

Not Just a Story

The media's engagement with people with lived experience of mental ill-health, distress or trauma

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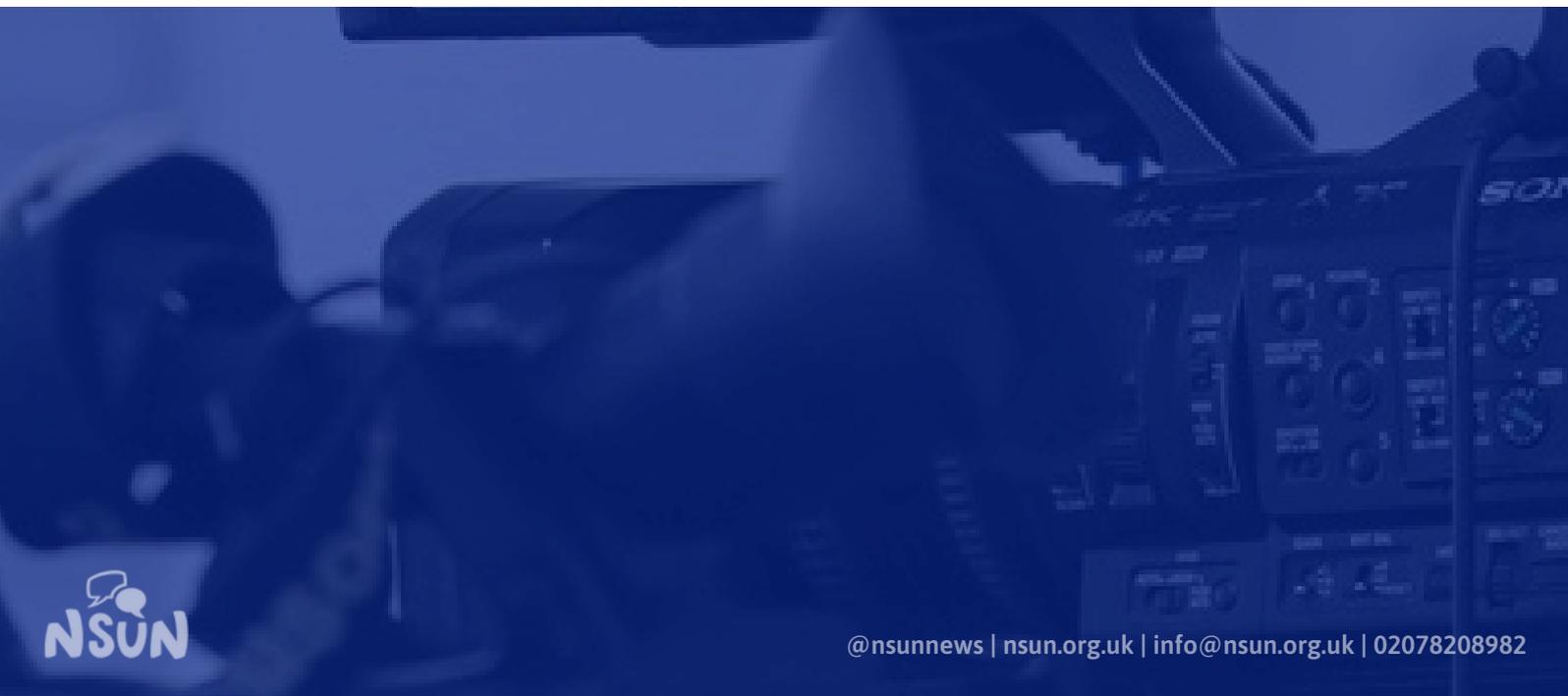
**National Survivor
User Network**



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Introduction



Be very clear in your own mind beforehand what you are and are not prepared to share; ask for questions in advance; be confident in refusing to answer questions you don't feel comfortable answering; don't assume journalists are necessarily on side; whilst I would never want to undermine anyone's agency to engage with media, I wish I had been in a more robust place and had a better support network. I thought naively it would be a straightforwardly positive experience and in actuality, I came away feeling interrogated and at points disbelieved.

Survey respondent

During the spring and summer of 2025, we surveyed 141 people and ran two focus groups with NSUN members to hear about their experiences of engaging with the media as people with lived experience of mental ill-health, distress or trauma. What we learnt was clear: the media and its journalists are consistently failing to genuinely and supportively engage with people with lived experience and sensitively represent their so-called 'stories'.

People with lived experience of mental ill-health are often motivated to share their experiences with the media because of a desire to raise awareness, provide representation – particularly of lesser-platformed experiences which may not receive much mainstream attention – and advocate to improve the experiences of others. However, even when it might aim to spotlight injustice, provide activists and 'experts by experience' with a platform, or challenge the status quo, the media's approach to extracting and sharing deeply personal and often painful or traumatic parts of peoples' lives can cause harm.

