

How to respond to distress



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Introduction

This guide considers how to respond when a Public Contributor to research or teaching becomes distressed. The Public Contributor may be acting as a research co-interviewer, committee member or guest lecturer. As this is a very broad area, this *How To* guide will concentrate on a data collection interview where three people are present in the room – the academic researcher, who is salaried and has several years training in research methods; the Public Researcher, who brings their lived experience, is in receipt of recognition payments and may have a few hours training in research methods; and the research respondent, who is the subject of the research interview. Principles from this specific setting may be applicable to broader coproduction activities.

Sometimes additional people need to be considered too, such as interpreters¹; family members, managers and colleagues of the researcher; other research participants (when data is collected via a group setting, such as through a Focus Group) or other participants in the setting (when Go-Along interviews or other in-vivo approaches are used). The general messages from this guide can be easily extended to include all stakeholders.

Relevant to all

We should not assume that salaried professionals live settled lives that are invulnerable to distress or that Public Contributors are especially susceptible to it². A comprehensive approach to distress will include all stakeholders and consider how academic researchers, public researchers and respondents will gain access to the support that they need. Whilst each of these groups may journey along different routes to get support, describing all the pathways in a shared document will reinforce the ethic of equality between people who occupy the different roles.

This paper concentrates on a data collecting interview which is part of a research study, but distress may also arise during other parts of research production (such as when a potential participant is told they are ineligible³ or when the transcriber reviews the content of an interview⁴), and in the longer-term relationship between a Public Contributor and the organisation that engages them. The Public Contributor or a researcher may choose to disclose the feelings that arise in their personal life or they may reveal distress associated with their general role in the organisation. They may find that specific activities trigger distress. The Public Contributor may find themselves acting as a reverse mentor⁵ with the staff member, or conversely, their behaviour may be unacceptable, causing distress and even vexation⁶ to others.

Singh and colleagues⁷ point out that the academic researcher may be a newcomer to the subject of the research and, if it is complex and emotionally charged, they may need to do a considerable amount of emotional, moral and reflexive work to gain insight into the issues. In their case, the research topic was the stressors on transgender young people and the mental health consequences of them. In this situation, the academic researcher may attempt to inappropriately delegate this labour to a trans Public Contributor, requiring them to ask questions and probe experiences that are of merely clinical interest to the academic, but which have great significance to the Public Contributor who has 'skin in the game'. Such an unreasonable demand could generate distress for the Public Contributor.

Sensitive topics and provocative environments

Interview topics that require disclosure of private material, ask about unwanted experiences or revisit trauma might be labelled as sensitive, since respondents are more likely to become distressed unless they are particularly resilient. The concept is useful, but it inadvertently locates the source of the distress with the individual respondent rather than the environment⁸. Similarly, a mechanistic model would see distress as the immediate, proportionate and direct response to a specific disclosure by the respondent, when in fact emotional responses can be trivial at the time and amplified much later, perhaps as experiences accumulate or sensitivity ebbs and flows. A social model of distress would consider whether there are environmental factors that restrict or dehumanise the person and whether distress has arisen from self-disclosure or from hearing the revelations of the research respondent.

For example, respondents who live in hospital or care homes often lack opportunities for a real conversation, as the staff are too busy, and so meeting an attentive researcher highlights their loneliness in a distressing way. In another situation, transgender Public

Contributors interviewed family members of trans young people and were sometimes distressed by the transphobic attitudes that were expressed⁹.

Moral distress¹⁰ occurs when allies¹¹ want to alleviate suffering, but their working conditions or structural power differentials prevent them from doing so. Public Contributors and research respondents may be invited into research projects on the pretext that their viewpoint is valuable, but the implementation gap between research and practice is then so wide that their efforts appear futile, services do not improve, and the person's frustration is manifested as distress.

The culture of the research organisation will affect the Public Contributor. If academic researchers are burnt out, lack regular, psychologically informed supervision and interview respondents in a cold, emotionless and mechanical way, then the Public Contributor may either suppress their own feelings or defy convention and take on enough passion for both. Neither of these responses may lead to improvement.

Whilst everyone has the potential to make an emotional response to life experiences in general and the interview in particular, a case has been made for this to be particularly significant for people with lived experience. Sarah Carr¹² has suggested that emotional labour is expended when people engage their lived experience at work, while Watson¹³ goes further and calls this 'love labour', reinforcing the idea that the lived experience practitioner is present emotionally to a greater extent than other members of the team. In a healthy organisational culture, everyone has permission to make appropriate use of their life experience and disclose their emotional responses; only those explicitly engaged as experts by experience are obliged to do so. Both experts by experience and facilitators of Patient and Public Involvement will likely face the challenges (and benefits) of relational work¹⁴. Where the workplace culture favours rational over emotional expression¹⁵, others may observe this work being done and label it as distress while a failure to recognise the effort involved, overwork and exhaustion will also have emotional consequences.

