*Regular Article*

# Participating in Research: Experiences of People Presenting to the Emergency Department With Self-Harm or Suicidality

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**Abstract**

Research on sensitive topics with vulnerable populations is challenging in terms of ensuring safety and obtaining ethical approval. We explored the experiences of people with self-harm/suicidality who had taken part in research that included being video-recorded. Twenty-two semi-structured interviews took place within 2 weeks of attending the Emergency Department and were thematically analysed. Participating in research when in distress and in a challenging environment was found to be overwhelmingly positive. Participants valued contributing their time and insight, particularly when research was conducted in a skilled and kind manner. They identified personal (e.g., talking as part of the healing process) and wider benefits (e.g., helping to improve services) of participation, which for most, negated the difficulty of discussing highly sensitive topics when in crisis. Despite the potential 'intrusiveness' of video-recording, it was found to be acceptable by those who participated in the follow up interviews, a better method for learning and capturing interactions than e.g., questionnaires, and did not impede communication and the disclosure of distress.

**Keywords**

emergency care research, vulnerable participants, suicidality, video-recording

## Background

Suicide is a leading cause of death worldwide and suicidality is expected to increase with rising cases of mental distress, due to social inequalities, under-resourced services, and the effects of the recent pandemic (Boden et al., 2021). Research informed by first-hand accounts of people in serious distress is paramount for the development of new interventions and improvement of current practice in prevention and recovery (Byrne & Wykes, 2020). However, research that is co-produced and based on lived experience remains small (Maple et al., 2020) and there is even less evidence from real-life observations in mental healthcare settings, often made difficult by ethical and recruitment challenges.

In the UK, the British Psychological Society's (BPS, 2021) 'Code of Human Research Ethics', focuses on four main principles: respect for the autonomy privacy and dignity of individuals, groups and communities; scientific integrity; social responsibility; and, maximising benefit and minimising harm. To address these, researchers engage with people with lived experience during the development stage of research study to ensure that participation is ethically sound and will not be harmful to participants. High risk research involves (a) vulnerable groups, e.g., children and those who have prior experience of psychological/physical harm or adversity, and (b) exploring sensitive topics (BPS, 2021). A challenge in recruiting people who are deemed to be vulnerable is ensuring that research will not cause any harm (Alexander, et al., 2018), e.g., physical, emotional or in relation to confidentiality, and convincing sponsors and ethics review boards that the research study will be safe for the participants. This is particularly

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important in suicide-focused research, where perceived risk of harm directly resulting from participation in the research is often cited as an exclusion criterion for research participants. In order to overcome such challenges, researchers have increasingly focused on exploring participants own opinions and experiences about their participation so that potential risks are identified and recruitment processes improved.

In healthcare research, there is growing evidence that discussing sensitive issues, including traumatic experiences, is found to be acceptable by participants (Becker-Blease & Freyd, 2006; Crane & Broome, 2017; Decker et al., 2011). Previous assumptions that research questions about sensitive issues/traumatic memories may cause distress have been challenged, as an increasing number of studies show that few participants report unanticipated distress related to research participation (Becker-Blease & Freyd, 2006). A recent review (Alexander, et al., 2018) of the experiences of vulnerable people and evidence from research with people who self-harm (Littlewood et al., 2019), suggests that participation is mainly a positive experience with little indication of harm to participants, and that given the opportunity, vulnerable populations want to participate in research. Despite the evidence that conducting research with vulnerable/suicidal participants does not significantly increase risk (Alexander, et al., 2018; Carter, et al., 2020; Eynan et al., 2014), gatekeepers, such as ethics committees, sponsors and professionals (e.g., doctors, teachers) are often reluctant to recruit participants who may be in distress (Loades et al., 2019). Misconceptions and over-protective 'gatekeeping' practices can cause obstacles to conducting research with vulnerable populations, and as a result remove their choice of participating in research (Alexander et al., 2018).

