action plans to enhance active listening among mental health professionals operating in all CMHTs.
- 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 User Recommendations

- 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.
- HSE MHSs should ensure full cover in terms of multi-disciplinary supports to account for staff absences among the professional disciplines.
- 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.



Service User Recommendations

- 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.
- 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.
- 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 FFCs) should be clearly made aware of what to do in the event of a crisis.



Service User Recommendations

- 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.
- Service users should be informed by GPs and their mental health team about local charity and voluntary sector community supports.
- 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.



Service User Recommendations

- 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.
- HSE Mental Health should produce a time-lined action plan in 2019 to implement these recommendations.
- The Minister with responsibility for mental health should ensure accountability in the implementation of these recommendations through ongoing monitoring and evaluation.



FFCS Recommendations

- HSE MHSs should provide FFCSs with information of a general nature, including information on how to provide long-term support to the individual concerned, information and advice on what to do in a crisis, information about support groups in their local communities, and guidance on how to make a complaint about the MHSs.
- All HSE MHSs should work with FFCSs at local level to develop high quality information that adequately meets their needs, taking into account the literacy and language barriers experienced among certain groups.
- HSE MHSs should encourage and facilitate opportunities for FFCSs to be involved in the assessment, care and treatment of the person they support, except where the individual does not consent. This includes incorporating the views of FFCSs in individual care plans and in the discharge planning process.



FFCS Recommendations

- HSE MHSs should formally assess and address the support needs of FFCSs. In particular, the support needs of FFCSs should be assessed and appropriately addressed during the discharge planning process.
- HSE Mental Health should invest through development funding in a range of supports for FFCSs in their local community, including individual talk therapy, peer support groups and peer workers, family talk therapy, family mental health information and education, online and/or listening supports and advocacy services.
- HSE MHSs should ensure that every FFCS is appointed a designated key worker following contact with the MHSs, and for the duration of the time the person they support is engaged with the services.



FFCS Recommendations

- HSE Mental Health should ensure that mechanisms are established and widely publicised at local, regional and national level to provide opportunities for FFCSs to participate in service improvement initiatives.
- The Government should ensure that independent advocacy is available for FFCSs to support their engagement with MHSs.
- To ensure a smooth transition for service users and their families from CAMHSs to adult MHSs, formal collaboration processes between CAMHSs and adult MHSs must be established. This should include the appointment of a key worker for the child/ young person and their family member during the transition period.



FFCS Recommendations

- This consultation on FFCSs' experiences of the MHSs should be repeated every two years to ensure that the HSE and other key stakeholders are receiving national independent feedback from FFCSs on a regular basis. This would not only demonstrate progress but would facilitate priority setting by the Minister with responsibility for mental health, the Department of Health and the HSE for annual service plans.
- HSE Mental Health should produce a time-lined action plan in 2019 to implement these recommendations.
- The Minister with responsibility for mental health should ensure accountability in the implementation of these recommendations through ongoing monitoring and evaluation.



Q&A



#MyVoiceMatters

Official Launch

John Farrelly

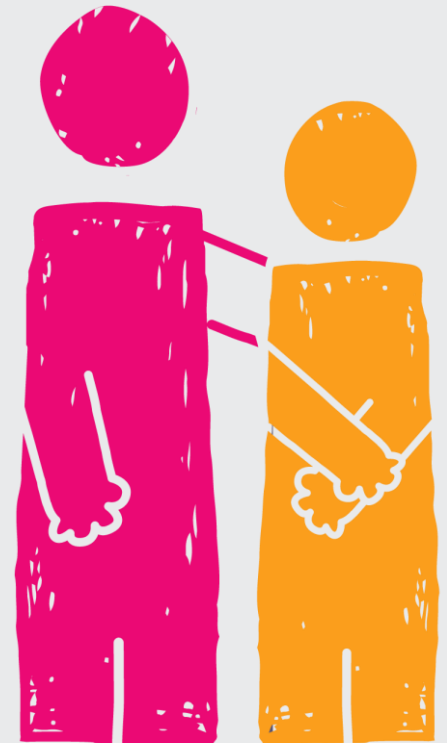
**Chief Executive
Mental Health Commission**



Service User & Family Member Response

Dr. Mike Watts

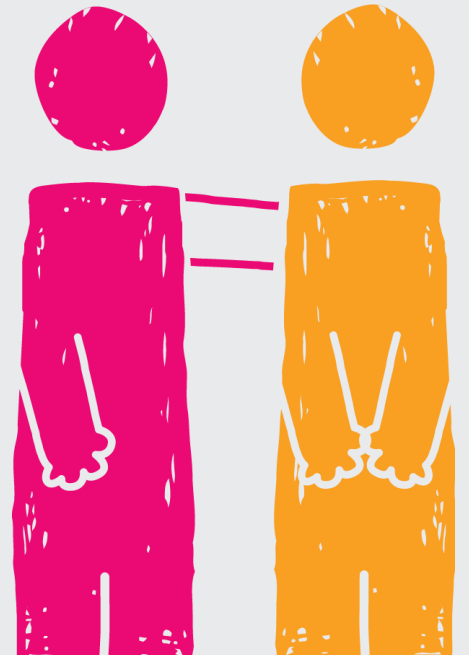
**Independent Researcher
Mental Health Expert by Experience**



HSE Response

Jim Ryan

**Assistant National Director for
Mental Health Operations
HSE**



Mental Health Supports

Samaritans Ireland

116 123

jo@samaritans.org

www.Samaritans.org

Your Mental Health

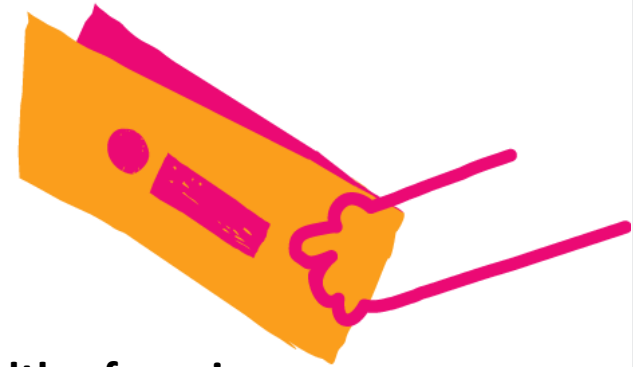
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**THANK
YOU!**

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