Distress and wellbeing

Some research teams have thought about how to respond to distress and then written a Distress Protocol¹⁶ and provided funding for support¹⁷. Others reject this focus on distress as an isolated feature, point to a more positive concept of wellbeing and invite people to set out their own personal wellbeing plan¹⁸. By using this broader approach, individuals may recognise in advance some of the things that might trigger distress, how they self-manage, whether they want any support and how that should be given. Drafting a wellbeing plan could be part of an approach to supporting all employees which could include access to an Employee Assistance Programme, which itself should offer support to Public Contributors as well as employees. Arrangements should not neglect research participants.

A further standpoint from which to perceive and respond to distress is safeguarding. Everyone involved in designing and delivering the research needs to be aware of their duty to keep people safe, whilst attending to the assumptions and differences that team members adopt. For example, Edwards¹⁹ and her Public Interviewers worked with respondents who were known to often disclose risk to strangers in brief contacts, and this influenced their joint decision to conduct sessions where the academic researcher remained

in the room at all times, ready to take responsibility for responding to such matters should they arise.

Katz-Wise and team²⁰ have written about a research situation where a research participant disclosed suicidal distress to the researcher and then negotiated what would happen next. As a result, in this one situation, the academic researcher set aside the Distress Protocol in favour of an individual solution. The Social Research Association warn that 'research managers may have to decide against using existing staff if the content of the interview will arouse strong feelings or cause distress.'²¹ Meanwhile, one of the peer researchers in the study by Hutchinson & Lovell²² said, 'Distress is a necessary thing, not something to be shoved away.'

Risk of discomfort and harm

Lynch et al (2020) distinguish risk, which is the same for all participants; from harm, which is the materialisation of that risk in the experience of a particular respondent. The severity of the response also varies, ranging from a temporary sensation that is easily tolerated, to a reaction that permanently affects daily life and requires skilled intervention to ameliorate. The former they name as discomfort, recognising it is sometimes a necessary inconvenience for all participants while the more severe reaction will be experienced only rarely and is called harm. To use an example, a health research project may require all participants to give a blood sample. The pinprick of a needle piercing the skin amounts to discomfort, while fainting or a needle stick injury might be considered harms. Similarly, an interview that includes questions about a sensitive topic might be expected to create discomfort in all respondents, but a few might react more strongly.

The categories of discomfort and harm are not mutually exclusive and the threshold between them is a matter of individual judgement. To pursue the example, whilst the research team may consider that taking blood is merely a minor discomfort, one respondent may be phobic about needles and find the experience traumatic.

Harmless discomfort

A meaningful encounter between two or more human beings is rich in information, emotion, communication and companionable silence. A range of painful emotions might arise, ranging from tears to blushing, shame to blame, depression to rage, betrayal to grief, fear to anger. Some people respond emotionally without needing to discontinue, and without needing specialist help – for them, the distress is a necessary part of telling their story. They are determined to finish, feel better after expressing their distress and report afterwards that the interview was uncomfortable but helpful rather than harmful²³. They are eager to share their information and would feel robbed if their distress knocked the interview off course, triggered foreclosure, disqualified their data, or meant that the interview overran. Only a few interviewees who experience distress during a research interview will regret attending, consider their own emotional response unwanted, and rate the overall experience as negative²⁴.

Responding to discomfort

Inexperienced interviewers can feel obliged to keep moving through the topic guide, driven by a fear that the person's time is wasted unless they are speedily wringing pithy, quotable statements from the interviewee. In contrast, the best interviewers build a buffer in their schedule so that the interview can overrun while they wait and listen with their whole being. They will have prepared some strategies for responding to material that is shared which is beyond the scope of the interview, and for unusual reactions to their questions. It may be useful to pause the interview, provide some reassurance that an emotional response to the events is normal, and offer time out. That may mean that you leave the room, they leave the room, you sit together for a time, or perhaps they spend a few moments with someone else who they would like to be available for them in those moments. A drink or some fresh air can help, as can grounding exercises²⁵. Stay calm (but not cold) and don't ask them if they want to stop the interview until after the pause.

From the perspective of some commentators²⁶, anyone involved in conducting an interview about a sensitive topic should be clinically trained and sufficiently experienced in providing a professionally defined response to people experiencing distress or living with the effects of trauma. Adopting this requirement would exclude most Public Contributors.

Responding to harm

If the likelihood of causing harm is low, it does not mean that it is zero, and one can imagine that research which is well-meaning but poorly designed or executed, as well as the activities of thoughtless, callous or mischievous researchers could cause unnecessary harm, while some respondents will incur harm in the best designed and executed studies. Compensation is sometimes paid out to research participants who are injured through their involvement in drug trials²⁷, so, in theory at least, there should be a parallel mechanism for those who suffer emotional harm in a research interview.