Key findings

-  **The long-term implications of taking part in public media engagement work are a key concern.** People who took part in this project often reported limited opportunity for anonymous contribution or support to think through possible consequences following publication.
-  **While being asked to share experiences with the media can feel validating, it can also enforce a sense of obligation to disclose painful experiences for a 'good cause'.** This can be retraumatising when it is not undertaken with care.
-  **People often feel tokenised when engaging with the media.** This is particularly significant when people feel that their contributions are used to endorse a pre-determined narrative, or are isolated or reduced to their most 'dramatic' or 'shocking' elements.
-  **People experience a lack of clarity and guidance when engaging with the media.** This includes receiving limited information on what the process will entail, and not being told clearly when they are speaking on or off the record.
-  **Limited control is offered over the process of engagement.** This includes not having a say over the angle and content of the final piece, which is often not shared with contributors for approval.
-  **There is a lack of consideration around support and access needs for both Disabled and/or neurodivergent people undertaking media engagement work.** This includes adjustments that can be made to make the experience less emotionally taxing for people with lived experience.
-  **Participants are usually uncompensated for media work.** This contributes to a sense that the time, expertise and emotional labour of people with lived experience is not valued or respected.

Who is this report useful for?

Towards the end of this report, we have shared guidance for people with lived experience who are considering engaging with the media, as well as guidance for journalists. This guidance aims to:

-  Provide support and questions to consider for people with lived experience who are deciding whether they wish to speak to journalists.
-  Provide recommendations for journalists who wish to meaningfully and supportively engage with people with lived experience.

While this project focussed on gathering insights from people with lived experience of mental ill-health, distress or trauma, similar issues with the media may have been encountered by people with other experiences or marginalised identities, therefore the guidance for journalists may be more widely applicable.

We also encourage anyone whose work relates to gathering 'stories' in settings such as charities and research institutions to think about how the guidance can apply to their own practices, for instance when publishing 'case studies' or putting forward people with lived experience as 'spokespeople'.

Scope of this research

The themes and recommendations of this research relate primarily to 'soft news' and evergreen content (more in-depth, analysis-based journalism which often has a longer lead time and aims to give a deeper understanding of the issue in focus) rather than breaking news or 'hard news' (which is more immediate, time-sensitive content). Breaking news coverage offers little room for relationship building and participant involvement, since a recent event is most often covered by a third party. However, the subject of engaging with the media as people with lived experience of mental ill-health, distress or trauma is a key concern in discussions of breaking news; with even less scope for involvement, we often see the reporting of breaking

news around mental ill-health (for example stories which relate to iatrogenic harm, abuse, or inquests) exclude lived experience voices and perpetuate harmful, misinformed narratives. While this is not the focus of this report, readers may be interested in the **Independent Press Standards Organisation's resources and guidance for journalists and editors**, as well as Samaritans' media guidelines for **reporting suicide** and **inquests**.

Questions relating to format (e.g., whether contributions were published in print, digitally, or via broadcast) were not included in our research, however, anecdotal evidence shared in both our survey and focus groups suggests that while the specifics of a particular format (e.g., a live interview) can introduce context-based challenges (such as by removing the possibility of re-recording answers), participants' reports of broadly negative experiences, explored throughout this report, were shown to be consistent across all formats of engagement and publication.

Acknowledgements

We are grateful to everyone who responded to our survey to provide their insights about their experiences of engaging with the media and suggestions of ways to improve this experience for others in the future. We would also like to thank the eight attendees who gave their time and expertise at our focus groups, and those who reviewed and provided their feedback on this report: Hat Porter, Ellen Bean, Lucy Fyles, Natalie Mark, and Sara Metz.

About NSUN

NSUN is a membership organisation creating a mental health justice movement with the power to fight harmful systems and better alternatives. As the only lived experience-led national mental health charity in England, we connect, support and amplify the work of our members: people with lived experience of mental ill-health, distress or trauma, as well as user-led grassroots groups. Our work focusses on building and sharing knowledge, resourcing grassroots groups, and disrupting harmful structures, policies, and practices. **Find out more about us on our website.**

Implications of engaging with the media



While it is everyone's individual choice to share their story, remember that you do not owe the world your story. For me, I find it most helpful to see if a potential piece of media is aligned with my values, and then if there is any piece of my story that can be used to further specific social/political aims. I advise trying to be intentional about why you are sharing what you are sharing and to have an idea at the outset of what you personally are hoping to get out of it.

Survey respondent

A key theme which emerged across this research was concern about the long-term implications of personal experiences being made public, possibly permanently. This is particularly significant in a digital era where, as one participant put it, “there's the potential that it can end up popping up in places that they didn't know it was going to be”. Other media outlets can republish content on their own platforms without consent from original journalists or contributors, and the public voice, including “harmful comments online”, can be heard loudly via the comment section or on social media.

While it can be difficult to predict what feelings might come up after a media piece goes live, many survey and focus group participants encouraged the consideration of “possible fallout” and “longer term consequences” before agreeing to speak to a journalist. Ideally, support to think through these consequences would be provided by the journalist or media outlet soliciting the involvement of people with lived experience.



