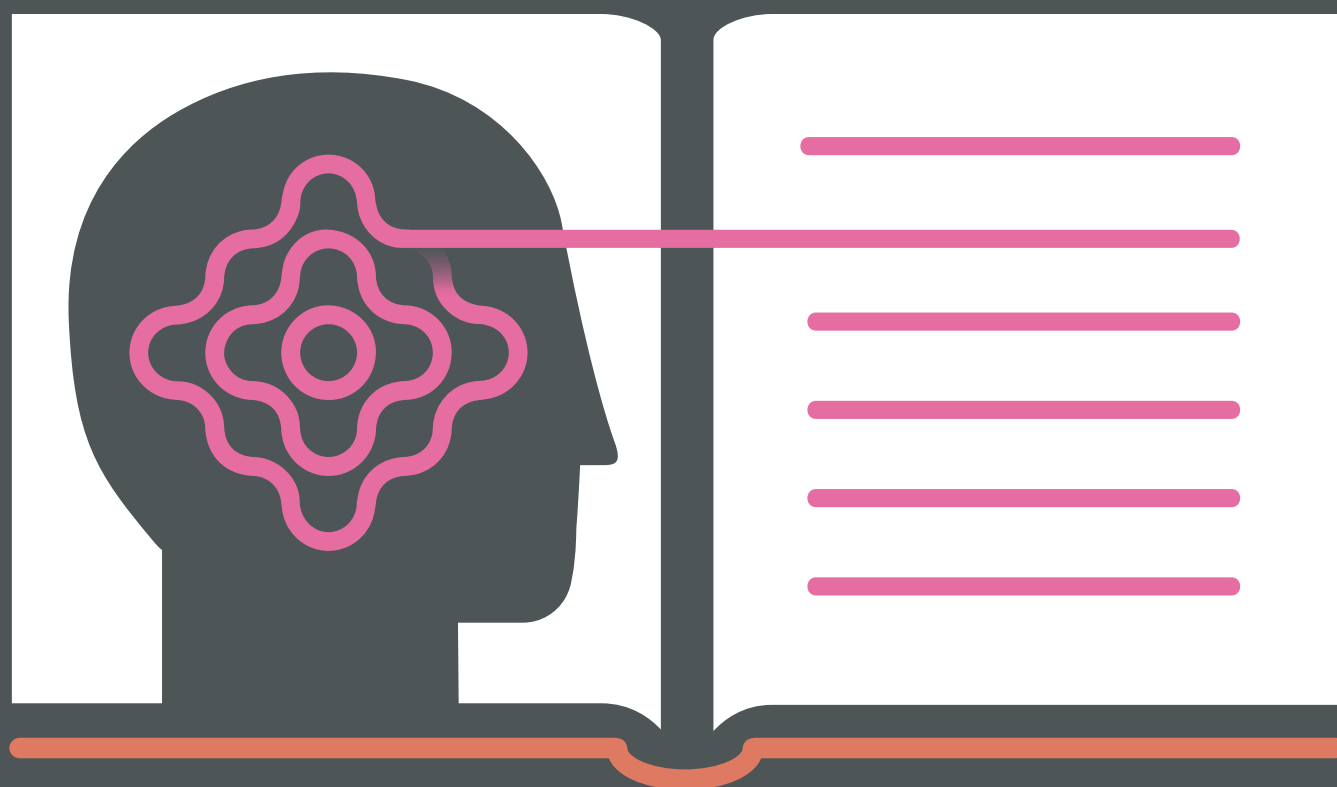


We need to tell a story



Research on the Engagement of People
with Severe and Enduring Mental Health
Conditions as Media Participants

HEADLINE

Supporting media, changing attitudes

We need the media.
They need us.
We need to tell a story.
They need a story.

MENTAL HEALTH PROFESSIONAL

COMMISSIONED BY



DEVELOPED IN 2021 BY



FUNDED BY

The National Office for Suicide Prevention under
Connecting for Life: Ireland's National Strategy
to Reduce Suicide



SUPPORTED BY



St Patrick's
Mental Health Services



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At the end of the day
it's about increasing
understanding of one
another... telling
first-person accounts
makes so much more of a
difference, more so than
figures and statistics.

MEDIA PROFESSIONAL

Foreword

For over a decade Headline has been a bridge between the media and mental health sectors in Ireland. While they differ significantly, both have a mutual understanding of what can be gained by sharing people's stories of recovery, resilience, injustice and hope. In 2018, Headline published our Challenges Facing Journalists research. In it, journalists asked for guidance not guidelines, practical hands-on tips, not abstract ideals. They spoke about the fear of "getting it wrong", of mishandling a story to such an extent that a person's mental health could be jeopardised, that fear leading some to drop a story altogether.

In the end it comes down to trust – trust in the value of people and their experiences, trust in the media professionals whose work has the power to change a nation, and trust in audiences to really listen to and see the person and the heart of each story, not just their diagnosis.

Good research can't exist without also showing a way forward. I believe our Media Practice Guide, the product of the research in these pages, acts as a blueprint for proactively and progressively moving the conversation on mental ill health – all mental ill health – forward.

I am grateful beyond words to the people on both sides of this bridge who trusted each other enough to build this guide together, in a year when physically coming together was not an option. To the media professionals, mental health organisations and people with lived experience of severe mental health conditions, thank you for lending your expertise to this project – it has been invaluable. I am grateful to Aoife Dermody and her team at Quality Matters for their commitment to and enthusiasm for a difficult brief, managed and delivered under even more difficult circumstances.

My thanks to our funders at the National Office for Suicide Prevention for seeing the value of this work, knowing that investing in breaking down barriers, challenging stereotypes and improving the lives of those living with severe mental health conditions is so worthwhile.

Lastly, a huge thank you to my colleagues in the Headline team and wider Shine family for your continued professionalism and heart.

Áine O'Meara
Headline Programme Leader

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The research and development team: Aoife Dermody, Caroline Gardner, Isabel Aust, Emma Allen, Áine O'Meara, Elaine Haskins, Jen O'Shea and Juliana Garcia, The National Union of Journalists, The Press Council of Ireland, Shine, See Change, Mental Health Reform, St Patrick's Mental Health Services, Tamara Nolan, Patricia McKeever, Derek Pepper, Ray Burke, Shauna O'Connor, Barbara Brennan, Séamus Dooley, Michael Foley, Peter Feeney, Sinéad Keating, Denis Mockler, Rick Rossiter, Carmel Hennessy, Nicola Wall, Brian Scallan, Brian McNulty, Marie Devine, Deirdre O'Shaughnessy, Colm O'Callaghan, Aoife Kavanagh, Yvonne Judge, Nicky Gogan, Gerry Nelson, Sylvia Thompson, Conor Gallagher, Gráinne Ni Aodha, Sheila Wayman, Tom Shiggins, Garreth McNamee, Kitty Holland, Kim Porcelli, Mel Gardner.

We also express our sincere gratitude to those who took part in this research who wished to remain anonymous.

Glossary

The following are key terms used in this research:

Engagement Stage: For the purposes of analysing literature and interviews, as well as for the purpose of developing media guidance, the media engagement process has been segmented into a three-stage process which includes: before, during and after engagement.

Media Engagement: This is an umbrella term encapsulating the variety of ways in which a person with lived experience of severe and enduring mental illness can engage with media professionals to tell their story for the purposes of a media product. It includes interviews for traditional or digital print articles, live and pre-recorded radio, live and pre-recorded television, documentary and film.

Media Participants: This describes the role of a person who is engaged with the intention of providing their story or opinions for publication or broadcast.

Media Professionals: This includes any media professional who may have direct contact with a Person with Lived Experience for the purposes of a media engagement and may include researchers, journalists, photographers, producers, directors, filming crew and others.

Person with Lived Experience: This term describes people who have, in their past or currently, experienced severe and enduring mental illness, for the purposes of this report¹.

Self-Representation: This describes the process whereby a person with lived experience is engaged to tell their own story as a media participant, as opposed to having another person such as a professional expert present these experiences.

¹ This is further explored in the context section on page 10 of the report.

I'd share my story 1,000 times if I knew I was going to get to another person, save their life, and change the depth of their despair, if I can be a glimpse of light in their life that's my goal.

PERSON WITH LIVED EXPERIENCE



01

Introduction

1.1 Rationale for the research

The purpose of this research is to document challenges and good practice in the engagement of people living with severe and enduring mental health conditions as media participants. The research was commissioned to develop an evidence base for good-practice guidelines for media professionals. It is envisioned that the guidance, primarily for journalists but with additional guidance for mental health organisations and media participants themselves, will fill a needed gap in the practical resources available to journalists and other media professionals in Ireland. The research involved people with lived experience of severe and enduring mental health conditions² who had also participated in media engagement previously; print and broadcast media professionals with an interest in, or experience of, creating media content relating to this issue; and mental health professionals who had supported people that they work with to engage with the media.

The need for this research and guidance was identified through earlier research undertaken by Headline that noted the absence of voices of people with severe and enduring mental health difficulties in the media, and reasons for this (3). Headline's findings echo international research which has reported, first, that media coverage relating to severe mental health conditions is poorer both in quantity and quality when compared to that of other mental health issues (e.g. milder depression) (4,5) and, second, that where it exists this rarely involves first-person accounts (5,6).

Headline's earlier research explored the reasons why people with lived experience are not engaged as sources or voices in articles about these issues.

The reasons documented related to journalists' perspectives or experiences, which included:

Limited understanding of severe mental illness, the complexities of the conditions, and a lack of confidence to engage appropriately with the issues.

Not knowing how to appropriately manage the relationship with the participant, which involves aspects relating to relationship-building, and finding balance between trust, care and control over content.

Concerns regarding how to balance accuracy, being informative and also being sensitive to those involved.

Lack of clarity in the role of stories regarding ongoing struggle; stories with positive spins or those focused on recovery tend to have more coverage.

There is no clear direction on how to cover ongoing illness in media and there are also concerns around the management of media exposure for people who are dealing with continued illness.

Other studies similarly explore the reasons for lack of engagement of people with a mental health condition as media participants, which included journalists' difficulty overcoming their own biases (e.g. not finding a person with a mental health condition credible or suitable) and/or perceiving the process as overly challenging (7). Headline's research, however, indicated a willingness from journalists to increase their knowledge and skills in this regard (3).

² There is no single or consistent definition of severe and enduring or persistent mental illness. However, the National Institute of Mental Health in 1987(1) (2) provides a framework for the definition which is described in detail in the literature review

1.2 Scope of the research

It is important, for the sake of clarity, to distinguish the purpose of this research from the wider body of research on **media reporting** on mental health and associated issues. There is an established body of literature and a wide range of helpful guidance for journalists in this regard. How issues relating to mental health are represented in media (print and broadcast media) and the impact of such reporting on stigmatisation, public opinion and wellbeing of people affected has been addressed extensively in studies internationally (8–14) and in Ireland (3).

Guidance for reporting on mental health and/or suicide and/or self-harm has also been developed internationally (15–24) and in Ireland (24–27) and more recently in Ireland, guidance has also been developed for reporting on domestic abuse (28,29). However, the body of literature and practical guidance on good practice in engaging people through the interview or media participation process is limited, and what is available and relevant is analysed in detail in the literature review section of in this report.

1.3 Contents of the report

In order to confirm the need for this research and assess the scope of the challenge, a brief analysis of traditional and digital print articles was undertaken which affirmed the continued absence of the voices of people with lived experiences in media; this is detailed in section 3 of this report.

To clarify the rationale and context for this research, a review of literature was undertaken in order to further understand how 'severe and enduring' mental health conditions are defined, to detail the importance of self-representation, and to identify any documented harms or negative impacts for people engaging as media participants.

Undertaking an analysis of existing guidelines that deal specifically with engagement practices for journalists facilitated the collation of existing good practice upon which new guidance can be developed. Section 3 of the report details how such media guidance was identified, selected for inclusion and subsequently analysed thematically. It also presents a thematised summary of relevant guidance documents.