It is perhaps easier to plan for tears than to know how to respond effectively to other uncomfortable emotions, but they can all evoke emotional responses in the listener, prompting them to feel uncomfortable too, as well as a compulsion to fix things for the person. Lewis²⁸ has suggested that some organisations actively suppress the expression of distress. It may be helpful to consider responses to Post Traumatic Stress Disorder where the evidence suggests that some attempts to help can harm²⁹.

Screening questions

Drauker's team³⁰ used the following questions to identify potential interviewees who should be excluded from their study of partner violence as they considered that participation may result in harm. Persons who were excluded from the study for these reasons were signposted to sources of help, or, in the case of imminent danger, appropriate agencies were notified whether the person had asked for help or not.

Initial question	If yes, ask...
Are you experiencing a high level of stress or any emotional distress?	<ul style="list-style-type: none"> • Tell me what you are experiencing. • Is it getting in the way of you doing the things you need to do (school, work, family obligations)? • Is it getting in the way of you taking care of yourself? • Have you been in the hospital recently for this problem?
Are you currently having thoughts of harming yourself?	<ul style="list-style-type: none"> • Tell me what thoughts you are having. • Do you intend to harm yourself? • How do you intend to harm yourself? • When do you intend to harm yourself? • Do you have the means to harm yourself?
Are you currently having thoughts of harming someone else?	<ul style="list-style-type: none"> • Tell me what thoughts you are having. • Do you intend to harm someone else? Who? • How do you intend to harm them? • When do you intend to harm them? • Do you have the means to harm them?
If you participated in the study, would you be in any danger if anybody else found out?	<ul style="list-style-type: none"> • How might you be in danger? • How might the other person find out you were participating? • What do you think the other person would do if they found out you were participating in the study?

Before the interview

Good research ethics insist that discomfort and harm are anticipated and minimised³¹, the respondent gives informed consent beforehand³², and their right to privacy is upheld³³. They need to know what will be discussed; if difficult feelings or memories may arise as they 'recall, re-examine and reveal' their experiences³⁴; that they can stop at any time; that they are not obliged to answer all the questions they are asked; and that they can withdraw both themselves and their data from the study. The interview should not follow immediately after these procedures are explained, but rather the person should have sufficient time to consider their options and prepare for the interview.

Seeking formal consent includes making promises about confidentiality, so the person will be informed that their identity, the information they share, and the emotions they experience will not normally be disclosed to others³⁵. While some distress is predictable, this is not always the case, and so interviewers should always be alert. Not all interviews require formal consent (staff supervision would be an example), but in these relationships beyond the research interview, a general discussion in advance will help everyone to speak about their personal distress triggers and how they would like to be supported.

The interviewee may arrive at the interview already distressed by other events that are ongoing in their life, or anticipation of the interview and the topics that will be discussed may have generated distress. Similarly, interviewers may have experienced recent trauma or distress and will need to manage the effects of this in the interview, whilst being

sufficiently observant of the other person so that they pick up any signs of distress, perhaps by asking directly how they are feeling at the start. Not all distress is easy to detect, and some people will show only a few subtle signs while others prefer to have the interviewer overlook their emotional state.

The person may bring distress with them that may be unrelated to the topic of the interview, and some clear negotiation may be needed to ensure that the interview remains focused on its intended purpose or is only set aside after careful consideration.

Practical arrangements for the interview may cause distress – insufficient warning, changing the date, the wrong time of day³⁶, complex travel and a venue that is hard to find, meeting in a stressful environment, being kept waiting, meeting a stranger, or overrunning the booked slot, can all erode the person's sense of control and ease. If the person usually lives without social contact or intimacy, the encounter with a warm, socially adept researcher who is genuinely interested in their thoughts and feelings can bring their isolation into distressingly sharp relief. The inequality that is built into an interview may be difficult to handle, as the interviewer remains in shadow and the life of the interviewee is laid bare and open to scrutiny and even the most egalitarian interviewer may be perceived as powerful. If the meeting is online or by telephone, the person may have difficulties achieving a connection and will not have the opportunities for informal introductions, small talk and wind-down that are available before and after face-to-face interviews.

Interviews are always emotional

Distress may be caused by stimuli in the interview itself, even by the conduct of the interviewer. People with sensory processing issues may find the sunshine too bright or the florescent tubes too noisy, while others may find the whole experience reminiscent of an interview with an authority figure or react strongly to a single word that triggers feelings of distress.

Some topics of inquiry are more likely to evoke distress and so preparations should be appropriate, such as ensuring that the conversation is private, tissues are available and others are anticipating the possibility of distress. Interviewers, both academic and public, should take some time to think about the place of their own emotions in the interview. For some topics, and where the respondent is eager to display their knowledge and opinions, the interview may be a mechanical process of asking questions and recording answers. For others, the interview itself is a profoundly emotional event, where the interviewer creates a psychologically safe space by conveying welcome, warmth, acceptance and dignity to the respondent through the appropriate use of their own emotions.