In the beginning, I was like, oh, wow. People want to interview me. People want to, like, hear about my story. And I didn't sort of think about the longer term consequences of it.

Survey respondent

One implication which was reiterated by people who responded to the survey was long-term association with the piece; the possibility of a participant changing their mind about the decision to take part and how it feels “in 5, 10 years' time when what they said was still out there somewhere”, with information that you “might not always want people to know [...] in the future”. In our focus groups, we also heard about the implications that involvement might have on those around you, including your friends and family – some felt that the impact of sharing experiences which might cause those around you distress, or include mention of their secondary experiences, should be considered.

Similarly, one participant named the impact that engaging with the media can have on employment as a reason they had turned down media requests, “e.g. people can Google and find them in future jobs etc”. This concern also came up in focus group discussions, where an attendee shared the experience of having their job title listed alongside their contribution without consent.

From those we surveyed who had experience of undertaking media engagements, 39% were not offered the option for anonymous contribution, which can help mitigate concerns about the future implications of taking part. Anonymity could be achieved by allowing quotations to be attributed to a pseudonym, with the removal of any potentially identifying information, or by using a voiceover/actor in live or visual coverage.



I went in being like, I don't want my name on this at all, and then being put under pressure to waive that anonymity.

Focus group participant

Similarly, less than half (45%) of people who responded to the survey were offered the chance to review their contribution before it was made public, risking the possibility of their name being published alongside a misquote, something that was said off the record, or within a framing they did not expect.

As seen in much lived experience work, there is often a pressure on people with lived experience of mental ill-health, distress or trauma to speak 'for' their community, to use their experience 'for good', and to fight for change. Whether paid or unpaid, in requesting personal contributions of this nature, media engagement can enforce this sense of obligation to disclose painful experiences for a 'good cause'.



I think there is this kind of attitude that just that it's automatically a good thing if you speak about your experiences and you're like, breaking the stigma.

Focus group participant

While difficult – due to the sense of obligation and the power dynamic between journalist and contributor – people who took part in this research project highlighted the importance of being able to say no to media requests, and to the impulse to engage, at the expense of your own wellbeing. Journalists should make it possible for contributors to withdraw at any point during the process if they wish, including to retrospectively ask for pieces to be removed, or for contributions to be edited out.



The onus is put on the person to even understand that they can say no. And I know when I'm sort of been most unwell, I just really lose the capacity to say no to people.

Focus group participant



As individuals, we do, you know, we have the right to stop these things, and there's no, you know, there's no obligation to finish an interview or go through the whole thing or, you know, you can stop at any time and withdraw.

Focus group participant

Respect and sensitivity

Commenting on their motivation to engage with the media, people who took part in the research project emphasised the significance of being asked to share their experience by a journalist, which can feel “validating”.

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You have the story that you just sort of need to get out, and the fact that someone wants to listen to you, it feels like, Oh, I'm not, not crazy, you know, like someone actually wants to hear this.

Focus group participant

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At the time I think I was just grateful someone wanted to hear about my experience and doing media work made me feel kind of “special” which for a depressed, isolated, lonely girl in her 20s, was everything.

Focus group participant

However, within the context of an underfunded and ill-equipped mental health system in the UK – where many seeking support from services, including those we spoke to during this project, describe feeling disempowered, and often harmed – it is worth noting the power dynamic which can exist between someone with lived experience who has been traumatised by a system, and someone promising to believe and support them, and campaign against their negative experiences.

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Often you're in your most vulnerable place, and sometimes it's because you're just seeking that validation because the services have failed.

Focus group participant

A personal relationship between a journalist and an individual with lived experience is at the heart of media engagement. In making direct contact with an individual with lived experience of a particular kind, the implication is that the individual will be believed, supported to share their story, and that the story itself will be used to advocate for others who may be in similar experiences. Focus group participants spoke about the importance of a journalist building trust with contributors in this process, rather than “going straight for, like, tell us everything deeply personal about your life”.



Care more about the whole person and what they need to safely tell their story and also make sure people know they don't have to tell everything but only what is relevant for the aims or objectives of the piece the journalist is working on. It can save people from opening up lots of wounds as only a portion of what they say will be used.

Survey respondent

If this trust is broken, the experience of being failed by an individual or institution that promised to provide support can leave people feeling retraumatised as they witness power dynamics within the mental health system between service users and ‘professionals’ re-emerge.



I wasn't forewarned that the Sunday Times legal department would be factchecking my account and that the onus was on me to provide evidence. This process had parallels to my experience of reporting to the police and the lawyer I was in email contact with.

Survey respondent

Of those surveyed with experience of engaging with the media, around a quarter (23%) of participants felt that they were not supported and treated with respect and sensitivity during the process. Focus group participants named the feeling of tokenism as central to many of their experiences; that

the approach to getting them to share personal experiences was extractive and/or that their contributions were being used to “endorse” a story that already existed, rather than inform or influence its shape. This left people feeling disempowered; that their experience was “exploited to have more of an impact on the audience”.

