

# Guidance for people with lived experience

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

This guidance was produced as part of NSUN's 'Not Just a Story' research project. **You can find the full report here on our website.**



**National Survivor  
User Network**








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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 our research project suggested:

- ① 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.
- ① 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.
- ① 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.
- ① 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).
- ① 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).



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