The interviewee may need to be reassured that their distress is a natural and normal response to the things that have happened and that they are not the only person to react in this way. Calmly spoken, compassionate words from a person who has adopted a physical posture of openness will help to activate the 'soothe system'³⁷ and enable the distressed person feel safe enough to continue with their disclosures.

The focus then shifts to seek a threshold beyond which the interviewee or indeed the interviewer's distress is considered excessive and beyond a proportionate response to the experience that is being described. Draucker's team considered this to have occurred when

the interviewee exhibits uncontrollable crying, incoherent speech or indications of flashbacks, when they feel unable to go on with their day, when they describe detailed plans to harm themselves or someone else or when they express fear that they will be subject to violence from someone else.

For the interviewer, this threshold may be overstepped when the spotlight shifts from the respondent to the interviewer themselves, when the interviewer's emotional response impairs their ability to complete the task or distorts the data, or when it affects their ability to move on to the other things in their working day. In settings where trauma may be revealed, the interviewer may benefit from access to good third-party professional supervision so that they deepen their own emotional sensitivity and understanding, as well as improve their ability to respond appropriately to the person.

Distress is contagious, so if one person in the room is expressing intense emotions, others sharing the space will find that their emotional responses heighten too. This can make others over-eager to provide comfort and solutions, or alternatively, to distance and protect themselves by cutting short the expression of distress, objectifying the person or hurrying on to the next task.

The interview may be given a deliberate shape, with greeting rituals at the beginning and introductory material which then leads into the emotional heart of the interview, followed by lighter and forward-looking content to finish, so that people do not leave feeling overwrought or as if the interview has been cut off in the middle of their turmoil. Recovery from a distressing segment of the interview may be achieved by focusing on the person's strengths and resilience, such as their positive achievements or survival from previous moments of this kind. While preparation is helpful, continuous 'ethical triage' is needed, through which the emotional status of the person is under constant review and options for immediate or delayed action are kept in mind³⁸. Public Researchers are no less adept at monitoring the ethical dimension of the interview³⁹.

People who have been harmed may need to tell the perpetrator or others about the distress they have experienced. In these situations, the survivor may wish to reveal how the event has affected them emotionally, and so the distress will be a vital part of the message. They may also need a separate environment, away from the perpetrator and their colleagues, where they can meet with an ally to debrief, relive the emotions, reflect and make sense of the experience. The charity Victim Support offers just such a professional service⁴⁰.

Incidental findings

In health research, tests and interviews sometimes reveal unanticipated information, such as when a routine scan turns up evidence of a tumour. In the same way, a research interview may reveal underlying threats to the safety and wellbeing of the interviewee or others, such as when the respondent reveals suicidal ideas or discloses abuse. This requires a more substantial response⁴¹ than those situations when a person who has good mental health is briefly distressed during an interview.

Again, suicidal ideas and serious mental health challenges may be found amongst academic researchers and Public Contributors as well as in research respondents, so effective organisations will offer training in Mental Health First Aid⁴² and support both the person and their colleagues⁴³ to access other services as needed.

A web of relationships

Perhaps the very idea of a distress protocol or even a wellbeing plan is faulty, and it would be better to focus on role-play⁴⁴, training and raising awareness in a context of meaningful relationships rather than assuming that things can be fixed by writing documents. Distress is a very human experience, both caused and cured by interaction with others, defying any attempt to pin it down to a set of rules and tickbox responses. While some people are willing to disclose intimate material to a stranger, others want to get to know the listener before they are willing to trust them with private and distressing material. This prompts two questions: first, do I know the person well enough to ask these things? Second, is part of their distress actually shame⁴⁵ over revealing this material?

Academic researchers are not therapists and neither the Public Co-researcher nor the Research Participant is their patient, so any need for counselling or other support should be referred to the relevant person. While the interviewer is not the therapist they may take on the role of an ally, standing publicly against injustice and abuse⁴⁶. This also keeps the relationship between the academic researcher and the public researcher relatively simple, prevents unnecessary overlapping of roles⁴⁷ and assists everyone in deciding the right moment for the relationship to end. However, when the academic researcher and the public researcher work together in the live interview with the respondent⁴⁸, one might notice that the other is distressed. Since it is almost always better to acknowledge distress rather than pretend it is not occurring, asking the person about it demonstrates that you are paying attention to them.

This should prompt an honest discussion of what was seen, heard or felt, along with reflection on when it might be appropriate to rescue the person in the moment, how it might be explored afterwards and whether any other actions should be taken. It may help researchers to record their thoughts, feelings and reflections in a journal. In some research projects this journal can be included in fieldwork notes and written up as part of the evidence gleaned from the study, but this expectation may lead some researchers to sanitise their record and so gain less personally from the process. Other strategies such as joining online support forums can validate the experiences and help to disentangle the structural from the personal sources of distress⁴⁹.