I’m not just a walking quote or story.

Focus group participant

Many people described issues with the way in which contact was made by journalists, and the process of engaging was conducted. One survey respondent explained that they were “interviewed by the journalist (for a written piece) in a busy restaurant in central London, which made the discussion a lot more difficult and impeded my ability to ensure I was only sharing information I felt comfortable being public”, and a focus group participant explained that not knowing whether a journalist was calling them from “a crowded newsroom where everyone else can hear” brought up concerns about the confidentiality of what they were sharing.

Other survey participants noted various ways in which a lack of respect and consideration showed up, for example: “I’ve had real issues with the wrong pronouns being used for me which cause a lot of upset for me”. Some described experiences of being spoken to “disrespectfully” by reporters on live TV, and others of being “ghosted” by a journalist after being approached and providing comments.

Individuals should always be treated and written about as if they are complex humans, rather than being weird, dangerous or broken.

Survey respondent

A respectful and sensitive approach which demonstrates that consideration has been given as to how to make the experience comfortable is incredibly important in creating a feeling of safety and ensuring that the process of

sharing painful personal experiences is less likely to feel transactional or retraumatising. Describing a positive experience of media engagement, one focus group participant talked about a particular journalist's approach: "she asked the questions very calmly and gently, and she completely stepped back. She didn't talk over anybody. She didn't try to put words into anybody's mouth. She just, like, facilitated the kind of questions in a very gentle and pared back way, and gave them all the space that they needed to speak, and she kept checking in with them emotionally".

We asked people who took part in this research about whether the journalist having (and disclosing) their own lived experience with the subject matter would make them feel more comfortable. While some people said that they would feel "more open to engaging with it", others said that while "there might be a little bit more psychological safety... it doesn't necessarily mean they understand".

If a journalist's motivation to write the piece is connected to their own lived experience, they might consider sharing this with those they approach (if they feel comfortable to do so) to support in establishing trust and an element of mutual understanding. However, they should not expect that this precludes them from having to maintain awareness of the power dynamic and responsibility to approach people with lived experience with care, thoughtfulness, and an open mind as to how perspectives may differ to their own.



If they're going to come in thinking, oh, I know everything because I have lived experience, not understanding there's a spectrum, there's a whole there's a lot of diversity to lived experience, then that could almost be even worse, thinking that their view is the only right view.

Focus group participant

Payment

A subject that underpins the entire discussion of media engagement as people with lived experience (or 'experts by experience') is payment. Payment can play a part in respecting and honouring people's time, expertise and emotional labour when engaging with the media. A survey respondent who had experience of undertaking media engagements said: "although my first incentive is always just to help improve the future decisions, policies and services, recognition of my input means so much and gives me much self esteem".

Of those surveyed who had engaged with the media, only 13% were offered any form of payment. There was a feeling of pressure that "having your voice heard" and having the opportunity to "speak for your community" should be enough, and asking for payment might suggest less "genuine" motivations. This emphasises the importance of transparent communication around payment, so that individuals do not have to shoulder the burden of raising the subject, and feel the potential of judgement for doing so.



It's a sensitive topic that people have to open up about and they also need paying for their time in general and then some, for the rehashing of sensitive topics that we have to go over and over again with various people throughout our lives.

Survey respondent



Don't be afraid to be an advocate for yourself. Don't be afraid to talk about pay, don't be afraid to set boundaries, even if it means that it doesn't happen. Just try to be as assertive as possible.

Focus group participant

When our focus group participants met, they shared similar experiences around payment, and a feeling that “working within lived experience in general, it's always so awkward to talk about payment”. They emphasised the need for clarity around payment before engagement begins or is agreed, alongside detailed and well-researched advice for people who might not be able to accept payment (or certain forms or amounts of payment), for example, if they are in receipt of benefits.



The very first sort of interview I did with the media, you know, it was that hour long interview, and at the end, I was like, there was no mention of payment. I just assumed I was going to get paid. And then they come back and they're like, no, sorry, you're not getting paid.

Focus group participant

At NSUN, we believe that it is only right that individuals should be offered payment for their time and commitment across all areas of lived experience involvement, covering and going beyond any out-of-pocket expenses for things like travel and accommodation. This includes recognising the labour of condensing experiences into a digestible format – while reliving those experiences at personal cost – for media engagements, particularly intensive ones such as taking part in televised interviews.

We understand that journalists or media outlets may have concerns about incentivising participation in this way, especially given the concerns we explore in this report about the potential long-term implications of media engagement and its emotional tax, but we feel these concerns can be mitigated if the engagement is handled ethically and with care: with anonymity offered, support provided, and contributors afforded autonomy and control over how their contributions are used.

Often, the request for adequate remuneration is met with the same response: there is no budget for it. We recognise that budgetary constraints can pose a challenge, especially for freelancers, but we would urge media outlets to

initiate internal conversations around this subject; to begin allocating budget for contributors to media pieces before reaching out to potential participants.