The methodology section of the report, section 4, details the steps taken to consult with relevant stakeholders for this research. This includes the development of an appropriately skilled research team, ethical considerations for the research, the identification of stakeholder groups and inclusion criteria for them, the recruitment of stakeholders, the development and refinement of research instruments, and the process for undertaking consultation and developing the thematic findings.

The final section and main body of the report presents the findings of this research in sections 5–11. In order to facilitate the development of guidance, a framework was developed that segmented the media engagement processes into three stages: before, during and after engagement. Participant perspectives on challenges and difficulties, as well as solutions and good practice, are presented relevant to each phase, as well as overarching or general challenges and solutions relevant to all stages.

1.4 Mental Health Organisations Informing the Research

The design of this research and final report was the result of a collaborative effort by a number of mental health organisations. These organisations provided input on the data to be collected, supported the identification and engagement of participants for the research, and/or inputted on the final report and guidance.

We are grateful for the input of the following organisations and projects

Shine

See Change

St Patricks Mental Health Services

Mental Health Reform

1.5 Input and Oversight by Headline

The research and development process was commissioned and overseen by the Headline team. In addition to oversight, members of the team also provided input to the research process and guidance development and design.

1.6 Print media analysis of self-representation in Ireland

Overview

The research team undertook an analysis of published articles (traditional and digital) to discern levels of self-representation of people with lived experience. This was done in order to a) establish the gap in self-representation in the media and b) to identify an initial sample of media professionals working in Irish print and digital publications who had previously written about severe and enduring mental health conditions in the past three years, with a view to consulting them for this research. The analysis did not include broadcast media such as radio and television, as a) there is no equivalent database for broadcast media and resources were not available for this project to undertake a full archival review and b) a snowball sampling methodology for broadcast media was identified as more appropriate for the

purposes of this research, which is further detailed in the methodology section of this report.

Search strategy

An analysis was conducted on the database LexisNexis, and on TheJournal.ie (articles from this widely read publication are not on the LexisNexis database).

The parameters chosen were;

1. The publication was based in the Republic of Ireland
2. The article was published between the dates 21/5/2017 and 21/5/2020
3. The article was written in English

The keywords used to search within the database were those describing symptoms associated with severe and enduring mental health conditions: schizophrenia, bipolar disorder, paranoia, hallucination, hearing voices, and auditory hallucinations.

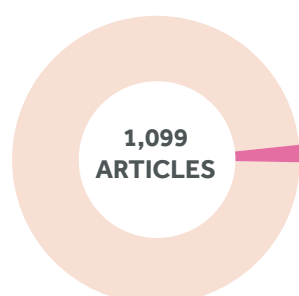
Statistics on representation

In total, 1,099 articles were found that included any of the keywords. Of the 1,099 articles ('total articles'), only 6% (70 articles) met the criteria for relevance described above ('relevant articles'). Of the 70 relevant articles, 23 included people with lived experience as interviewees or guest authors; this equates to just 2%.

Relevant articles were then identified by excluding:

Articles about criminal charges, proceedings or court outcomes

Articles related to celebrity or entertainment news where the celebrity was not representing themselves or telling their mental health story (specifically, an article about a celebrity's behaviour that references their mental health was not relevant, while an article where a celebrity shares their experiences was relevant).



LIVED EXPERIENCE MEDIA PARTICIPATION

2% Within a three year period, of all articles that referenced severe and enduring mental health conditions or associated terms, only 2% involved direct engagement of people with lived experience.

Table 1: Article selection data

	Schizophrenia	Paranoia and/or Hallucination	Hearing Voices and/or Auditory Hallucinations	Bipolar disorder	Total
Total Articles	243	36	11	809	1099
Relevant articles	36	1	3 (one duplicate of paranoia & hallucination search)	30	70
Self or family representation	11	1	2	16	30
Family only	3	0	0	4	7
Self only	8	1	2	12	23

3% involved direct engagement of people with lived experience

Schizophrenia

243 Articles

RELEVANT

3% involved direct engagement of people with lived experience

Paranoia and/or hallucination

36 Articles

RELEVANT

18% involved direct engagement of people with lived experience

Hearing voices and auditory hallucinations

11 Articles

RELEVANT

1% involved direct engagement of people with lived experience

Bipolar disorder

809 Articles

RELEVANT

KEY Not relevant articles Relevant articles without self-representation Family only Self only

Summary

There is a low rate of self-representation of people with lived experience of severe and enduring mental illness in print and digital media in Ireland. While additional analysis of broadcast media would provide a more nuanced understanding on representation generally, this analysis, considered in the context of literature detailed further in this report, highlights the value of addressing this gap through a range of measures which includes supporting journalists to build skills and confidence in engaging this cohort.



02

The Context for this Research in Literature

2.1 Overview

This section summarises published literature relating to issues underpinning this research, namely, what is meant by 'severe and enduring mental health conditions', why self-representation in media matters, and what is documented in relation to harms that can arise as a result of undertaking a media engagement for people sharing vulnerable stories.

2.2 Defining severe and enduring mental health conditions

There is no single or consistent definition of severe and enduring or persistent mental health conditions. However, the UK's National Institute of Mental Health in 1987(1)(2) provides a framework for the definition with three elements included:

- **Duration:** it is a long-term experience, an ongoing illness an individual endures throughout their lifetime, or which has had a long history of previous treatment (30)(31)(32)
- **Diagnosis:** it involves a diagnosed mental illness including:
 - Schizophrenia (30) (31) (33)
 - Psychosis (30) (31) (2)
 - Affective disorders (bipolar disorder, depression, anxiety) (31) (33)
 - Personality disorders (31) (2)
 - Other chronic functional disorders (30)
 - Self-harm and eating disorders (31)
- **Disability:** It can cause significant impairment in the person's ability to function in major life activities (34)

The National Institute of Mental Health makes a distinction between 'any mental illness' (AMI) and 'serious mental illness' (SMI), defining the latter as "a mental, behavioural, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities", further adding that "the burden of mental illnesses is particularly concentrated among those who experience disability due to SMI" (34).

2.3 Why self-representation matters

There are a number of well-articulated reasons why increasing self-representation of people with mental health difficulties in the media is important. Primarily, if the goal of journalism is to tell a fair and balanced story concerning mental health, which avoids stigmatising people or perpetuating myths that can result in stigmatisation, then engagement of those most affected will improve their capacity to deliver on this. The international body of evidence on the benefits of self-representation in the media, although scant, provide some promising insights, detailed here.

Preliminary findings in a small-sample study in New Zealand highlighted that self-representations can provide a distinctive discourse and point of view that is not available through experts or other third parties (7). This distinctiveness had the ability to deepen the quality of journalism and offer "accessible and recognisably human self-portrayals" (p. 281), where people with an experience of mental illness would depict themselves "as normal, human and understandable" (p.286) (7). Nairn & Coverdale (2005) argue that because of the high scarcity of these

self-representation stories in the media, these unique portrayals are largely passing unnoticed not only in mass media but also in the research field, meaning "*many researchers (...) do not appear to have considered what the absence of those voices means for the way in which most people understand and respond to mental illnesses*" (7) (p.282).

Indeed, the over-reliance or over-representation of experts and clinical voices in media portrayals of mental illness has been said to, in some occasions and unintentionally, lead to increase stigma even when striving to do the opposite. Holland (2012), in a study looking at anti-stigma campaigns in Australia, states there is a risk that the reality of mental illness is being portrayed just as it is conceived in the medical model, assuming people diagnosed with a mental illness are a homogenous group whose views and own representations are not subject to other social and contextual factors (i.e. gender, class etc.) (35). In this sense, the inclusion of self-representations of people with mental health difficulties in the media is also a way of acknowledging and respecting these differences as well as assuring they can be known to media audiences.

Additionally, an analysis of television news conducted in Australia in 2009 showed that stories including self-representation provide, more often than not, more positive depictions of mental health than those without the perspectives of people with lived experience (36). This same study reported substantial positive change in media coverage of mental illness when compared to earlier analyses, with most television coverage being positively framed (85% of news samples), and second, a considerable increase in the amount of stories involving people with mental illness giving first-person reports (49% of news samples) (36).

2.4 The potential for harm through media engagement

There is little empirical data on the impact of media participation on the mental health of those involved (37)(38) when coverage is related to personal and/or socially sensitive topics (i.e. traumatic events, personal experiences). However, a small number of studies, mainly conducted in Scandinavian countries, with trauma survivors of terrorist attacks have explored this issue. The studies examined whether participating in the media was related to increased post-traumatic stress symptoms in the aftermath of the traumatic event. Findings are mixed; one study showed being interviewed about the event was associated with increased post-traumatic stress (PTS) (38) and another did not show such an

association (37).

There is, however, some evidence showing a link between people with higher levels of PTS or who had lower levels of support³ finding the experience of participating in media more distressing and negative than those with less PTS or more social supports (37). This finding was echoed in another study exploring the effect of witnessing one's own story reported in media on people who had been

Stories including self-representation provide, more often than not, more positive depictions of mental health than those without the perspectives of people with lived experience.

crime victims. It was observed that people with lower psychological wellbeing experienced, to a greater extent, negative reactions towards this media reporting (39). These findings indicate people who are experiencing some form of psychological distress may find participation in media particularly challenging, at least when this involvement is related to their own trauma story. Such an awareness invites journalists to adopt a specifically sensitive approach when relating to people who are having mental health difficulties. Indeed, Thoresen et al. (2014) states:

"Individuals with a high symptom level may be less in control of their emotions and may have reduced available cognitive capacity to cope efficiently with interviews and be less able to set adequate limits for their disclosures to the public. As a result, individuals may find interviews more distressing, be less happy with their exposure, and possibly have more regrets about participating." (37) (p. 644)

³ There is no causal relationship established to explain this association. Thoresen et al. (2014) hypothesises it could either be: negative experiences with media leading to increased symptoms; increased symptoms leading people to attribute negative emotions to the media experience; or people having an experience of psychological distress finding it more challenging to engage with media.

For trauma victims, this effect bears particular relevance. It is widely known one of the main experiences that characterises trauma is a loss of sense of power and control over one's own life (40), which is frequently accompanied by feelings of shame and blame (16). The exposure in media, especially if not done with care, may contribute to reinforce these feelings and unintentionally cause harm (37)(38). The recognition of the risks of re-traumatisation and re-victimisation in guidelines and manuals for journalists acknowledges this predicament (41)(16).

Another way that participation in media can also cause a negative impact on mental health, highlighted in Thoresen et al. (2014), is by creating a sense of 'negative social support', which can happen when people feel disheartened by journalists (i.e., when perceiving their main interest is to exploit their story) (37). 'Negative social support' is also associated with increased PTS-related symptoms (37).

Maercker & Mehr (2006) undertook research with crime victims which assessed the impact of media exposure on 63 victims of crime. For the majority of people involved in the study, listening, watching or reading about their own story in the media had predominantly triggered negative reactions (39). This negative experience could occur up to 5 to 11 months after the event and was regardless of the accuracy of the story. Maercker & Mehr (2006) describe this experience as follows:

"Very few (5%) of the participants were pleased or felt supported (11%) by the reports, the latter regardless of the accuracy of the report. In general, negative evaluations predominated. Two-thirds of respondents stated that reading, listening to, or watching the reports made them feel sad. Half of them felt frightened, one-third felt angry, and only 10% were indifferent." (p.139-140) (39)

The authors explained that the negative reactions had a different, independent source to that of the traumatic event (39), meaning it was the media experience itself that caused the distress. While these findings refer only to the experience of witnessing one's story in the media, as opposed to the experience of engaging with the media, they shed light on the risks of media exposure in producing adverse psychological effects for those who are involved. Comparative research has not been undertaken with people with mental illness, and so while it cannot be confirmed that the experiences of trauma survivors have commonalities with those of people with severe and enduring mental health difficulties, it is a rational perspective to support safeguards being taken, in the possible instance that these challenges do extend to people with enduring mental health difficulties.

A fifth or less of survivors either regretted their participation in the media interviews (11%) or reported feeling worse after the interview (19%). This shows that involvement in media does not translate automatically into a negative experience and, therefore, that it depends on the way it takes place.