Where support and supervision is not provided, the distressed person⁵⁰ may find someone else with whom to debrief – perhaps discussing their distress and its triggers with family or friends. This emotional pressure valve has been used by transcribers, and there is no reason to think that it will not be used by others, as telling the story whilst withholding identifiers will release pressure. Public Contributors who are less strongly socialised in research culture and have less to lose if they are caught breaking promises about confidentiality may be especially vulnerable. However, stereotypes should be avoided here as everywhere, since a Public Contributor who has made extensive use of health or care services will have considerable lived experience of what it feels like to be written about and talked about by staff, so may work harder than their academic colleagues to uphold confidentiality, rather than taking a lax approach to it.

Interviewers who have packed their diary with appointments may have little or no opportunity to check in directly after the interview to explore their own emotional state or consider how to improve their practice, and then it is too late.

Choice and control

If it is obvious to everyone that the interview will be covering distressing topics, the interviewer may invite the interviewee to select a safe word or gesture that they can use at will as a shorthand way to suspend the interview without appearing to storm out and slam the door. The person chooses their own word and explains how they want the interviewer to respond if it is used.

Where the academic researcher, public researcher or research participant has a key worker or care coordinator, the person themselves should retain as much choice and control as possible. This means that they should decide whether the academic researcher should know the identity of such a professional, speak to them and in what circumstances that would occur in their absence or, under exceptional circumstances, without their consent.

Be as clear as possible about where the duty of care obliges staff to report safeguarding or other serious concerns, whether that be in respect of a perpetrator or victim, risk of self-harm or suicide, criminal acts of which the police may be unaware, a breach of the organisation's own policies or a substantial concern about the person's competence. Naccarato et al⁵¹ studied opioid misuse and in so doing, were eager to avoid triggering the interviewee to seek out and use these dangerous substances. In line with advice on sensitive interviewing⁵², they carefully considered the potential impact of each interview question, thoroughly learnt them so that the interview could flow freely, ensured that therapists were in the building and available to offer immediate help after each interview and clarified their duty to report. In some situations, interviews should not be conducted on Fridays, as the distressed person would have to wait three days to make contact with support staff.

Except for these serious issues, the person should retain control of the information they have shared, in line with the General Data Protection Regulation. This means that they can ask for part or all of the information which they have shared to be destroyed, and this may be especially important for research interviews that are terminated before the end. The person may be willing for the researcher to use the information they have shared up to the point where they became distressed, but they should always be offered the choice for it to be retained or discarded from the research dataset.

Provide contact details of helplines, out of hours services and other people to whom the person can speak if they wish. Consider whether it is appropriate to brief others in advance. Offer to contact the person after the interview to check that they are OK and see if there is anything else that they need, asking when would be the right time to do that – perhaps later that day or the next day, as some people process distress more quickly than others.

The greater the degree of engagement with the research organisation, the greater the duty of care. This means that general information is probably sufficient for research participants, but a Public Co-researcher should be offered a more comprehensive opportunity to debrief, and access to external mentoring and support. In this situation, the distress protocol for the

public co-researcher will be highly personalised to match their current support network and preferences.

At the end of the interview, the interviewer may wish to ask the person how they are going to look after themselves for the rest of the day. This puts the agency back on to the person and mentioning it to the interviewer can enhance the feeling of accountability which will help them to carry out their wellbeing plan – by going for a swim perhaps or visiting a friend.

Three (not four) distress protocols

Some Guides begin with a general discussion and then draw together the lessons from that discussion to generate an evaluation tool or set of recommendations that summarise the themes that have been explored. This section does not attempt this task. Rather, the discussion above provides the reader with some concepts that may be used to critique the following examples of distress protocols that have been previously published.

We have not yet found an example of a distress protocol for Public Contributors or Public Co-Researchers. Protocols for other stakeholders in the interview process are set out below.

*Research participants*⁵³

Distress or upset	<ul style="list-style-type: none">• A participant indicates that they are distressed or exhibits behaviours of upset such as crying
Stage 1 Response	<ul style="list-style-type: none">• Stop the session and ask the person how they are feeling• Review• If the person feels able to carry on, resume• If not, go to next stage
Stage 2 Response	<ul style="list-style-type: none">• Discontinue the session and thank all participants for their time and input• Talk to the person in distress one-to-one and seek further information on the support that they need• Encourage the person to seek that support OR• Offer, with consent, for a member of the research team to contact the appropriate support
Follow up	<ul style="list-style-type: none">• Follow up with a courtesy call or email if the person consents• Encourage the person to make contact with the research team if they have any concerns about the study itself