We asked people who responded to our survey how much they believe individuals with lived experience should be paid per hour for media engagements. For written work, such as providing comment for articles over email, responses ranged from £20 to £30. For physical involvement (both online and in person, such as taking part in an interview), responses ranged from £25 to £50. While there are no standardised rates of payment for what can be broadly classed as lived experience involvement work, NSUN encourages amounts based on time commitment estimates (including preparatory work) that are, at minimum, in line with **the National Institute for Health and Care Research (NIHR) payment rates**.

Support and flexibility



No thought was given about what would happen to me after 'giving my story' and no support was in place.

Survey respondent



The exposure and telling our story really is cathartic, in a sense, but it can be triggering.

Focus group participant

We heard from participants about a lack of support when engaging with the media, which can be especially problematic when the nature of the engagement is particularly intensive (for example taking part in a live interview in a media environment). More than half (60%) of survey participants with previous media experience felt they were not offered any kind of support or adjustments when approached by a journalist.

Many participants referenced the absence of access to any type of therapeutic or emotional support before, during and/or after engagement to support with aspects that may be triggering. This could be something that is mediated/facilitated by or signposted to by the journalist/media outlet (if signposting, a wide range of support and resources should be included, as some types of support e.g. helplines are not always helpful for everyone), but participants also highlighted the importance of connecting with trusted people in your personal life during the process. Participants also encouraged taking the time to consider for yourself whether “it’s the right time”, or if there is the possibility that taking part might “trigger any distress for them now or potentially later”.

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Make sure you have support around you during the process and in particular on the day and days after it is broadcast. It can feel far more exposing than imagined.

Survey respondent

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Have a conversation with other people that you trust beforehand before you do it, because it isn't necessarily a bad thing, but I think you need to definitely be in the right place to do it.

Focus group participant

Other issues raised by participants around a lack of support included not being given the opportunity to bring a trusted person along to engagements, not being offered alternative ways of contributing, and a lack of thorough preparation to ensure the participant felt ready for/comfortable with what they were doing and what they would be expected to speak about (for example by receiving the questions in advance and having the chance to identify subjects they would not be happy to discuss).

A focus group participant outlined some of the things that they would expect journalists to make clear in order to make the experience feel more supportive: being told “if they can take breaks or ask to stop if they need to during it, if they feel overwhelmed and knowing who they can contact, if they feel the coverage is inaccurate or like an unfair representation of what they have said”.

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If I don't know the questions, I kind of just freeze and just give really bad answers, and then I have to come back and sort of like, correct myself.

Focus group participant

A positive example of a flexible approach which helped ensure someone's support needs were met was an instance in which a participant was encouraged to pre-record their own video, using their own script, which was accepted and platformed without edit, instead of taking part in a live interview. Other flexible approaches for written content could include giving people the option to provide written responses over email rather than speaking to a journalist over the phone.



I wasn't offered to do written responses. But from a sort of like trauma point of view, that would have been much, much better.

Focus group participant

Of those surveyed who chose not to engage with the media upon request, or who have never been approached, other considerations which might encourage their participation included being given access to some sort of media training in advance “to be able to learn how to get my message across and cope with difficult or challenging questions and what to share and what to keep private”, having limited or no travel involved with the engagement, having a quiet/private environment for in-person engagements, and overall, receiving detailed information about what the entire process would entail.



What is required of me? Where will my information go? Do I need to have my camera on? What are the interview questions or topics? What kind of things do you want to hear about? What will my information be used for, who has access to my information? Who will be attending the interview?

Survey respondent

Those with previous media experience spoke about the impact of a lack of consideration around access needs for Disabled and/or neurodivergent people in their survey responses: “I was the only person out of large group that needed assistance and the organisation had not considered that before

so I felt like I was asking for the world and was socially excluded”.

The impact – in an environment which may already be distressing, where you are being asked to share personal experiences with the public – of a lack of prior consideration of access needs can contribute to a wider feeling of disempowerment or disrespect. It is incredibly important to consider where processes may be exclusionary and to offer adjustments to meet access needs and make the experience more supportive.

One small way in which the experience could be improved would be by sharing a pre-prepared document detailing accessibility needs; one participant said that “having an accessibility document can be helpful and starting the working conversation with that and your needs and preferred means of communication can be helpful too”. A template document with examples of accessibility adjustments that could be made may be created by media representatives and proactively shared with each contributor for completion ahead of engagement. Alternatively, a person with lived experience who regularly engages with the media might choose to create their own access document and share this with approaching journalists for confirmation that their requirements will be met before accepting engagement requests.

Overall, providing support and flexibility must include making adjustments that may help make the experience less emotionally taxing for participants, such as sending the questions in advance, building in breaks, and having the opportunity to provide written answers rather than taking part in a live interview, and more practical or physical adjustments that meet access requirements, for example ensuring the provision of hearing loops or sign language interpretation, considerations of lighting and noise reduction in physical environments, and the use of locations with features such as ramps and accessible toilets.