It is also important to note that the experience of participating in media does not need to be a negative one for people from vulnerable or traumatic backgrounds. In both of the studies, looking at the psychological impact of media participation, a fifth or less of survivors either regretted their participation in the media interviews (11%) or reported feeling worse after the interview (19%). This shows that involvement in media does not translate automatically into a negative experience and, therefore, that it depends on the way it takes place. Thoresen et al. (2014) suggests that both "*the manner in which the interview is performed and how the interview is perceived by the interviewee may be key to its effect*". (p.644) (37)

When it comes to schizophrenia and bipolar [disorder], there's so much negativity in those words and how it's portrayed - it's shown in the media and people are raised to view it that way.

PERSON WITH LIVED EXPERIENCE



03

Analysis of Current Guidance on Media Engagement

3.1 Overview

The first point in the research process was to establish what is already known and promoted in relation to good practice for media engagement with adults who have experienced trauma, adversity or mental illness. A search was undertaken to identify policy and practice guidance for journalists which included guides published in English and available through public or academic databases. Reports, articles and guidance focused exclusively on good practice in media reporting, working with children, or those that were opinion pieces were not included.

In total 40 documents met the inclusion criteria. Each document was then reviewed to further identify resources written specifically for media professionals that included practical guidance on undertaking media engagement or interviews with vulnerable adults or adults who have life experience of mental illness, disability, or experiencing and surviving traumatic event(s), which reduced the list of 40 to 8⁴. In most instances, the guidance on engagement was a sub-section or point within larger guidance documents about content but included significant and helpful guidance for media professionals.

The final list included:

BBC Editorial Guidelines Section 6: Fairness to Contributors and Consent (42)

Justice Solutions. A Guide for Journalists Who Report on Crime and Crime Victims (43)

The Canadian Journalism Forum on Violence and Trauma. Mindset: Reporting on Mental Health (44)

Mental Health Foundation. Media Guidelines: Portrayal of People Living with Mental Illness and Mental Health Issues in Aotearoa (44)

BBC Media Action. Editorial policy guidance note for BBC Media Action on working with Vulnerable Contributors (45)

National Union of Journalists Scotland. NUJ Guidelines for Responsible Reporting on Mental Health, Mental Illness and Death by Suicide (46)

RTÉ Journalism and Content Guidelines (47)

Dart Center for Journalism and Trauma: Ethical Reporting on Traumatized People (16)

⁴ Codes of ethics such as the Press Council of Ireland Code of Ethics (Ireland), and the Office of the Press Ombudsman Code of Ethics (UK) were excluded; while they state that there should be standards on issues such as respect for privacy, protection of sources, respect for particular groups etc., no specific practice guidance is provided in relation to working with vulnerable or marginalised populations.

Each document was reviewed to identify specific practice points for the media engagement process (again, as distinct from reporting). Each practice was then categorised by stage of the media engagement process (e.g. before, during or after), in line with the staged framework developed for this research as detailed in section 4, although most guidance documents did not use a phased or staged approach.

3.2 Existing General Guidance

These practice points from a variety of guides were relevant to all stages of media engagement.

Do no further harm; promote the safety of contributors during the engagement process (42) (45) (48)

Avoid additional distress from asking participants to recount what has happened to them or from being involved with the media body in any way (45)

Treat participants as you would like to be treated if the situation was reversed (48)

Be compassionate and sincere (48)

Don't overpromise on the impact the story will have (48)

3.3 Existing Guidance for the 'Before' Stage

It may be appropriate to approach a potential contributor via a third party / ensure they have support (17) (20) (42)

Offer anonymity and/or clarify the extent of it (20) (45) (17) (44)

Provide information in a way that can be understood by the participant (42)

Tell the person how much time you need (43) (48)

Explain the ground rules and parameters of the interview (48)

Ask permission to record the interview (43)

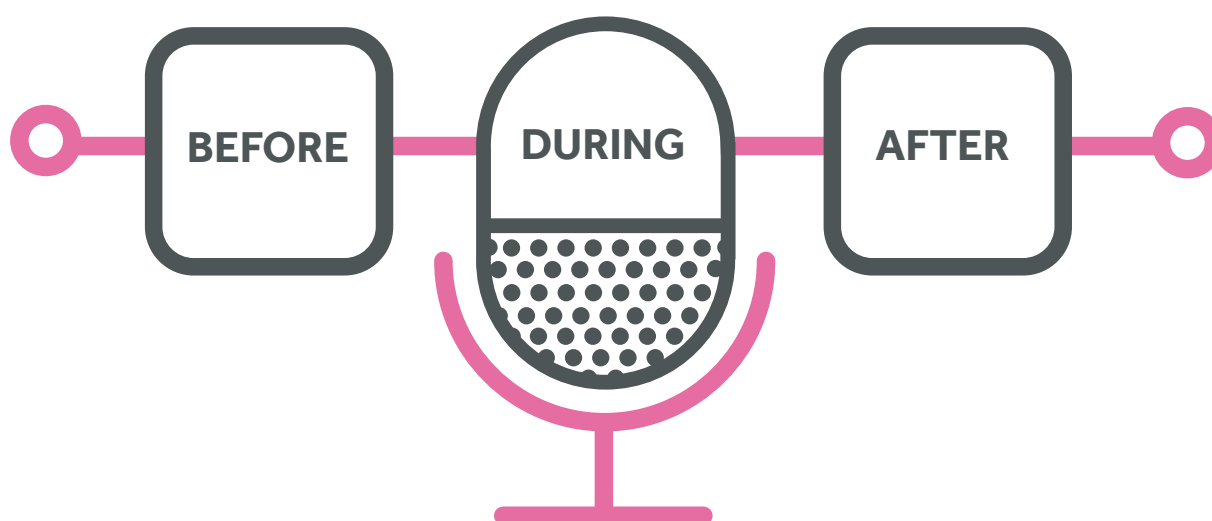
Provide interviewees with the questions that will be asked prior to the interview (17)

Share control: let the interviewee decide some of the conditions such as a preference for where they are interviewed or to have a friend or relative present during the interview (48)

Use respectful language (20)

Use the person's own words to represent their experiences (17)

Find out whether the vulnerable person is considered to be medically fit and psychologically robust enough to take part (44) (45)



3.4 Existing Guidance for the ‘During’ Stage

Ongoing consent

Consider consent as a two-stage process – recording and transmission (45)

Consider consent as an ongoing process and seek it each time a contribution is expected (42)

Check whether it’s OK to ask a tough question (48)

Promoting comfort and responding to distress

Make sure the person is as comfortable as possible (43)

Be friendly, set a comfortable pace of questioning, ask open-ended questions, and take care not to push too hard or to re-traumatise, but still seek clarity and insight (44)

Show empathy, not detachment, but be careful to control personal emotions (48)

Understand and manage personal responses to behaviours that may seem disconcerting and take advice where necessary from those who are familiar with the contributor and the nature of their condition (45)

Allow time for breaks. Crying, silence and other distressed behaviours do not mean the interview is over, but time may be needed to allow the person to compose themselves (48)

Allow vulnerable interviewees to tell you when they’d like to take a break, whether they want you to put your notebook down or turn off recording equipment so they can say something they don’t want used (48)

Resist the cliché of filming people in a distressed or emotional state (48)

Thoroughly check and re-check facts, names, times and places. Errors are a second wound to people who have been traumatised by loss or tragedy (48)

3.5 Existing Guidance for the ‘After’ Stage

Discuss the potential consequences of the interview, including additional trauma (45)

Determine if it would be appropriate to keep in touch with the contributor and their family to monitor any specific after-effects that might have resulted from the person’s participation (17)

Don’t end the interview abruptly; remembering to say thank you (43)

If a vulnerable person’s contribution has evolved during post-production, it may be advisable to let them know before transmission (45)

Include them [the participant(s)] in any decisions you can – for instance, read back their quotes or replay raw tape (48)

Leave a phone number (44)

3.6 Summary

The range of practice guidance for media professionals, although limited, in some instances demonstrates a depth of understanding of the inadvertent harms that could be done through the media engagement process, and how to prevent or avoid these. There remains a gap in the guidance literature that comprehensively addresses good practice in this regard, particularly in an Irish context, and it is anticipated that additional guidance in this regard will be a useful addition to the range of existing resources available to journalists.

This is the most vulnerable story that a person may have, and it may involve a lot of pain. They are not doing this for their personal gain. They are doing it for others, to get a message out there. This should be treated with the utmost care.

MENTAL HEALTH PROFESSIONAL



04

Methodology for the Research Consultation

4.1 Overview

This section details how the research consultation was undertaken including the principles guiding the process, ethical concerns, and all details regarding how participants were identified, selected and engaged in the interview process.

4.2 Values informing the research process

Strengths-based: while learning from mistakes is a crucial underpinning for qualitative research and good practice development, this research also inquired as to what worked in the past that could be replicated for the future. Understanding the strengths and motivations of various stakeholders helps to develop shared understanding, language and good practice.

Expertise by experience: media professionals, people with lived experience and mental health professionals all present unique perspectives and experiences, all of which are valid and valued in the research process.

Creating shared language while respecting

difference: the roles, functions, cultures and perspectives of the media, mental health services and individuals with lived experience are unique and distinct from one another. The purpose of this research is to identify good practice, and language to describe it, that can be understood by all, and facilitate shared understanding of, and communication about, what works in media engagement.

Rights: the research aims to support the right of people with lived experience to have access to the media and the responsibility of media to ensure that can be exercised

4.3 Ethical considerations

Ethical considerations are those factors in a research process that could cause inadvertent harm to participants. These risks must be considered, prevented and responded to in order to ensure the research does not cause harm to those involved. The following table delineates identified risks and prevention/mitigation strategies implemented:

If the opportunity to get a story out is lost, it's disappointing for everyone involved, but it's never worth it to get a story out in a way that harms one of our people. The opportunity does not supersede the well-being and comfort of the person with lived experience.

MENTAL HEALTH PROFESSIONAL

Risk Identified	Strategies for Prevention, Mitigation and Response
<p>Participants are not fully informed of the research</p>	<p>Initial information sheets detailing all facets of the research process, the purpose of the research and the nature of the interviews were disseminated to lived-experience participants through gatekeeper organisations and by email to journalists. The points included in the sheet included:</p> <ul style="list-style-type: none"> - Purpose of the research - Research process - The fact that they would not be identifiable in the research - The fact that nobody would know if/whether they had participated in the research unless they chose to divulge this to another person - That engaging in the research would have no impact on their access to future support - That they could choose to withdraw at any time, or not answer any question - Process for the development of guidance - Opportunities for continued engagement in guidance development - The availability of a small expense stipend (participants with lived experience) <p>These points were revised again during initial information calls and at the beginning of interviews with participants to ensure consent was full, informed and enthusiastic.</p>
<p>Participants feel compelled to engage in the research</p>	<p>At all stages, the following points were highlighted to all participants:</p> <ul style="list-style-type: none"> - Participating is completely voluntary - There will be no negative outcomes for participants if they choose to engage or not to engage - They were, at all stages, thanked for their decision to give freely of their time, experience and expertise for the development of the research and guidance
<p>Participants with lived experience are harmed, primarily the risk of retraumatisation or triggering through retelling difficult stories</p>	<ul style="list-style-type: none"> - The risk that difficult stories could come up, or difficult feelings triggered in the course of the research was identified at the beginning of the interview - Participants were reassured that they could stop at any time, and there was no need for them to answer any question they did not feel comfortable with - The researcher was trained in trauma-informed practice, and was coached on the implementation of this for the purpose of the research - At the end of the research, participants were checked in with to ensure that they were feeling OK, and reminded that if anything difficult arose later as a result of the research to seek support
<p>Participants views or identities are discernible in final reports or records</p>	<ul style="list-style-type: none"> - No stories were detailed in a way that would identify any participant in the research - No other identifying information was used in the research or guidance - Participants had the opportunity to review their interview notes, which were disseminated in a Word document by email to each participant - Participants had the opportunity to review the final guidance and input into it - The only data retained was transcribed notes for interviews identified by a code. The code was stored in a secure, password-protected document. Once analysed and the report was published, all original notes were deleted
<p>Participants are disempowered, objectified or feel exploited by the process</p>	<ul style="list-style-type: none"> - Participants were invited to give their feedback on the guidance - Participants were offered the opportunity to be named as contributors in the research - The value of developing guidance involving all perspectives was highlighted during the research, while not being overstated - A strengths-based, trauma-informed approach was undertaken in the recruitment, data collection and write-up phases

4.4 Stakeholder groups and participants engaged

The following table indicates the stakeholder groups engaged, inclusion criteria for same, and the number of participants

involved. In total, 36 people engaged in interviews for this research.