*Researchers*⁵⁴

Pre-data collection	<ul style="list-style-type: none">• The research team should consider the potential physical and psychological impact on the researcher of the participant's description of their life experiences• The research team should consider how many interviews could be undertaken in a week• The research team should be aware of the potential for emotional exhaustion
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Data collection	<ul style="list-style-type: none"> • If the topic is potentially sensitive or distressing, data collection should be undertaken by two members of the research team • Regular scheduled debriefing sessions with a named member of the research team • The researcher could be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches
Analysis	<ul style="list-style-type: none"> • Transcribers and analysers should be alerted before they start work of potentially distressing material • Transcribers and analysers should have regular scheduled debriefing sessions with a named member of the research team
Follow up	<ul style="list-style-type: none"> • Encourage the researcher to access a research mentor if s/he experiences increased distress in the hours or days following their work.

*Transcribers*⁵⁵

Pre-data collection	<ul style="list-style-type: none"> • The transcriber should be considered in any research proposal, with a clear indication of how this person will be provided with a safe working environment while also maintaining the quality of the research
Ethical review	<ul style="list-style-type: none"> • The transcriber should be included in the ethical review process • The transcriber should be informed in advance of the nature of the research and the type of data
Pre-transcription	<ul style="list-style-type: none"> • Is alerted prior to the transcription of any potentially distressing interview transcripts • Has regular scheduled debriefing sessions with a named member of the research team
During transcription	<ul style="list-style-type: none"> • Has prompt access to an appropriate person for crisis counselling • Has a clearly documented termination from the transcription process that includes resolution of personal issues which arose as a consequence of the work • May be encouraged to journal their thoughts and feelings which may then become part of fieldwork notes in some research approaches
Follow up	<ul style="list-style-type: none"> • Follow up with a courtesy call if transcriber consents OR • Encourage the transcriber to call if s/he experiences increased distress in the hours or days following transcription.

What is the status of this paper?

Most of the documents we read are finished pieces of work, carefully crafted and edited in private before being shared with anyone else. This is a different kind of paper – it was shared online [here](#) from the first day, when the initial handful of ideas were incomplete, poorly phrased and tactless. It has been edited many times, but may still lack crucial concepts, evidence, structure and grammar.

As readers continue to provide feedback⁵⁶, further insights will be used to update it, so please contact me with your contributions. Similarly, if you would be willing to edit this material with me and submit a co-authored manuscript to an academic publisher, please get in touch.

It is one of a suite of documents that try to open up debate about how to return choice, decision-making and control to people using health and social care services – in research, implementation and evaluation.

This way of writing is risky, as it opens opportunities to those who may misunderstand, mistake the stopping points on the journey for the destination, and misuse or distort the material. This way of writing requires courage, as an early version can damage the reputation of the author or any of its contributors. At least, it can harm those who insist on showing only their 'best side' to the camera, who want others to believe that their insights appear fully formed, complete and beautiful in their simplicity. It can harm those who are gagged by their employer or the workplace culture, lest they say something in a discussion that is not the agreed party line. It can harm those who want to profit from their writing, either financially or by having their material accepted by academic journals.

In contrast, this way of writing can engage people who are not invited to a meeting or asked for their view until the power holders have agreed on the 'right message'. It can draw in unexpected perspectives, stimulate debate and crowdsource wisdom. It can provide free, leading-edge resources.

¹ See Darroch, Emma and Dempsey, Raymond (2016) 'Interpreters' Experiences of Transference Dynamics, Vicarious Traumatization, and Their Need for Support and Supervision: A Systematic Literature Review', *The European Journal of Counselling Psychology* 4(2). Also Lai, Miranda and Heydon, Georgina (2015) 'Vicarious Trauma among Interpreters', *International Journal of Interpreter Education* 7(1): 3.

² We need to start from "the assumption that coresearchers are capable and intelligent people who wouldn't fall apart at the mention of the topic they hold lived expertise in." Quoted in Dembele, L., Nathan, S., Carter, A., Costello, J., Hodgins, M., Singh, R., Martin, B., & Cullen, P. (2024). Researching With Lived Experience: A Shared Critical Reflection Between Co-Researchers. *International Journal of Qualitative Methods*, 23. <https://doi.org/10.1177/16094069241257945>

³ In a study of treatments for depression, candidates pinned their hopes on the chance to gain clinical benefit from participating in the research and some became very distressed when informed at screening that they were ineligible to participate.

⁴ Hutchinson A, Lovell A. (2013) Participatory action research: moving beyond the mental health 'service user' identity. *Journal of Psychiatric and Mental Health Nursing*. Sep;20(7):641-9.

⁵ Bates P (2021) [How to do reverse mentoring](#).

⁶ Bates P (2020) [How to respond to vexatious behaviour](#).