Control and agency



I think it's you often feel like you've had this really good conversation with them, and then yeah, that you just get one or two lines that doesn't sum up your story whatsoever.

Focus group participant

A consistent issue which arose across our research was the absence of opportunities for participants to review the final piece – and approve the way in which specific parts of their personal contributions have been selected for inclusion, as well as how they sit within the wider content – before publication. Just under half of survey participants who had engaged with the media were given the opportunity to review their contribution before it was published. In live contexts, this is an impossible request, but in that scenario, contributors expressed a desire to be able to pre-establish with the journalist what they would or would not be willing to speak about during an interview, and have this wish respected.

In our research, people described their contributions to media pieces being manipulated to “rubber-stamp” or give weight to an unapproved perspective, positioned in opposition to an alternative argument without prior awareness or consent, or “twisted” to encourage a particular angle, stripped of the context in which it was originally provided. Again, we return to the question of trust within a journalistic relationship – if these are the experiences people are having when taking part in media engagements, it is unsurprising that there is a lack of confidence in talking openly with a journalist or representative of a media outlet.

The sensationalism of personal experiences arose repeatedly in examples of journalistic engagement – people found that their contributions were

isolated from their wider details, or “the whole story”, to be reduced to their most “dramatic” or “shocking” elements – which are often the most painful to share – possibly for the purpose of increased clicks or views, which left people feeling “misrepresented”. One survey respondent said “I felt there was less focus on the issues I was trying to raise and more on getting a lurid personal experience story”.

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They kept pushing me for the "darkest" details. It felt like an interrogation with no support to follow.

Survey respondent

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I think the most important thing is think ahead about what you're prepared to share, and don't move on that. Because I think it can be very easy to get sort of dragged in and to share more than you're comfortable with.

Focus group participant

One survey respondent noted that “some of the terminology and wording used is something I disliked and would not have agreed to”, an experience that was shared by multiple people who took part in this research. In these instances, where language is used that differs from how the person themselves understands and describes their experiences, contributors lose agency over the way in which they are presented, as well as the narrative that is presented around mental ill-health, distress or trauma. A survey respondent noted that they had “concerns about how my story [...] would contribute to an agenda that I didn't approve of e.g. further stigmatising mental ill health”, and another urged journalists to “understand and respect that people have a very, very wide range of experiences, and there is no “right” way to understand or respond to distress/trauma”.

Of people who had engaged with the media in the past, a large proportion

(66%) had not received details of other contributors who were simultaneously being approached for comment, and 34% were not given the primary messaging (i.e. if it was neutral, supportive, or unsupportive of the issue in focus) of the news item. This speaks to a wider issue within the media wherein contributors may not be provided with enough information to be able to provide informed consent to take part.



It would have been most helpful if the framing of the narrative was clear from the outset. I didn't like being pinned against a psychiatrist, because that was only going to replicate the power [dynamic] endemic to our society.

Survey respondent



I do feel it was slightly tokenistic, they published the bits they wanted people to hear/see and not necessarily what they needed to see or hear.

Survey respondent

When we spoke with our focus group attendees, many named their disappointment that the piece they contributed to did not meet their hopes or aims, and the feeling that the story existed before they were approached, thereby positioning them simply to reinforce, rather than influence, the narrative.



You're fighting so hard to get people to be aware of something, and then... they sort of rewrite and like twist the story a bit.

Focus group participant



They've already decided that they want to find someone with this very, very specific experience, and that they can then weave into the story that they've already written.

Focus group participant

Some contributors also shared experiences in which their personal, identifying information – including full names, locations or professions – had been made public without their consent.



It had my full name, it had the location that I lived in, and it also had the job that I was working in at the time, which I then had to leave because of my health issues, and she didn't say at any point that she was going to publish any of that information.

Focus group participant

Much more clarity is also needed around whether participants are speaking on or off the record at various points when speaking with a journalist. During a focus group, this topic was discussed, and we heard how this custom can be disregarded: “basically, anything you say to a journalist is liable to be used”.

People who took part in this research expressed the need to know more from the outset about the angle of the piece and the journalist's previous work and possible personal stance, encouraging people considering media engagement to look at articles that had already been published by the journalist, or to “check who the media organisation is going to be and how they have portrayed people with mental health conditions in the past”.



Being given more information about the stance of the pieces and who else was being quoted, and having a chance to see the draft and be allowed to refuse to be included without edits.

Survey respondent



The context and angle of the article in which I would be featured, as well as information on who else might be interviewed (i.e. to determine whose perspectives are valued vs whose perspectives might be deliberately excluded).

Survey respondent

While it may not be possible to be in full control of the angle or framing of the piece, the way it is received by other people, or even the digital spaces that repurpose the story for their own use, there are ways in which journalists and participants can attempt to minimise unexpected repercussions and mitigate against a loss of control and agency.