Additional challenges can be created by both the environment within which the research takes place as well as the methods used. Recruitment in healthcare settings, such as an emergency department (ED) can be challenging due to e.g., identifying eligible participants from patient records, limited support from healthcare practitioners, and limited face-to-face interaction between researchers and patients (Price et al., 2020). Research methods that are new and invasive can create additional concerns. Video-recording interactions is not commonly used, especially in professional-patient settings (Parry et al., 2016). Although some evidence suggests this is due to its 'intrusiveness of the method', limited evidence on participant views regarding the acceptability of this method suggests that it's more acceptable to people who have participated in video-research than those who have not, hence people do not dislike the experience but the idea of it (Parry et al., 2016). Benefits of video-recording interactions are mainly the fact that it enables researchers to gain in-depth understanding of complex interactions and settings (Asan & Montaguem 2014; Coleman, 2000), by capturing a large and rich amount of data in natural settings (Asan & Montaguem 2014). However, video-based observations are underutilised as a research method. Few studies focusing on patient-participant views report a positive experience (Parry et al., 2016) and suggested there were no issues (Karlsson et al., 2012).

Evidence into how vulnerable individuals make decisions regarding participation in research as well as their experiences, is important in order to improve practice and provide evidence to those who have the power to allow or deny access to participants. This paper adds to the growing evidence of the benefits of involving people with mental ill health/in emotional distress in research, by presenting evidence from people who are considered vulnerable, discussing a sensitive topic, and in a challenging environment – before, during and after a psychosocial assessment, in a busy ED. The aim was to explore the experiences of people presenting with self-harm or suicidality (suicide attempt/ideation) to the ED, of participating in research and being video-recorded.

## Methods

### *Participants and Recruitment*

Data was collected as part of mixed methods observational study which explored the quality of conversations about self-harm/suicide between patients and mental health professionals in the ED. The study obtained ethical approval from the London - Central Research Ethics Committee (17/LO/1234).

In-depth interviews were employed as a method of eliciting accounts of people's experience and perspectives. Participants were interviewed by a researcher 2 weeks after the observation of their psychosocial assessment on their experience of a) the psychosocial assessment (Xanthopoulou et al., 2021), and b) their participation in this research study (see Figure 1). Analysis of 'participating in the study' data is presented in this paper. Interviews took place between 10/09/2018 to 09/04/2019.

Participants were approached by a clinician who assessed if they met the inclusion criteria: Adults (>18 years age) who had capacity to give informed consent (45 participants - 59% of the number approached, agreed to participate in the observational study). We excluded patients who had cognitive/psychiatric difficulties (lack of capacity to consent), were experiencing a psychotic episode, needed an interpreter, and Ministry of Justice patients (subject to a restriction order/convicted of an imprisonable offence). Clinicians assessed patients' capacity to participate and give informed consent, and then asked patients if a researcher could talk to them about the study. Ideally, 24 hr would be allowed to consider participation in the research, however, in a hospital setting it is not known in advance who will present. To compensate for the short period that potential participants would have to decide whether or not to take part, a three-step process to ensure informed consent was adopted:

1. A clinician or triage nurse asked patients if they are willing to be approached by a researcher: the researcher obtained written informed consent.

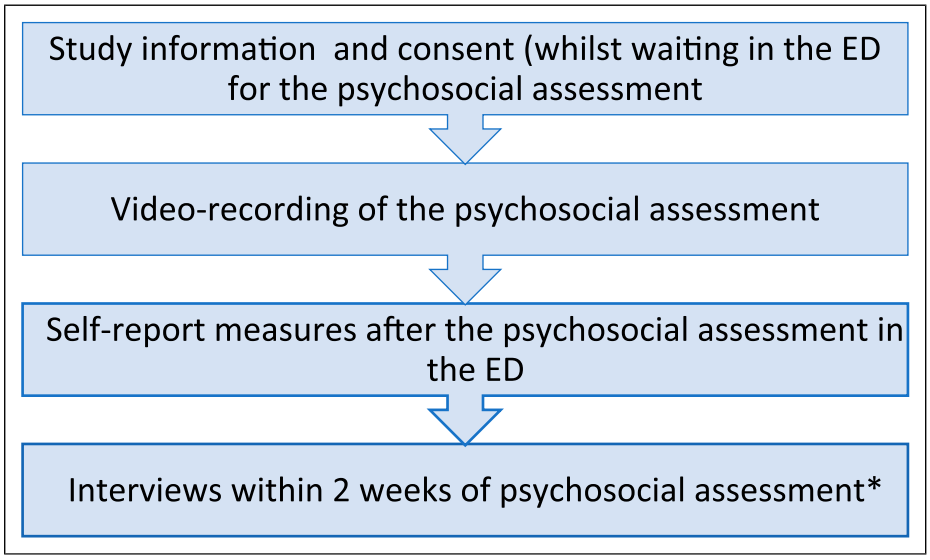


**Figure 1.** Participation process and study methods. *At this stage participants were asked about their experience of taking part in this research study.