⁷ Singh AA, Richmond K, Burnes TR. Feminist participatory action research with transgender communities: Fostering the practice of ethical and empowering research designs. *International Journal of Transgenderism*. 2013 Jul 1;14(3):93-104.

⁸ See, for example, page 4 of NHS Research and Development Forum (2019) [Involving Service Users and Carers as Co-Applicants, Project Team Members and Co-researchers in Research Guidelines for Sponsors, Research Managers and Governance Leads](#).

⁹ Katz-Wise, S. L., Pullen Sansfaçon, A., Bogart, L. M., Rosal, M. C., Ehrensaft, D., Goldman, R. E., & Bryn Austin, S. (2019). Lessons from a community-based participatory research study with transgender and gender

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¹³ Watson, E. 2017. “The Mechanisms Underpinning Peer Support: A Literature Review.” *Journal of Mental Health*: 28(6): 677–688.

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¹⁶ Draucker CB, Martsolf DS & Poole C (2009) Developing Protocols for Research on Sensitive Topics. *Archives of Psychiatric Nursing* 23(5), 343-350.

¹⁷ ‘Project costs might include extra fieldwork time (working in pairs, providing a ‘shadow’ or reporting back to base), taxis or hired cars, appropriate overnight accommodation, special training and counselling for staff researching sensitive topics.’ [Social Research Association](#) (2001) [A Code of Practice for the Safety of Social Researchers](#).”

¹⁸ See an example template for a personal wellbeing plan (and a lot of additional resources on researcher distress and wellbeing) at [Preventing and Responding to Secondary Trauma in Researchers addressing Sensitive issues \(PRESTARSS\) | Institute for Health Transformation](#).

¹⁹ Dr Clem Edwards, personal communication 16/09/2024.

²⁰ Katz-Wise, S. L., Pullen Sansfaçon, A., Bogart, L. M., Rosal, M. C., Ehrensaft, D., Goldman, R. E., & Bryn Austin, S. (2019). Lessons from a community-based participatory research study with transgender and gender nonconforming youth and their families. *Action Research*, 17(2), 186–207. <https://doi.org/10.1177/1476750318818875>

²¹ Social Research Association (2001), op cit.

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²³ Lakeman R, McAndrew S, MacGabhann L, Warne T. ‘That was helpful... no one has talked to me about that before’: Research participation as a therapeutic activity. *International Journal of Mental Health Nursing*. 2013 Feb;22(1):76-84. Also Hawton K, Houston K, Malmberg A & Simkin S (2003) Psychological Autopsy Interviews in Suicide Research: The Reactions of Informants, *Archives of Suicide Research*, 7:1, 73-82, DOI: 10.1080/13811110301566.

²⁴ Newman E & Kaloupek DG (2004) The risks and benefits of participating in trauma-focused research studies. *Journal of Traumatic Stress*, 17(5), 383–394.

²⁵ Diaphragmatic breathing may be helpful, whilst focusing on the five senses in turn – name five things you can see, four things you can touch, three things you can hear, two things you could taste and one thing you can smell. These exercises help the person who is reliving a trauma to return to the present.

²⁶ Griffin MG, Resick PA, Waldrop AE, Mechanic MB (2003) Participation in trauma research: Is there evidence of harm? *Journal of traumatic Stress*. Jun;16(3):221-7.