Stakeholder Group	Inclusion Criteria	Number of people who engaged
People with lived experience	Have had experience of engaging with the media as media subjects Live currently or previously with severe and enduring mental health difficulties	13
Media professionals	Work in print or broadcast media and have an interest in or experience of engaging with the issue of mental health	19
Mental health professionals	Provide support to people with lived experience of mental health issues to engage with the media	4

4.5 Step-by-step summary of research process

STEP ONE

Establishing the research team

Interviewers were selected who had experience in their relevant fields (e.g. experience working in the media for media professional interviews, experience working with people living with mental health difficulties for interviews with people with lived experience, and experience of management of health/health-affiliated services for gatekeeper interviews). This was to ensure that initial barriers regarding culture and terminology would not interfere with rapport-building or information gathering required to create an effective and engaging research-interview experience.

STEP TWO

Developing research framework and instruments

A series of three exploratory interviews with people working in the fields of mental health and media production facilitated the identification of important topics and potential structures for research interviews. The three-stage approach (before, during, after) was agreed as an appropriate framework for the research as it facilitated a logical flow of conversation in the interviews, and useful format for future guidance.

The stages were defined as:

GENERAL

This includes themes relevant to the whole media engagement process and includes shared goals regarding the purpose and process, past history of challenges and negative experiences of media engagement and issues relating to consent and capacity

BEFORE

This includes all activities where the media professional or their organisation are engaging someone with a view to them taking part in an interview and includes communications and actions around identifying a participant, providing information to support engagement and providing any relevant details in advance of engagement

DURING

This includes all activities from when the person is engaged and undertaking the interview or media engagement and includes the interview itself, the location and support during the interview

AFTER

This includes all activities relating to the media participant and the media product, from when the interview is ended, through to publication, broadcast and any activity surrounding the story.

The research questions were then included in an information sheet and circulated to all gatekeeper organisations to share with potential research participants.

STEP THREE

Recruiting and selecting interview participants People with lived experience

People with lived experience were recruited through a convenience sampling approach – all partner organisations (Mental Health Reform, Shine, See Change and St Patrick’s Mental Health Service) reached out to some or all of their connections to invite any person with lived experience of severe and enduring mental illness, who also had previous experience of media engagement, to partake in an interview.

Media Professionals

Media professionals were recruited using a purposive sampling approach. The purposive sampling approach included a review of all articles (print and digital) referencing people with lived experience of severe and enduring mental health conditions in the past three years, and approaching journalists based on whether they had included people for self-representation or not, while also seeking representation from a diversity of publications. The sampling approach included approaching broadcast professionals who had previously undertaken work with the subject group or similar vulnerable professionals as a more robust approach to analysis of broadcast media was not within the scope of research. Participants included representation from those working in both local and national news, print, digital and broadcast (television, radio and documentary)

Mental Health Professionals

All partner organisations were invited to have a staff member with relevant experience take part in gatekeeper interviews.

STEP FOUR

Scheduling interviews

Participants with lived experience were initially contacted through the research manager. Although the research manager was not the interviewer, they were the person named in information sheets and communications about the research. It was felt that a continuity in terms of contact point was important for consistency and might support trust building and engagement of people with lived experience. In the initial call, the research manager provided initial information about the research and achieved consent to pass on their details to the interviewer.

The research manager then, with the participant’s permission, sent a connecting email between the interviewer and the research participant.

The interviewer then emailed the participants to schedule an interview. At this point, the researcher invited participants to advise her of any particular requirements they might have in relation to the interview that could help to make the interview a more enjoyable experience for them, or if they

had any particular needs in relation to undertaking the interview. While this was largely appreciated by most participants, only a small number of people communicated specific needs or preferences that related to use of language and other issues.

STEP FIVE

Undertaking interviews and taking notes

All interviews were undertaken by phone. Each call began with a summary of the project including the



final products (e.g., this research report and the guidance document), as well as any ethical considerations relevant to that stakeholder group (see earlier in this section for further detail on ethical considerations that informed this research). Interviews were partially transcribed – this means that relevant points were typed directly as verbatim quotes and regularly summarised back to the participant to ensure the correct meaning was inferred.

A semi-structured interview approach was undertaken, which facilitated the interviewer to gather the data needed to ensure the same issues were considered from all angles, while enabling the participant and the interviewer to explore any other relevant points raised.

At the end of the interviews, all participants were informed about next steps, and invited to express their interest in reviewing a draft of the research and a media guidance document that would be developed from the research. In addition, participants with lived experience were invited to provide their address, which would be stored separately to their interview data and subsequently deleted, to which a €20 shopping voucher could be sent to cover any expenses incurred by taking part.

STEP SIX

Participant review of interview notes

Interview notes were sent to participants to review, and then re-entered into an Excel database with any clarifications or corrections provided, where they were then anonymised and assigned a unique identifier.

STEP SEVEN

Analysis and Write-up

Three researchers undertook the interviews, with each being responsible for one stakeholder group (people with lived experience, media professionals and gatekeepers). All researchers reviewed their notes and developed an initial draft of emerging themes individually. These themes were then discussed collaboratively with other researchers to further develop and refine themes. It was finally agreed that to analyse the feedback as relevant to stages of the media process would yield the most useable results for future guidance.

Individual researchers meticulously reviewed an initial selection of interviews to ascertain whether the staged approach to analysis was appropriate and sufficient. Following this, all interviews were analysed using a template interview analysis database for each stakeholder group. As a final step, the research team again came together to review the analysis collaboratively prior to the write-up. All researchers finalised their interview analysis databases and handed them over to the lead researcher for write-up.

The final write-up was undertaken by the lead researcher. This involved collation of findings from all interview analysis databases under the relevant themes.

STEP TEN

Collaborative review

Once the report was drafted, it was circulated to all participants so that they could see their anonymised input in the context of the whole report. In addition, as this report resulted in the development of guidance for the media, this guidance was also circulated. All participants were invited to provide commentary and feedback and were also invited to be named as contributors to the report if they wished to be so.

4.6 Limitations

Limited analysis of representation in Irish media:

no analysis was undertaken on broadcast (television or radio) media to analyse levels of representation of people with severe and enduring mental illness. This was due to a lack of easily analysable databases and limited resources for the research.

Representativeness of samples and analysis

of data: the only inclusion criteria for people with lived experience was that they had experienced severe and enduring mental illness and that they had previously engaged with the media. No further criteria such as the type of illness they had experienced, or socio-demographic information such as gender, age, ethnicity or sexuality were included as criteria. This was a decision by design as it was anticipated that the number of participants engaged in the research would be small, and any further analysis would compromise confidentiality. For media, the sample sought to include professionals working in a range of media types, publications or news outlets, as well as those who had engaged people with lived experience in interviews about severe and enduring mental health and those who had not. However, the sample size meant that further analysis in relation to these criteria could compromise confidentiality.





05

Challenges and Solutions

5.1 Overview of challenges and solutions

This section presents challenges and solutions in the media engagement process from the perspectives of all three stakeholder groups (people with lived experiences, media professionals and mental health professionals). Information was collected and analysed based on stages of the media engagement process, as previously detailed in section 4, namely, before, during and after engagement.

Notes on reading the findings:

- **Presentation of numbers and statistics:** Where there were 5 or more individuals in a single stakeholder group identifying a certain point, the number of individuals or percentages of a stakeholder group is named, however, if fewer than 5 people from any category identified a particular issue, the number or percentage is not reported on to ensure confidentiality of correspondents.
- **Variation in capitalisation:** The terms 'media professionals', 'people with lived experience' and 'mental health professionals' are capitalised where they refer specifically to the participants in the research. Where they are referring to the population more generally, they are not capitalised.

5.2 General challenges relating to all stages

Overview

This section details concerns identified throughout the interview process that relate to issues that either a) relate to the whole process of media engagement, or b) relate to the overarching rationale for this research.

CHALLENGE 1

Including people with lived experience as media participants can influence mental health-related stigma.

The role of the media in either perpetuating or challenging stigma associated with severe and enduring mental health conditions was spoken about by most people with lived experience (69%, n=9). The common challenges were how severe and enduring mental illness is presented in the media: relating to crime or rationalising/justifying criminal or negative behaviours, the use of stigmatising language, and the absence of stories relating to severe experiences of mental illness:

When it comes to schizophrenia and bipolar [disorder], there's so much negativity in those words and how it's portrayed - it's shown in the media and people are raised to view it that way.

PERSON WITH LIVED EXPERIENCE

There seems to be endless amounts of people [in media stories] with minor mental illness – anxiety, depression – who get interviewed and they talk about their experience in huge detail. There's a big difference between their struggles in life, and having a complete break with reality, which is what I have experienced.

PERSON WITH LIVED EXPERIENCE

I understand the pressures they [media professionals] are under. If we can communicate better about how we both work, we can come together and make it an enjoyable experience for all.

MENTAL HEALTH PROFESSIONAL

A number of people with lived experience highlighted the positive impact engaging with the media had on both personal and societal levels:

Up until the point I told my story publicly, I felt stigma; after that I decided to not give stigma a place in my life.

PERSON WITH LIVED EXPERIENCE

Thankfully, things are getting better; the stigma is getting less. I think the strong message is finally getting through – people can recover, and they don't lose their personality or intellect; it's part of their life but not all of their life. It doesn't have to define you.

PERSON WITH LIVED EXPERIENCE

Media professionals (68%, n=14) recognised the ongoing prevalence of stigma relating to severe and enduring mental illness and the positive role the media can play by publishing stories that have the effect of reducing stigma. Many identified the importance of providing new perspectives on mental health that can educate the public. Providing the perspective of people with lived experience was also viewed as helping others to share similar experiences.

We tell a story so broader Irish society can look at it, and understand what it is like and transform their perception.

MEDIA PROFESSIONAL

I'd share my story 1,000 times if I knew I was going to get to another person, save their life, and change the depth of their despair. If I can be a glimpse of light in their life, that's my goal.

PERSON WITH LIVED EXPERIENCE

There was an acknowledgement both among Mental Health Professionals and Media Professionals that many stories remain untold, or where they are told, the voices of people with lived experience are too frequently not included:

Sometimes we think we can't go near people with mental health issues; even having this conversation, I am thinking about it in a different way. These people are not well represented.

MEDIA PROFESSIONAL

According to media professionals, reasons these stories often remain untold are

Fear of the vulnerability of potential participants

Inability to get a source perceived as reliable for the story

Severe and enduring mental illness being an issue that affects a minority of people so additional airtime or column inches for these issues may not be justified

A perceived reluctance on the part of people experiencing the issues to expose themselves through media stories

CHALLENGE 2

Negative media engagement experience impacts on participant well-being

Participants from all stakeholder groups were invited to discuss any previous positive or negative experiences and what was learned from them. Positive media engagement experiences with media professionals were reported by People with Lived Experience and Mental Health Professionals alike. The comments related to: experiences characterised by rapport-building, a sense of control in the interview, feeling respected, safe and important, and being consulted after the interview. As highlighted in the following quote:

I felt very respected, visible, important, heard, supported, knew what was going to happen, how it was going to happen. I felt in control, which is very rare in interviews. She explained everything, checked in throughout, followed up afterwards, sent stuff over to sign off before she finalised it, sent me the interview on disc after it went live. This was my best experience.

PERSON WITH LIVED EXPERIENCE

However, the majority of both groups (77% of People with Lived Experience) had examples of challenging experiences during past media engagements (which inform the following sections of this report). The vast majority of stakeholders recognised that for some people, the retelling of difficult stories relating to severe and enduring mental illness can be triggering:

The most stressful thing is the time pressure, and the reliving of the experience every time you tell it.