Journalists should be open to shifting the angle they had initially planned for a piece, including being advised by contributors on the framing and language of the story – as one survey respondent put it: “respect the words that we use to describe our experiences and [do not] change such descriptions”.

Journalists should provide clarity on what is and is not on the record, and offer participants the chance to establish what they do and do not want to share before engaging; the chance to specify if they have any preferences for how their experiences are described in the text that contextualises their quotations, and the opportunity to review the final piece before publication and withdraw their comments if necessary. One survey respondent noted that they would have liked a “sufficient period post interview to reflect on what I had shared, and to allow for any details I shared in the moment but decide I don't wish to be included, to be noted and respected”.



Being kept informed

It is incredibly important that people are made fully aware of what they are agreeing to when they engage with the media, and that they have full clarity during every step of the process. As one focus group attendee explained, they would appreciate knowing “what is the purpose of the piece, who the audience is supposed to be, how the story is going to be used, whether it's going to be, you know, on TV or radio, print, social media, or a mix of different platforms”.

Of survey participants who had engaged with the media, around half said they had not been kept up to date with information about when the piece would be going live, or any updates or developments resulting from the piece. Uncertainty around what might happen after engagement also played a key role in deterring people who might have otherwise chosen to engage with the media.

Similar experiences were shared in our focus groups. Participants spoke about uncertainty over the date they might expect to see or hear their words shared publicly, and a lack of control – sometimes due to a lack of communication – over where their contributions might appear, or whether the piece would even end up being published at all.



Don't have some lengthy conversation that isn't going to be used, because it's a waste of everybody's time.

Focus group participant

Focus group participants echoed the experience shared in survey responses, where a story was picked up after publication by other platforms, and contributors were not prepared to see their story shared by outlets they had not expected or might not endorse, recommending that journalists

“specifically [tell] people that other outlets may pick up your story and that you will have no choice about this”.

In terms of how contributors felt the post-engagement experience could be improved, the overall consensus was in favour of detailed communication: “being given a really clear roadmap of what the process is going to be”, and for thorough relationship-building to take place, allowing for a point of support and contact after engagement: “journalists need to help people think through how they're going to feel afterwards”.

”

I actually found it about three years after it had been published, and it was when I was looking for something else by this particular journalist, and I was on her website, and I found it through her website, and I didn't even know that that article had been published.

Focus group participant

Guidance for people with lived experience

These are suggestions for people with lived experience who are considering engaging with the media. Ideally, journalists would proactively volunteer the information and support that we suggest requesting. However, we know that this is not the experience of many people taking part in this work, so this guidance outlines considerations you may want to make before agreeing to get involved.

When asked what advice they would give to others, participants in this research project suggested:

-  Taking some time to consider whether you may find the experience triggering before agreeing to take part. You may want to reach out to trusted people to talk about your decision and consider what support you could utilise if any part of the process was distressing.
-  Considering if there may be any implications, now or in the future, of your name and personal information being made public along with your contributions. You may wish to ask to be kept anonymous/for your contributions to be attributed to a pseudonym.
-  Researching the journalist who has approached you, and/or the media outlet your contribution will be published on. Have a look at the type of content written and shared to get a better sense of the likely angle/stance of the piece.
-  Asking if out-of-pocket expenses (if applicable) will be covered if you feel able, and if any payment will be on offer for your time. You might find it helpful to share the National Institute for Health and Care Research guidelines to give an example of the rate of payment expected for lived experience work (while the rates relate to research environments, they can be used as a benchmark).
-  If you have access and support requirements, considering sharing these with the journalist (such as through a pre-prepared access document) and only agreeing to take part if these needs can be met.

-  Asking for adjustments such as the opportunity to provide written responses to questions over email instead of taking part in an interview, getting the questions in advance for a live interview (or to pre-record a clip to be shown in the segment), the inclusion of breaks into an interview, a quiet and private place for in-person meetings or interviews, and the ability to bring a supportive person to an interview.
-  Asking the journalist for information on any part of the process they do not provide clarity on. For example, you may want to ask about things like the purpose of the piece and the intended audience, which parts of your conversations are on/off the record, venue details for in-person arrangements, who else has been approached for comment, and whether they expect your contributions to be utilised on other platforms/mediums e.g. if clips from a TV interview might be shared on social media.
-  Establishing what you are and are not willing to speak about before taking part, and communicating this to the journalist (especially if taking part in a live interview) in order to decrease the chances of being asked questions that you do not feel comfortable answering. Consider preparing some sentences to communicate this in the moment if need be, for example, “as I previously shared, I’d prefer not to discuss that particular topic during this interview”.
-  Asking the journalist if you will be able to review and approve the final draft/edited recording before publication to ensure you are happy with what has been selected from your contribution for inclusion within the piece, as well as the language/terminology used outside of direct quotations to describe you and contextualise your contributions in the piece.
-  Asking the journalist if, how, and until when you will have the opportunity to withdraw your contributions after the piece is live (for example having your quotations removed from a written piece or having a recording of an interview deleted/taken down from a website/social media platforms).