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- ²⁹ National Institute for Health and Care Excellence (2018) *Post-traumatic stress disorder NICE guideline [NG116]*. Available at [Recommendations | Post-traumatic stress disorder | Guidance | NICE](#).
- ³⁰ Draucker et al (2009) op cit.
- ³¹ Bates P & Ward C (2021) [How to avoid doing bad research](#).
- ³² Bates P & Ward C (2021) [How to gain informed consent](#).
- ³³ Bates P & McLoughlin B (2019) Respecting privacy in care services *The Journal of Adult Protection*, Vol. 21 No. 6, pp. 276-284. <https://doi.org/10.1108/JAP-06-2019-0020>. Also Bates P (2019) [Challenging the hive mind](#).
- ³⁴ Jorm AF, Kelly CM & Morgan AJ (2007) Participant distress in psychiatric research: A systematic review. *Psychological Medicine*, 37, 917–926.
- ³⁵ A confidentiality statement should be clear about the circumstances under which this bounded confidentiality is set aside. It will also be explicit about how this conversation fits in with care management, clinical and supervisory relationships.
- ³⁶ The Participant Information Sheet for the NIHR SSCr funded study ‘Avoidable harm in mental health social care’ asks respondents to complete an online questionnaire. Respondents are advised to ‘answer the survey at a time of day when you feel most able to do so.’ See https://qualtrics.kcl.ac.uk/jfe/form/SV_cOSNF64cNTaMDsy.
- ³⁷ Paul Gilbert (founder of compassion focused therapy) describes the role of the soothe system (‘rest and digest’ parasympathetic emotional regulatory nervous system) which is activated when we feel a sense of safety and an absence of threat.
- ³⁸ Buchanan D & Warwick I (2021): First do no harm: using ‘ethical triage’ to minimise causing harm when undertaking educational research among vulnerable participants, *Journal of Further and Higher Education*, DOI: 10.1080/0309877X.2021.1890702.
- ³⁹ See Bates P (2021) [How to make the case that Public Contributors are Citizen Ethicists](#).
- ⁴⁰ It would appear to be self-evident that any organisation that invites people who have suffered serious harm to recount their experiences for the benefit of others should contract with a service like Victim Support to establish a 24/7 helpline and offer a series of booked appointments for a skilled debrief. This could be of substantial help to witnesses in certain court cases as well as those giving evidence in Public Inquiries on failures in social and healthcare, historic sexual abuse investigations, tragedies such as the Grenfell Tower Inquiry and some Serious Case Reviews. In addition, researchers who investigate very distressing life experiences and some lecturers who engage experts by experience to tell their traumatic story to trainee health and social care professionals should also have access to such a service.
- ⁴¹ Stevens, K., Thambinathan, V., Hollenberg, E. *et al.* (2021) Core components and strategies for suicide and risk management protocols in mental health research: a scoping review. *BMC Psychiatry* 21, 13. <https://doi.org/10.1186/s12888-020-03005-0> Also [Behavioral Research | CHOP Institutional Review Board](#).
- ⁴² See [Mental Health First Aid starts with you · MHFA England](#).
- ⁴³ Bates P (2016) [How to take your lived experience to work](#).
- ⁴⁴ Role playing can be a powerful way to prepare for interviews, but trainers will need to decide who to cast in the play. See Bates P (2017) [How to choose between an actor and an expert by experience](#).
- ⁴⁵ Becoming upset and feeling that they have not been strong enough or mature enough to overcome these emotions reduces the person’s sense of mastery over their situation, which can, in turn, lead to shame. This shame then activates the fight/flight threat system.
- ⁴⁶ Forber-Pratt AJ, Mueller CO, & Andrews EE (2019) Disability identity and allyship in rehabilitation psychology: Sit, stand, sign, and show up. *Rehabilitation Psychology*, 64(2), 119–129. <https://doi.org/10.1037/rep0000256>.
- ⁴⁷ See Bates P (2020) [How to manage overlapping roles in research](#).
- ⁴⁸ See Bates P (2021) [How to involve the public as co-interviewers in research](#).
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- ⁴⁹ “Personal strategies included writing and keeping a journal, therapy, talking to friends and family, participating in social media groups, and reading and researching issues such as race and white privilege as a form of seeking external validation.” In Faulkner & Thompson (2021) op cit.
- ⁵⁰ Wilkes L, Cummings J, Haigh C (2015) Transcriptionist saturation: Knowing too much about sensitive health and social data. *Journal of advanced nursing*. Feb;71(2):295-303.
- ⁵¹ Naccarato N, Wacker N, Gagnon L. Opioid Crisis: A Qualitative Analysis of Financial Influences and Addiction. *Diversity of Research in Health Journal*. 2021 Jan 5;4(1):16-.
- ⁵² Dempsey L, Dowling M, Larkin P (2016) Murphy K. Sensitive interviewing in qualitative research. *Research in nursing & health*. Dec;39(6):480-90.
- ⁵³ Adapted from Draucker CB, Martsof DS & Poole C (2009) Developing protocols for research on sensitive topics. *Archives of Psychiatric Nursing* 23(5), 343-350.
- ⁵⁴ McCosker H, Barnard A, Gerber R (2001) Undertaking sensitive research: Issues and strategies for meeting the safety needs of all participants. *Qualitative Social Research* Feb 28 (Vol. 2, No. 1).
- ⁵⁵ Gregory D, Russell CK, Phillips LR. (1997) Beyond textual perfection: Transcribers as vulnerable persons. *Qualitative Health Research*. May;7(2):294-300.
- ⁵⁶ A request for advice on this topic was circulated on the Future NHS Collaboration Platform - Professional Network for Public Participation Practitioners on 21 June 2021, to NDTi staff and Associates on 24 June 2021 and others have been invited to comment too. Contributions and challenges have been offered by Dave Barras, Jackie Claxton-Ruddock, Madeline Cooper, Jeremy Coutinho, Jessie Cunnett, Emma Davenport, Laura Davis, Karen Forrest, Alison Giraud-Saunders, Sarah Gordon, Kate Horton (Public Involvement Coordinator, Institute of Mental Health at the University of Nottingham), Antonia Knifton (Senior Engagement, Activation and Empowerment Project Manager, Design Solutions, NEL CSU), Paul Marshall, Sam Sly, Katie Stepanian and Helen Toker-Lester, although all errors and weaknesses that remain in this document are the responsibility of the author.