PERSON WITH LIVED EXPERIENCE

This is the most vulnerable story that a person may have, and it may involve a lot of pain. They are not

doing this for their personal gain. They are doing it for others, to get a message out there. This should be treated with the utmost care.

MENTAL HEALTH PROFESSIONAL

Almost half of the Media Professionals engaged (42%, n=8) referenced the risk of triggering or retraumatisation through the process either directly or indirectly. The well-being of the media participant is not the only factor considered by media professionals in the media engagement process. All stakeholders identified conflicting interests and agendas that media professionals must balance, against the need to support the well-being of the media participant including time, the need for content with a specific angle, the need for objectivity and the corroboration of stories, and other editorial pressures. Many of these issues are explored further in the following sections on challenges and solutions:

Everyone is always looking for a story, an exclusive, even in a regular news feed. Cognisant of duty of care, you are dealing with human beings. There is always that conflict between duty of care and trying to get the scoop.

MEDIA PROFESSIONAL

Mental health professionals had a stronger line – regarding the well-being of the participant as a factor that should not be compromised:

If the opportunity to get a story out is lost, it's disappointing for everyone involved, but it's never worth it to get a story out in a way that harms one of our people. The opportunity does not supersede the well-being and comfort of the person with lived experience.

MENTAL HEALTH PROFESSIONAL

People with Lived Experience and Mental Health Professionals both reported that previous negative experiences with Media Professionals had resulted in negative outcomes not only for the participant at the time, but on their likelihood to engage again in the future or to work with a particular media professional again. Below, one Mental Health Professional describes the impact of a negative experience:

When that trust or sense of safety is broken like the [media professional] ended up doing, it impacts not only on that story, but on... the chance of that story ever being heard. They can communicate this negative experience to their peers. It had a huge impact.

MENTAL HEALTH PROFESSIONAL

Despite this, stakeholders from all groups were quite pragmatic in relation to this issue, noting that

Engaging with the media is anxiety-inducing for most people without prior media experience, whether they have severe and enduring mental health difficulties or not

Most people with lived experience are capable and able to discuss difficult past experiences without becoming triggered, or can manage it if they do

The most compelling stories are those with the most detail and which touch on the most challenging experiences of mental health conditions, which means journalists need to probe into difficult personal areas

Almost all stakeholders commented on the value of additional guidance for all stakeholders to promote better engagement experiences.

CHALLENGE 3
The culture and pace of media organisations and mental health organisations is vastly different

All Mental Health Professionals, and almost half of the Media Professionals (47%, n=9) noted a difference, if not a tension, between the culture and pace of the media and mental health organisations and by extension people living with severe and enduring mental illness. Differences also included language and manner:

The pace of the media is very fast, and things change all the time. We ask them for a huge amount of information before they even approach us. They say they just want 'a quick comment' or 'a quick chat'. It's taken a lot for our service users to get to a stage to put themselves forward, so they have to be very clear on what's being asked before we put them forward.

MENTAL HEALTH PROFESSIONAL

Time pressure is one of the main things. Would love to have longer or go back to them a few times or over the course of couple of days, but often this is not possible with deadlines. Sometimes people want to go away and think about things. You have to be honest and say look I am up against it so if you do want to talk it will be today or this week.

MEDIA PROFESSIONAL

The experience of feeling rushed during media engagement was frequently mentioned by People with Lived Experience:

People with mental illness don't respond well to stress/pushing – this is not just your story or deadline; this is someone's life.

PERSON WITH LIVED EXPERIENCE

Some Media Professionals illustrated the difficulty in balancing the responsibility to ensure people are cared for in the process while getting work done to deadline:

You get used to dealing with people in your work but it's very hard to manage a filming schedule, alongside minding people. Filming has to get done.

MEDIA PROFESSIONAL

Both Mental Health Professionals and People with Lived Experience conveyed an understanding of the pressure on Media Professionals:

I understand the pressures they are under. If we can communicate better about how we both work, we can come together and make it an enjoyable experience for all.

MENTAL HEALTH PROFESSIONAL

The more specific issues that arise from this cultural difference – requests for a media appearance at short notice, a lack of consultation, media engagements feeling rushed, lack of post-engagement consultation – are explored in more depth further in this report.

CHALLENGE 4

Capacity to consent is a complex issue for all stakeholders

The issue of capacity to provide full and informed consent was an issue that was identified as requiring careful consideration by all stakeholder groups. This is the point at which the autonomy of the person with

lived experience may conflict with the duty of mental health professionals to protect them from harm, and with the responsibility of journalists to provide a platform to members of the public. The issue of capacity is not exclusive to media participation and has been an ongoing area of complexity and contention in mental health service provision and research. The dilemma is well-summarised below:

We live in an environment of presumed capacity – it's a basic human right. I should not stop them, but it doesn't make me feel less nervous or concerned. I'm concerned about it having a negative effect on them in the middle of the interview and afterwards. If I know the person is well and they go ahead and two months down the line they come out of hospital and the interview is out there forever. From a human rights perspective there's no dilemma, but from a personal perspective, they could do their own self more harm – credibility and reputation.

MENTAL HEALTH PROFESSIONAL

There's a balance to be struck. Especially when your journalistic side knows it's a good quote. However, you shouldn't be censoring them, or patronising them either. Your own sensibilities shouldn't be the judge. People have a perfect right to express their view or their feelings. In the area of mental health, you're often worrying if they know what they are doing, which also could be patronising.

MEDIA PROFESSIONAL

The issue was addressed by six of the people with lived experience (46%) who all identified significant risks for a person who is unwell when doing an interview, with a number highlighting that media professionals should not interview someone if they are unwell:

If someone is unwell, don't interview them.

PERSON WITH LIVED EXPERIENCE

People with mental illness don't respond well to stress/pushing – this is not just your story or deadline; this is someone's life.

PERSON WITH LIVED EXPERIENCE

However, it was acknowledged by all stakeholders that in some cases assessing whether someone is well or unwell is not easy or straightforward. Differentiating between behaviour that might be usual as part of someone's wellness and a behaviour that is present when they are unwell and have compromised capacity to consent is, in many circumstances, beyond the remit and ability of most journalists or other media professionals. Coping behaviours such as tensing muscles, repeated movement, crying or averted gaze could be an indicator of wellness or illness depending on what this behaviour means to the individual. To the casual observer, this is impossible to assess.

Journalists aren't skilled in mental health. They might not realise someone is going through a psychotic episode.

PERSON WITH LIVED EXPERIENCE

Despite this, a number of media professionals identified past experiences where either they, or another person, identified that a person may be too unwell to participate:

[During a time of media attention to the] Ryan Report we had very vulnerable people phoning, survivors of abuse, some with serious mental health difficulties as a result... most did not go on air; they could not.

MEDIA PROFESSIONAL

Both Mental Health Professionals and People with Lived Experience highlighted that there are particular times in a person's illness and recovery journey where they may be more vulnerable to being triggered by a negative media engagement. This is at a stage in early recovery:

If someone is just out of treatment, they're the wrong person to interview; it's too soon. The journalist should know not to approach someone who is in the very early stages of recovery.

PERSON WITH LIVED EXPERIENCE

While it was agreed that there is no easy answer to this dilemma, the benefits of engaging media participants through a gate-keeping mental health organisation, which can assess whether someone is well enough to participate, was discussed by a number of interviewees:

You should not be interviewing without an advocate, someone who has a knowledge of mental illness.

PERSON WITH LIVED EXPERIENCE

All Mental Health Professionals described robust processes in their organisations for supporting media engagement. This included helping people to identify worthwhile media engagement opportunities, to assess their own wellness to engage or deal with fallout from media, as well as supports to prepare for interviews. This is explored further in the solutions section below.

CHALLENGE 5

Mental health symptoms may be exacerbated by, or interfere with, media engagement

An area of inquiry in the interviews for this research was whether and how symptoms associated with severe and enduring mental illness manifest and/or are exacerbated by the media engagement process. The research focused on particularly stressful media engagements, for example live television, which could trigger or aggravate symptoms.

People with Lived Experience and Mental Health Professionals identified symptoms or coping behaviours that could manifest during an interview that journalists should be aware of. These behaviours in some cases could be a sign that the person is uncomfortable and could be exacerbated by the interview experience. However, many of the symptoms described above by People with Lived Experience were made hypothetically (e.g., speculations on the experiences of others rather than speaking from direct experience) and this was not something that most Mental Health Professionals felt was a particular area of concern. This may be explained to some degree by the commentary from Mental Health Professionals and many of the People with Lived Experience that most people, by the time they are engaging with the media, are out of early-stage recovery, and understand how to manage their symptoms:

Those with serious mental health diagnoses who we put forward for interview are generally living well with their diagnosis. They may be experiencing symptoms associated with their condition, such as hearing voices for example, but their symptoms shouldn't interfere with their ability to engage in a media interview.

MENTAL HEALTH PROFESSIONAL

Participants from various stakeholder groups identified that certain media engagement formats are more challenging than others, with live television

being most challenging, to interviews for print where you have an opportunity to review the content being the least challenging. Pre-recorded television and radio were also considered less challenging than live TV or radio.

All interviewees were asked whether there were specific aspects of media engagement that may be uniquely challenging to people living with mental illness. Again, many participants did not identify features that would be challenging for people living with severe mental health difficulties exclusively; a number of participants highlighted that media engagement is stressful regardless of your mental health state.

Some did mention particular features of the process that could be higher risk, including that the overwhelming energy of the process (particularly if there are high levels of social media/media attention in the aftermath) can result in loss of focus on triggers or recovery, and where people have unique triggers that have not previously been discussed with the media professional (e.g., words, mannerisms, locations, topics) etc.

The important point emphasised by people with lived experience is that many symptoms of severe and enduring mental illness might be indiscernible from the usual nervousness media professionals may be used to seeing. In addition, many of the symptoms will not be visible to media professionals:

People who aren't suffering from hearing voices, they don't know what's going through your mind. It's hard for someone to say I'm hearing voices. It doesn't get said like that.

PERSON WITH LIVED EXPERIENCE

Other symptoms such as muscle tension, stomach pain, the interviewer won't know that's happening.

PERSON WITH LIVED EXPERIENCE

The need for the journalist to be alert to possible discomfort and engage with it compassionately as the primary way to manage this was encapsulated by one Person with Lived Experience:

Go with your gut. If you think the person is slightly off/fast/slow/getting upset, you're probably right. Check in with the person.

PERSON WITH LIVED EXPERIENCE

5.3 General Good Practice in Media Engagement

Overview

The good practice suggestions presented in this section aim to support the Media Professional getting the information they need for the good story, and the Person with Lived Experience feeling they have positively contributed to public understanding through a process that was respectful, empowering and did not cause them harm. All suggestions have their source in interviews with participants. In some instances, questions were asked directly as to what is needed and in others, suggestions were proffered through reflection on challenging experiences, and identified by the research team as being applicable to the overall process.

Increase understanding among media professionals of mental illness, and why people can, for the most part, safely engage in media interviews

Media professionals should be assured that there may be unnecessary levels of concern or fear about engaging people with lived experience of mental illness. This research indicates that when people engage in media interviews through a gatekeeping mental health organisation, they are for the most part in a place where they can manage their symptoms and can manage the impact of their symptoms through the media engagement process.

However, there remain a number of ways in which the media engagement process could disempower, objectify or trigger people who have had difficult past experiences, and could discourage them, their support organisation or their peers from engaging with the media in future – the avoidance of such situations is addressed in detail in the following sections of the report.

Mental health organisations can support navigation through complex issues of capacity and consent

Research participants from all three stakeholder groups identified capacity to consent as a challenge. To address this challenge, many discussed the benefits of engaging a participant through a gatekeeping mental health organisation.