Guidance for journalists

These recommendations are for journalists and/or representatives of media bodies to take into consideration when approaching individuals with lived experience of mental ill-health, distress or trauma for comment, contribution or interview. It is important to communicate the full details of what involvement entails as soon as possible, so that an informed decision about taking part can be made, and contributors can ask questions and clarify uncertainties.

Implications of engaging with the media

-  Journalists should initiate a conversation about the possible consequences of taking part in media engagement, now or in the future. Participants should be offered full anonymity, or for their contributions to be attributed to a pseudonym. If recording for e.g. TV, other anonymising options can be offered, such as the use of a voiceover.
-  Identifying information such as someone's name, location or place of work should never be published without consent, and consideration should be given to whether sharing identifying information is necessary in any instance.
-  Journalists and media representatives should also consider sharing information about the nature of the media that may be unfamiliar to participants. For example, we heard that former media contributors were surprised by the way in which unfamiliar media outlets were able to cross-purpose published articles on different sites, with unmoderated comments. While this cannot always be avoided, we recommend communicating the likelihood of such events.

-  It is important to make it clear to contributors whether they can withdraw their contribution before publication/have their contribution removed after publication and if so, the process for doing so. If this isn't possible at all/by a particular date, this should be specified, along with the details of an alternative contact at the media outlet to ensure long-term contact can be maintained.

Payment

-  Participants should be paid fairly for their time, and expenses should be covered. We encourage journalists to start conversations in their places of work about budgets for contributors, referring to the **National Institute for Health and Care Research guidelines** to give an example of the rate of payment expected for lived experience work (while the rates relate to research environments, they can be used as a benchmark).
-  Information and signposting should be given to participants on the implications of receiving payment on tax and benefits.

Respect and sensitivity

-  Treat contributors as an individual rather than a story, not focussing explicitly on the most personal elements of a person's experiences while ignoring the wider picture, and maintaining an awareness of how uncomfortable it can feel to be asked probing questions about traumatic events.
-  Allow participants' contributions to shape the angle and content of a piece, rather than endorse an existing narrative. If you can't do this, explain the existing narrative clearly so that participants can give informed consent.

-  Use the language that participants themselves use to describe their experiences of mental ill-health, distress or trauma in relevant contextualising information outside of direct quotations – for example, respecting if someone prefers the use of non-medicalised language to describe themselves. Speak to participants in a private environment wherever possible, or inform the person you are speaking to if you are making a call from a location where there is the possibility they will be overheard by others.
-  Journalists could consider sharing if their motivation to write the piece is connected to their own lived experiences, if they feel comfortable doing so, in order to help establish trust and mutual understanding. However, it is important to be aware that there is still a power dynamic at play, and that perspectives may differ from their own.

Support and flexibility

-  Journalists should initiate contact by asking participants if they have any access or support requirements they would like to share via an access document or otherwise. Journalists and media outlets could consider creating a template access document for completion by participants, and proactively offering ideas for adjustments and flexibility.
-  During an interview, participants should be allowed to take breaks whenever they would like, bring a trusted person with them for support, or reword an answer/decline to answer any question. The ability to do these things should be communicated to the participant at the earliest opportunity.
-  If possible, alternative modes of contribution should be offered and arranged at request, e.g. by allowing a participant to record their own video, provide written answers to questions via email, or receive their interview questions in advance and prepare their answers.

-  Participants should be provided with a detailed schedule of events when in-person contribution is required, including a breakdown of the day and information on private spaces which can be accessed and used.
-  Journalists and media outlets should consider facilitating access to media training for people with lived experience who are acting as spokespeople.
-  Journalists should give consideration to the emotional impact that contribution may have on participants. If therapeutic support is available, this should be given to participants (and/or signposting to a wide range of external sources of support), and journalists should check in with participants at a scheduled date after publication has taken place.

Control and agency

-  Journalists should clarify what is and is not on the record from the outset, and at various points throughout the process.
-  Journalists should offer participants the chance to establish what topics they do and do not want to talk about before engaging.
-  When approaching participants, journalists should communicate which (if any) other contributors they are approaching for simultaneous comment, especially if their contributions are going to be presented as oppositional.

-  Participants should be given the opportunity to review the final draft and make changes. As detailed above, it is also important to make it clear to contributors if and how they can withdraw their contribution at any stage of the process, including after publication. If relevant, it is also worth communicating to contributors the hierarchy of decision making within the media outlet e.g. if there is a senior member of staff who may be able to make final adjustments to the publication without oversight.

Being kept informed

-  Participants should be kept in the loop throughout the process, including being informed of where and when the piece will be published and sent link(s) once it is live, and kept updated on any developments based on the piece, particularly for investigative journalism.
-  Participants should be told if there is a chance that a piece will not actually be picked up for publication, e.g. if a freelancer is collecting contributions for a pitch.



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