The following are observed benefits of engaging a participant through a mental health organisation:

Media training programmes for people with lived experience and/or media panels

Screening processes to support participants to identify opportunities that will be positive for them

Organisations often have guidance on a minimum length of time since recovery (e.g., a year in recovery prior to engaging with the media was referenced)

Mental health organisations usually have a policy to respect the autonomy of the individual's choice to engage with the media, even when professionals may not think this is the best course of action. Organisations have significant experience in managing these instances, considering duty or care and human rights principles.

Mental health professionals are available to journalists to discuss concerns with or consult on about good practice where needed.

Where a person is recruited for a media interview through a channel other than a mental health organisation, and the Media Professional has a concern about capacity to consent, then the following precautions were advised:

Seek to engage a support person/family member to be part of a conversation on the process

Raise the issue and clearly discuss any concerns regarding capacity

Consider after the fact if the most ethical thing to do is to continue to run the story in part or in full – if there's a possibility to delay and check back in, potentially when the person is well again, this is worth considering

A commitment to continued affirmation of consent can mitigate cross-cultural differences, anxiety and disengagement

There are various points in the media engagement process where information sharing, communication and reaffirmation of consent can be undertaken. However, participants agreed that journalists being attentive to discomfort that may or not be directly communicated can help to ensure they identify where a person may be experiencing difficulty, the possible cause, and how they may be able to alleviate it to ensure the person continues to tell their story and feels safe to do so. Checking in with the participant at all stages, proactively responding to signs of discomfort, and communicating clearly and directly about what is happening and why, can help to alleviate anxiety and promote continued engagement.

Media professionals should seek to understand a person's subjective experience of mental health and initiate a discussion on triggers and how they can be avoided

There are many ways in which a person can engage in the media, and while certain formats are understood to be more stressful than others, what will be experienced as particularly triggering or challenging for a person with lived experience will be unique to that individual. Some common triggers are predictable and within the control of the media professional such as lack of information, changing plans, a failure to attend to discomfort, and lack of feedback/thank you. However, other triggers or things that can create discomfort or trigger people will not be obvious, or may be outside of anyone's control (e.g. where someone is triggered by particular settings, personal characteristics, common words or gestures, etc). Media professionals need to initiate conversations with participants about what their needs and/or triggers are. Understanding this helps the media professional to create the conditions in which the person can participate with optimum levels of psychological comfort and safety, thus increasing the likelihood that they will remain engaged and their story can be effectively understood and retold.

People who aren't suffering from hearing voices, they don't know what's going through your mind.

It's hard for someone to say I'm hearing voices. It doesn't get said like that.

PERSON WITH LIVED EXPERIENCE



06

Before Engagement – Challenges

6.1 Overview

The before engagement stage includes all activities undertaken by media professionals, from first contact, to the point where the interviewer and interviewee are together for the interview.

6.2 Language and content

Preferred language to describe mental health experiences varies

Preferred terms to describe mental health experiences vary from person to person, while there are common stigmatising terms that people do not like. Interviewees described the language they preferred or did not like, which highlights significant variation in language preferences. The table below also illustrates there are some terms equally preferred and disliked by different people.

Preferred Language	Language participants do not like
Disability	Schizo, mad person Lunatic, psycho, crazy Service user
She has [condition] e.g. she has depression	She is depressed
Mental illness Mental health challenges, lived experience, mental illness, mental health difficulties Severe mental health issues	Mental health Generalised language that lumps milder conditions in with more severe conditions Severe and enduring
Specific diagnostic labels such as bipolar disorder, schizophrenia, anorexia etc.	Specific diagnostic labels such as psychosis or schizophrenia (note this in both columns, as was mentioned as favoured by some and disliked by others)

Media professionals should be wary of presuming what the 'correct' terms or words are; the clear guidance is to ask people for their preferred language. While a number of participants said they would not be particularly bothered if someone used a term they do not like, there is a risk that in trying to establish trust and build rapport to promote a positive and effective media engagement experience, the use of language experienced as hurtful or offensive could create a barrier at an early point in the development of the relationship between the journalist and the media participant. Even well-intentioned efforts to find the least offensive term might still result in a term that is not acceptable to the person being interviewed.

Issues that are not permissible for discussion vary from person to person

People with Lived Experience and Media Professionals were invited to identify whether there were particular issues that should not be discussed in the context of a media interview. Participants identified that people may be reluctant to discuss issues such as suicide attempts, medication, hospitalisation or problems with services that they continue to rely on for support. However, participants also identified that they can choose not to answer questions relating to topics they don't want to discuss, and that journalists have a job to do in trying to explore the issue in depth. An important conclusion in relation to this is that while a number of people with experiences of severe and enduring mental health conditions have issues that they would prefer not to discuss, there is no common agreement on this, so consultation is crucial.

6.3 Participant preparation and support

Lack of understanding of the media process or preparation for it

All participants identified a challenge where the Person with Lived Experience was not appropriately prepared for, or fully informed about, the experience in advance. The challenges included:

- Lack of communication about the fact that an interview might not go ahead
- Lack of clarity in advance that the interviewer wanted to use the person's name/image
- Lack of explanation about what 'off the record' means and when it is relevant
- Presumption on the part of the media professional that the Person with Lived Experience understood certain processes or facets of the experience such as consent, being in a studio, introduction of new questions etc.

Not having interview questions in advance

A number of People with Lived Experience and Mental Health Professionals supporting interviewees

identified that not having a list of interview questions in advance, or having interview questions changed at the last minute, can be a source of stress:

It was nerve-wracking – they said they'd send me the questions ahead of time, and then they didn't send them.

PERSON WITH LIVED EXPERIENCE

Lack of rapport-building in advance of the engagement

The importance of establishing a rapport and a reasonable degree of trust between the interviewer and the media participant was identified as important for the following reasons:

A significant degree of vulnerability is required for someone to disclose past experiences, particularly negative ones, which may be associated with feelings of fear, sadness or shame.

A journalist showing that they are interested in more than the person's mental health (e.g. inquiring/chatting about their lives) can reduce perceptions of judgement, shame or objectification that the participant may fear the journalist harbours.

A journalist showing that they are willing to take time to fully inform the participant about the process and check in on their comfort means the person is more likely to feel respected and less likely to be on edge and therefore provide a better interview.

Many Media Professionals mentioned the importance of rapport-building to creating a positive engagement experience and quality interview; however, a number said that pre-interview engagement is not part of their practice. The following quote highlights this experience from the interviewee's perspective:

The TV presenter has the producer in their ear. They're concentrating on what's coming up during a commercial break. The person coming in for an interview may be brought in to sit beside them and the interviewer may not even speak to them. This person is coming in to share their very difficult experience; they have really worked themselves up. But they are invisible on the couch until seconds before the interview.

MENTAL HEALTH PROFESSIONAL

6.4 Planning and Logistics

Last-minute cancellations or changes of plan

All Mental Health Professionals and a number of People with Lived Experience described times where interviews were cancelled, sometimes without any communication, or plans were changed, and outlined how this caused stress and sometimes distress for participants:

They tell you that the interviewer is going to call you tomorrow morning, then the next morning, then the next, and the call never comes... you've gone through a lot, maybe talking to a researcher for an hour, and then the interview never happens... It's soul destroying... They don't even ring to say sorry.

PERSON WITH LIVED EXPERIENCE

There was a general understanding from Mental Health Professionals that media timelines move quickly, and change based on emerging issues, editorial demands and other factors:

[Cancellations have] happened on numerous occasions. When you work in live television, things do drop a lot and you can forget to go back and apologise or not consider the work that went in.

MENTAL HEALTH PROFESSIONAL

Cancelling interviews and last-minute changes are an expected part of the professional culture in media. However, where people are preparing to divulge difficult and sensitive personal stories, the impact of cancelling may have a more severe impact than, for example, cancelling an interview with a politician or expert on a topic of interest.

6.5 Other issues in the 'before' stage

A number of issues were raised by one or two participants that bear potentially valuable learning for improving media engagement practice when working to engage an interviewee:

From the perspective of Mental Health Professionals

Last-minute requests from media professionals to mental health organisations for someone to tell their story are difficult for them to respond to, as there is preparation time required to support someone to share a vulnerable or difficult story

Media professionals who approach mental health organisations with an attitude that is pushy, or which does not show consideration for the needs of the person with lived experience or the mental health organisation are less likely to have someone referred to them

Media professionals who try to discourage a support person from being present (particularly where this is related to a broadcast engagement) will arouse suspicion and garner increased scrutiny of their processes or a reluctance to fulfil their requests in the future

From the perspective of People with Lived Experience

Media professionals not being honest about their angle or the purpose of their interview, or not communicating this clearly, increased distrust

Media professionals repeating tropes or using language that is stigmatising and causing offence or distress to the interviewee decreased interest in participation

Interviewers making presumptions about the person's experience, condition or diagnosis was common and decreased the trust in the experience and the quality of the interview

They tell you that the interviewer is going to call you tomorrow morning, then the next morning, then the next, and the call never comes... you've gone through a lot, maybe talking to a researcher for an hour, and then the interview never happens... It's soul destroying... They don't even ring to say sorry.

PERSON WITH LIVED EXPERIENCE



07

Before Engagement - Solutions

7.1 Overview

This relates to activities undertaken prior to engagement by the media organisation, from first contact to the point where the interview and interviewee are in the room together. This includes researchers, producers, journalists and any other professional who may be in early contact with the person being interviewed.

7.2 Consider engaging interviewees through a mental health organisation

Mental health organisations can help to find appropriate interviewees, provide pre-interview training and supports that aim to promote the well-being of the interviewee, increase the quality of the interview, and provide aftercare for the interviewee, if needed. Mental health organisations can also help journalists to navigate challenging issues around capacity and consent in the circumstance that they arise.

Almost half of the Media Professionals (42%, n=8) reported positive experiences of engaging people through mental health organisations.

People with lived experience noted that the organisation can act as a filter or buffer for them and help them to identify appropriate opportunities. In addition, some mental health organisations have specific expertise and training programmes for participants that can help to ensure people are prepared and have support in managing their understanding and expectations of the process. Where needed, mental health organisations can often provide an advocate for the media engagement.

7.3 Undertake preparatory research and agree language, content and process

Learn about relevant issues prior to the interview

Many of the media professionals involved (n=6) said that they were eager to learn more about various aspects of mental health and mental illness. Six of the media professionals (42%) recalled experiences where they undertook research or training, either in advance of a particular interview, or with their organisation more generally.

Enquire about interviewee preferences

The previous findings highlight that while business-as-usual interview approaches are likely fine for most people, there are facets of the process that can be particularly stressful for people with mental health issues. It was considered good practice to walk the interviewee through the process and to ask them if there is any preferred language and anything else in that process that could make them feel uncomfortable or anything the journalist could do to make their experience more comfortable:

Discuss with people before interview if they need special requirements, time, breaks, be aware of the time of day – anything to make them feel more at ease.

PERSON WITH LIVED EXPERIENCE

Things to be discussed prior to the interview include:

- Developing code words/actions to flag discomfort
- Preferred language and words (or sounds or gestures) to avoid
- Whether there is a need for a support person to be available on the day
- Whether there are mental health organisations which can support them and provide information in advance about the person, their boundaries, etc. to the interviewer
- Whether there are topics they wish to avoid



Provide a copy of the questions where possible

Provide a copy of the questions that will be asked in advance, and explain that some additional questions may arise if the person says something of particular interest, reassuring them that you will not probe on issues they have flagged not to be discussed, where relevant:

If someone has very bad anxiety, to think, okay, what are they going to ask me next... if they have the questions [that helps]. The journalist can then say that they might ask additional questions on the basis of the answers you give me.

PERSON WITH LIVED EXPERIENCE

Give full information and manage expectations

The participants should receive full information on the process from beginning to end. While many Media Professionals described processes, there was more often than not a focus on consent and use of information, with some examples of more comprehensive preparation.

Helpful information includes:

- What the engagement will involve
- Who will be there
- How long it will take
- What the atmosphere be like (noisy/busy/quiet, etc.)
- How equipment will be used (cameras, microphones, recording devices)
- How it will end
- What will happen afterwards and on what timeline
- Issues around consent and how/if privacy and anonymity will be protected
- If things need to be corroborated, what that will involve
- Potential impacts of going public with a story
- Any other relevant information.

Media Professionals and Mental Health Professionals highlighted the need for a shared responsibility across all stakeholders to ensure the interviewee has the information they need to engage. If the person is engaged through a mental health organisation with a strong media programme, it was highlighted that the person may well arrive to an interview informed and and prepared. The media professional may simply need to check that the person fully understands the process, provide any information specific to the occasion, and answer any questions the person may have.



08

During Engagement - Challenges

8.1 Overview

The 'during engagement' stage includes the time from when the person is in the room/on the phone/ in the studio for the interview, until the interview has ended.

8.2 Interview Content

Introducing questions not previously agreed or topics not approved

People with Lived Experience and Mental Health Professionals noted that the introduction of questions or topics not previously agreed, particularly questions that felt like 'curveballs', introduce unnecessary stress in the engagement:

[I was] talking about stigmatisation, and the question was put to me about people in prison, criminals with mental health issues. I have no expertise on that – most people with mental health issues aren't in prison.

PERSON WITH LIVED EXPERIENCE

A number of participants with lived experience recalled times where interviewers raised or sought to explore very difficult or personal issues that made the participant uncomfortable:

The interviewer asked, when you were young, what was that like [referring to suicide attempts], asking very specific things about dark times, I wasn't really prepared – it had nothing to do with the interview. He was genuinely interested, shocked, and went digging in a way that wasn't appropriate.

PERSON WITH LIVED EXPERIENCE

In both these instances, techniques that may be appropriate to use with seasoned media participants such as political figures or subject matter experts are less likely to be appropriate for interviewees with mental health conditions who were less experienced in media engagement.

8.3 Interview style and techniques

Lack of pauses or awareness of interviewee's needs

Journalists noted that in the day-to-day pace of their work they can forget that some people may need additional engagement, and a failure to recognise that can impact on the quality of the interview:

Especially working on daily programmes, you might put people through your hands and are not fully thinking of them as a vulnerable person like someone working in mental health would.

MEDIA PROFESSIONAL

Nothing is more important than the person in front of you, not the film, we have to respect that... When things go wrong it's usually because that has not happened, and people are upset with that.

MEDIA PROFESSIONAL

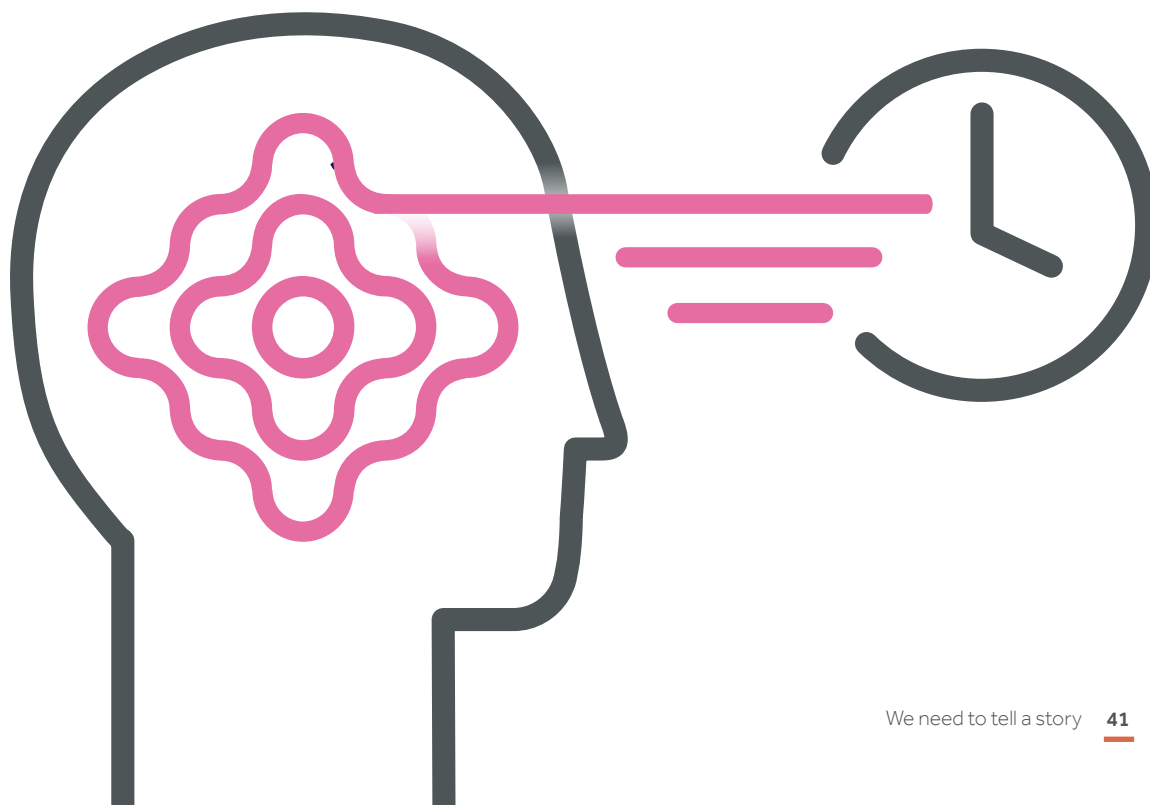
Other issues in relation to interview style, where people felt disrespected or taken advantage of, included:

Rushed by the interviewer, with a lack of control over the pace

That the interviewer didn't care about them or looked through them

Like they were only interested in them in a one-dimensional way (e.g. only about their sickness, only about their recovery, etc.)

Interviewers who conveyed a loss of interest or lack of care following the interview





09

During Engagement - Solutions

9.1 Overview

The 'during engagement' stage includes the time from when the person is in the room/on the phone/ in the studio for the interview, until the interview has ended. Solutions identified during this phase include building rapport and creating a respectful and psychologically safe interview experience.

9.2 Interpersonal

Build rapport before the interview

The majority of People with Lived Experience highlighted the importance of engaging in rapport-building or getting to know the person before the interview (77%, n=10). Six of the media professionals (30%) mentioned this as something important to their process. If the interviewee trusts the interviewer and has developed a rapport in advance of the interview itself, they are more likely to be honest about their difficult experiences:

If they're nice off-air as well as on air... it's very helpful if the interviewer acknowledges you before they interview you

PERSON WITH LIVED EXPERIENCE

Meet for the interview and have a general chat ahead of the interview itself. This calms them and calms myself... Relax them and let them know you are just a person doing a job, that you're not out to get them or relay information in a twisted sense. Allay their fears.

MEDIA PROFESSIONAL

A number of participants felt that an important preparatory step for journalists is to question and challenge their own assumptions before the interview, which can be supported by rapport-building.

Don't make assumptions; don't assume, or think you understand... Everyone you speak to is an individual with a different life story.

PERSON WITH LIVED EXPERIENCE

Convey respect and connection and create psychological safety

'Psychological safety' is the universal experience of feeling like there are no current threats to your safety or well-being, regardless of your mental health status. It describes the state in which your body and mind are relaxed and not on high alert from threats or danger from others (49, 50). The reason this is particularly important in a journalistic interview is that where people are in a state of psychological unsafety, their pre-frontal cortex, responsible for thinking, communication and decision making, is pushed into an inactive state and taken over by the

'old' brain – the part of the brain that is responsible for responding to immediate threats to safety (51). In such states, the brain is focused on activating the muscles, vision, hearing and other features needed to survive an immediate threat to safety. A person who is feeling unsafe and in fight-or-flight mode will have diminished capacity to remember, decide, communicate, and make meaning. People who have suffered trauma (this can include systemic abuse in institutions, abuse in the home, discrimination and other experiences associated with severe mental illness) are more likely to be triggered into fight-or-flight in situations, particularly where they must be vulnerable and give away their power, as in the context of a media interview about their personal experiences. Although it may feel like a stretch of the imagination to compare the subjective experience of a journalistic interview to fear of abuse or physical threats, the hormonal system does not differentiate between these situations, and activates and shuts down the systems of the brain in the same way, regardless of the nature or seriousness of the threat.

Some people lost their trust when they go to psychiatric hospitals; a lot of their trust is gone. They need to feel safe; it can be hard to open up to a huge audience of people.

PERSON WITH LIVED EXPERIENCE

It is in the best interests of the journalist, the interviewee, and ultimately the public, to ensure that the person feels as psychologically safe as possible in the course of the interview. This does not mean creating a therapeutic atmosphere, or even a particularly supportive one, but rather one that feels professional, respectful and in which their boundaries are unlikely to be crossed:

It doesn't have to be supportive, that's not their job, they're not trained to do it either, as long as they're responsible and appropriate in their approach, it doesn't have to go to the level of being actively supportive.

PERSON WITH LIVED EXPERIENCE

There are many tried-and-tested mechanisms for creating psychological safety in the context of a media interview. These include:

Treat the person as a capable adult: Many participants highlighted that while an interviewer should be respectful and kind, there is a danger that this can veer into being patronising. Treating someone as delicate or unable to take care of themselves can undermine trust between the interviewer and the interviewee, as it may be perceived as a form of disrespect.

Don't be worried or fearful interviewing someone who you think is going to fall apart or is at risk. If you're not sure, ask them, is this okay to ask about?

PERSON WITH LIVED EXPERIENCE

An example one participant provided of this being balanced well is where they were being interviewed about a particularly difficult incident in their lives that they had agreed to discuss:

He was patient and asked questions and said all the way through if you don't want to answer, don't; if you don't want to elaborate on something, don't. He was easygoing without being patronising.

PERSON WITH LIVED EXPERIENCE

Media Professionals must seek to create rapport and be respectful, but not to be afraid to do the work that needs to be done for the purposes of the production or publication. Acknowledging the other as a capable adult with the ability to give or remove consent is the way to achieve this.

Be authentically encouraging: In the course of an interview, a person may get lost in their own story, disconnect from the purpose, falter on difficult points, etc. For the Media Professional, having a clear understanding of their own motivations and the participant's, and when needed reminding the participant of the purpose of the interview (e.g. previous sections highlighted that people were eager to ensure that others in their situation would benefit from hearing their story) can be encouraging:

It's difficult to share. The people who interviewed me were empathetic, encouraging, said 'it's good you're sharing this', and reassured me that what I was doing was helpful to others.

PERSON WITH LIVED EXPERIENCE

Provide choice and control where possible: Much of the media process necessarily lies out of the participant's control, and this has been identified as a source of stress. Providing choices where possible to increase a sense of control can reduce feelings of disempowerment. This may be in relation to things such as the time of the interview, the location, or the order of topics to be discussed.

Sustain and convey respectful interest: People with Lived Experience highlighted that it is encouraging to feel like the person interviewing you is genuinely interested in you as a person, in your story and in your strength:

Going to the interview isn't a therapy session, but at the same time if I am talking about something deeply personal, I want that to be respected. When that does happen, it makes it worthwhile.

PERSON WITH LIVED EXPERIENCE

This can be done through remaining connected and listening deeply (and not just to the more dramatic aspects of a person's story). One participant highlighted the importance of doing this in a way that is authentic – that you can listen without pretending to understand.

Support communication and clarity: Due to inexperience, being in a fight-or-flight state,, managing active symptoms or a range of other factors, participants may not say things in the way that they mean in the context of an interview:

You can get fumbled up – you can be talking but what you're saying could be lost or misinterpreted.

PERSON WITH LIVED EXPERIENCE

The media professional can help to mitigate this by regularly checking in on meaning, reflecting back, and seeking clarity.

Do not rush but clarify limitations on time: The time pressure that is a feature of media culture is a challenge Media Professionals must navigate; however, the degree to which this impacts on the interview experience can be mitigated by tone and communication style. Media professionals can clarify at the beginning and respectfully signpost how much time there is during the interview where time is limited, but adequate time and space for the discussion of difficult stories should be allowed.

Personal stories are a difficult topic, and can be triggering for a person, so giving time is really helpful.

PERSON WITH LIVED EXPERIENCE

Be alert for discomfort, and proactively check

in: Under normal circumstances, many people find it difficult to articulate discomfort in the course of a conversation, for reasons which may include fear of being impolite, seeming needy, or upsetting the other person. In an interview, feelings of powerlessness and having to relive difficult experiences may also increase both the risk of experiencing discomfort and the fear of naming it. Where an interview participant is experiencing discomfort and it is inquired about, participants reported that this could increase feelings of trust and respect:

I was interviewed by a woman for [Irish broadcaster]. Something came up in the interview; she said, I felt you became emotional. She did identify with me. It was a good experience for me.

PERSON WITH LIVED EXPERIENCE

I was interviewed by a woman for [Irish broadcaster]. Something came up in the interview; she said, I felt you became emotional. She did identify with me. It was a good experience for me.

PERSON WITH LIVED EXPERIENCE



10

After Engagement - Challenges

10.1 Overview

The after-engagement stage includes all activities that occur after the formal ending of the interview, including activities regarding communication, production, broadcast or publication, and post-broadcast and publication feedback or engagement. Challenges in this phase include issues relating to final content, broadcast or publication and interpersonal engagement.

10.2 Content and production

Mismanaged expectations about the final product

People with Lived Experience and Mental Health Professionals described times where the person was disappointed that the information that they provided was not used in the manner they expected, which included much of the information not being used in the final article or programme, or information not being used at all:

With newspapers, the story is sometimes never published. You arrange a session with the photographer, taking a day to travel to Dublin and participate. Then nothing ever comes of it.

PERSON WITH LIVED EXPERIENCE

Media Professionals provided various accounts as to why stories may be edited, reframed or not used at all, which included editorial decisions, an inability to corroborate stories, or the news cycle being dominated by other issues:

Sometimes this copy can be changed as part of the editing process. Or it can appear in a headline. No mal-intent on anyone's part.

MEDIA PROFESSIONAL

A number of interviewees also experienced feeling they were misrepresented or taken out of context. One participant described how a journalist had included comments from them that they had not realised were part of the interview, and was told that because she had not told them it was 'off the record' that it was OK for them to use it:

When questioned on using things I said before the interview began, they said that everything I said when talking to them was admissible in the article as I hadn't said 'off the record' at any point.

PERSON WITH LIVED EXPERIENCE

If I'm going to share my story, someone should be checking in on me: are you ok after sharing that? Have you got someone to go to? There's no human element. They usually say, thanks for answering the questions, bye.

PERSON WITH LIVED EXPERIENCE

Lack of control over the final product

There was an acknowledgement among Mental Health Professionals and some participants that control over a final product is often an unrealistic hope. Participants described feelings of powerlessness in relation to the final product, with a number stating a desire to have some form of review before the final product goes to print or broadcast:

I know what I've said, but I don't know how it's going to appear or look when it's published. The next time I see it, it'll be in print. I've no say over what you do with my life story.

PERSON WITH LIVED EXPERIENCE

Media professionals working in longer-term projects highlighted that they often had the opportunity to review footage with participants, and this was usually a positive and empowering experience, but one they recognised is not feasible with many other types of media product.

Lack of information about broadcast / publication

People with Lived Experience and Media Professionals described that a lack of information about the story – and when it would be published or broadcast – was disappointing or frustrating. It was felt that this was a particularly important gesture where it involved people sharing deeply personal issues such as mental health experiences:

I had to chase the person to find out when the article came out. It feels like you served your purpose and now you're not important... For people being on media it's a huge deal; for journalists, it's daily life. If a person has been mentioned in an article, they usually save or clip it and tell someone about it... In the moment you feel it's really special, but if you're not told about it, missed it, can't get the paper or didn't even see it, it can be upsetting.

PERSON WITH LIVED EXPERIENCE

Verification can cause offence or delays

An issue that was raised by Media Professionals but not by other stakeholders was the role that verifying or corroborating certain parts of people's stories can play in relation to delays in publication or broadcast, or negative feelings for people with lived experience. This is an essential step in the process for journalists that helps to ensure that information being printed is true and protects the media organisation or journalist from libel. One journalist noted that some people may interpret this process as indicating that they are not believed:

We have to ask them for access to speak to doctors, solicitors, various people, as I can't take what they are saying as a given. We cannot take anything for granted [and] have to go through an independent process to verify it. Sometimes that can cause people strife as they feel that they are not believed.

MEDIA PROFESSIONAL

Withdrawal of consent to use the story

The withdrawal of consent was noted by some Media Professionals as a relatively rare, but challenging experience.

...one very recently, where a person doing the interview didn't go ahead with participation in a documentary – this is really quite rare! It's reassuring that it is not a common experience.

MEDIA PROFESSIONAL

It was felt by Mental Health Professionals that how a Media Professional or their organisation responds to or handles this is likely to impact whether or not the mental health organisation will work with them in the future.

The journalist may need to expect and accept [withdrawal of consent] is happening. It would be great if the media understood what a huge role shame plays in mental health and how not to feed into this.

MENTAL HEALTH PROFESSIONALS

10.3 Interpersonal

Lack of check-in

The need for a post-interview check-in was identified as important by both People with Lived Experience, and Mental Health Professionals.

If I'm going to share my story, someone should be checking in on me: are you ok after sharing that? Have you got someone to go to? There's no human element. They usually say, thanks for answering the questions, bye.

PERSON WITH LIVED EXPERIENCE

Over half of the media professionals confirmed that they do not have processes for checking in with the person after the interview is done that they systematically implement (53%, n=10), while a smaller number said that this is something they usually try to do.

Unanticipated impacts

Media Professionals discussed unanticipated impacts for participants, and many highlighted particular concerns around this. A number recalled times where people they had interviewed had unintended outcomes from the publicity surrounding their stories:

The participants had negative social media attention and calls from media.

MEDIA PROFESSIONAL

People with Lived Experience and mental health organisations also described concerns regarding high levels of attention, social media engagement or personal contacts arising after their story went public. In some cases, this was perceived as welcome and positive, while for others this was overwhelming and a negative experience.



11

After Engagement - Solutions

11.1 Overview

The post-engagement stage includes all activities that occur after the formal ending of the interview, including activities regarding communication, production, broadcast or publication, and post-broadcast and publication feedback or engagement. Solutions in this stage relate to input on final content, information on the use of the person's story and interpersonal issues.

the journalist after the interview (immediately or in the days following). While it was felt that providing emotional support is not the role of the journalist, checking that someone has emotional support if they need it, or just checking in to see how they are doing afterwards, is helpful. There was general agreement that this should be a respectful and authentic sign-off and does not need to be a long, drawn-out or a particularly effortful process. It is continuing the respectful rapport-building established at the beginning of the process.

11.2 Content

Explain whether and how control can be given over final content

All stakeholder groups expressed understanding of the reality that opportunities for reviewing content prior to publication or broadcast of pre-recorded material are not always present. Despite this, it should be noted that when People with Lived Experience were describing excellent media engagement experiences, in many cases the opportunity to review content prior to publication or broadcast was named as a factor in this.

Let people know when it will be published or released

People with Lived Experience and mental health organisations highlighted the importance of receiving timely information about broadcast or publication dates. In addition, any information that helps the person to understand their impact e.g., social media traction, follow-on programmes or articles etc., can be reassuring and positive for the person who shared their story:

I enjoyed some of the feedback and it's rewarding and a privilege to have a chance to help others understand what it's like to be me.

PERSON WITH LIVED EXPERIENCE

Even just asking the question can mean a lot to the individual and it means a lot to the organisation. We'll know that this is a caring media professional who understands the impact of these experiences on people.

MENTAL HEALTH PROFESSIONAL

It was highlighted by some research participants that there is a greater responsibility on the media professional in relation to this where the media participant is not engaged through a mental health organisation.

Other solutions

Ensure that the person is offered a cup of tea and their comfort is considered after the interview

Ensure that the person is thanked both in person at the time, as well as again at a later point

11.3 Interpersonal

50 **Check in** We need to tell a story
People with Lived Experience valued a check-in from

Even just asking the question can mean a lot to the individual and it means a lot to the organisation. We'll know that this is a caring media professional who understands the impact of these experiences on people.

MENTAL HEALTH PROFESSIONAL



12

Conclusion

There is continued stigmatisation of people with severe and enduring mental health conditions in the media, and an absence of voices of those with such lived experiences. Engaging the voices of people with lived experience of severe and enduring mental illness is valued as a mechanism through which a more robust and comprehensive perspective on mental health can be communicated to the public, which may result in reduced stigma. However, the lack of representation remains, and there are varying theories as to why these stories remain untold and people living with severe and enduring mental illness remain underrepresented in stories relating to them.

People who have suffered trauma (this can include systemic abuse in institutions, abuse in the home, discrimination and other negative life experiences) are more likely to be triggered into fight-or-flight in certain situations, particularly where they must be vulnerable and give away their power, as in the context of a media interview about their personal experiences.

Where people are in such a state of psychological unsafety, their pre-frontal cortex, responsible for thinking, communication and decision making, is pushed into an inactive state and taken over by the 'old brain' – the part of the brain that is responsible for responding to immediate threats to safety.

Although it may feel like a stretch of the imagination to compare the subjective experience of a journalistic interview to fear of abuse or physical threats, the hormonal system does not differentiate between these situations, and activates and shuts down the systems of the brain in the same way, regardless of the nature or seriousness of the threat.

Media engagement experiences can be difficult for people with limited experience of them, regardless of their mental health status. While many people who engage with the media will have positive experiences of that process, nonetheless the process of engaging someone to share details regarding difficult or vulnerable parts of their lives is recognised to carry real and tangible risks to the person and to their future willingness to engage as participants in the media. There is potential for some people to be triggered or re-traumatised through the interview process, and there is a corresponding appetite to identify and mitigate these risks.

There is a difference in culture in media organisations compared to that of mental health organisations that

The hormonal system does not differentiate between these situations, and activates and shuts down the systems of the brain in the same way, regardless of the nature or seriousness of the threat.

can cause friction or misunderstandings between media professionals and people with lived experience or the mental health organisations supporting them, and discomfort for those engaging in media processes.

These differences include pace, language and the manner in which people communicate. Despite this, there was an empathy demonstrated for the pressure under which media professionals work. There is a strong commitment to the agency

of people with severe and enduring mental illness to decide for themselves whether and when they should engage with the media regarding their experiences.

Likewise, there is a commitment by media professionals to ensure a platform is provided to those who wish to share experiences, grievances and learning from living with severe and enduring mental illness. However, there is an acknowledgement that there are times in many people's lives where they do not have full capacity to consent or consider fully the longer-term implications of engaging with the media at a time when they are unwell. It is beyond the capacity or remit of media professionals to determine capacity on a person's behalf, although in some instances they may have to withdraw the opportunity to participate or decide not to publish for ethical reasons in relation to consent. There is a crucial role for mental health organisations, where appropriate internal media engagement infrastructure is in place, to support a person to identify their own capacity and prepare adequately for media engagement.

Symptoms of mental illness can manifest in the course of a media interview and may indicate that the person is in discomfort, or may be simply a coping mechanism. There are features of the media engagement experience that may be triggering for people living with severe and enduring mental health conditions, some of which can be prevented and controlled, others that cannot. Importantly, organisations who put people with lived experience forward for media engagement will make all efforts to ensure that the person is confident in managing their symptoms.

It is widely acknowledged that a journalist may not be able to discern usual nerves from triggered behaviour, and many symptoms of severe and enduring mental illness may not be externally visible in the course of a media engagement. This highlights the shared responsibility across all parties, interviewer and interviewee, to be alert for difficulty and ensure there are robust processes in place to prevent discomfort, identify and name it if it does arise, and in the case of the media professional, to support the person experiencing it to return to comfort by checking in and seeing what they need.

Finally, there are numerous opportunities at the

This research highlights the potential positive impact of tailored guidance for media professionals that can support them to implement this learning, while adhering to principles of truth-telling, integrity and public accountability.

end of a media engagement experience that can consolidate a positive experience including, where possible, providing some control over final content, acknowledging the person's contribution, and keeping them up to date on publication and broadcast and impact of their story.

This research highlights the potential positive impact of tailored guidance for media professionals that can support them to implement this learning, while adhering to principles of truth-telling, integrity and public accountability.



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