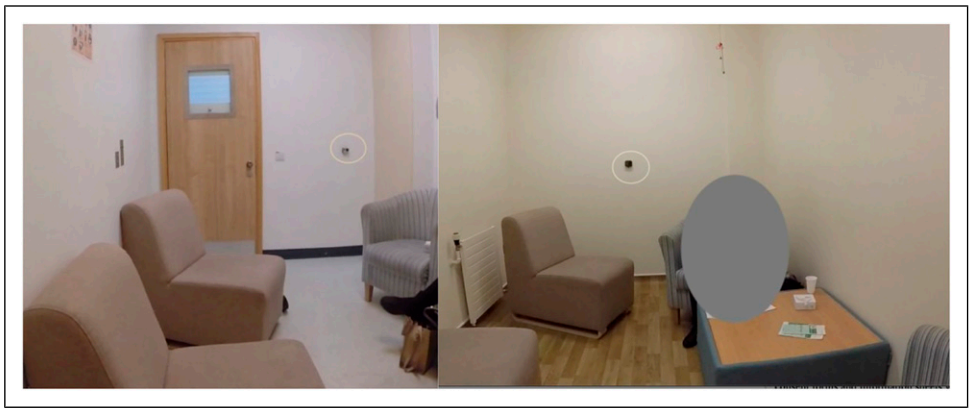

**Figure 2.** Camera 1 and camera 2 positions in the ED consultation room (cameras circled).

2. During the psychosocial assessment the mental health professional reaffirmed consent to be video-recorded.
3. Consent was reaffirmed by the researcher after 1–2 weeks, at an interview.

The participants who had consented to a qualitative interview about their experience were given the choice of place and time, in-person or over the telephone, to ensure privacy.

## *Data Collection and Analysis*

Semi-structured interviews took place at the patient's home or via telephone, with interviews lasting on average 22 mins. An interview guide aimed to elicit participants' understanding and experience of their psychosocial assessment including their experience and the impact of participating in research. The following questions were asked about their experience of taking part in the study and responses to these questions were analysed and are presented in this paper: "What do you think about taking part in this study?" and follow-up questions specifically about the video-recording: "How did you find it with the cameras in the room?". Two small GoPro cameras were used for two different angles, and were fixed on walls (Figure 2). The researcher was not present.

The interviews were audio recorded, transcribed verbatim and anonymised. Transcripts were initially coded line-by-line by PX using NVivo version 12. We used qualitative semi-structured interviews and thematic analysis as it is "independent from any particular theoretical approach or epistemology persuasion" (Evans & Lewis, 2018, p. 3). Inductive thematic analysis was conducted to identify patterns within data, by generating codes and organising them into themes (Braun & Clarke, 2006). The development of the coding scheme and interpretation was iterative and involved initial familiarisation with the data by all authors in analytic meetings, where subthemes and themes were then finalised. The researcher who conducted the interviews was

not involved in the data analysis, however, this paper does not report on the interviewer's judgments and their role in the interview process, which may have influenced participant responses (Potter & Hepburn, 2005).

### Patient and Public Involvement and Safeguarding

The procedures for approaching people and obtaining consent were developed with people with lived experience of suicidality, which include members of the Lived Experience Group at the University of Exeter and the Lived Experience Advisory Panel at Recovery Devon. Four workshops and individual meetings with members took place between February 2017 and April 2017. The potential risk of causing distress to participants by asking them about these experiences, was addressed by taking a sensitive approach to the interview, drawing upon the experiences of our Patient and Public Involvement (PPI) group, which focused on potential issues (e.g., disclosure of risk) and language used. This included the interviewer checking whether participants felt comfortable discuss specific issues or were happy to continue discussing these, i.e., by asking "is it alright if we talk (a bit more) about that?". Risk protocol procedures, were developed and used if the researcher felt concerned about participants' or their own safety. Participants were made aware of the limits of confidentiality during the consent process: "I understand that as part of your duty of care, if I disclose suicidal intent, I may need to be referred to my healthcare professional". When the researcher first approached participants to explain the study and obtain informed consent, they clearly explained how the video-recordings would be used and stored. This was also explained in the information sheets (see Supplementary Appendix 1 and 2).

## Results

Twenty-two participants (out of 28 who were interviewed) discussed their experience of taking part in the research study and being video-recorded. Participant age ranged from 18 to 76 (mean age: 37, SD: 16.9), with 7 male and 15 female participants. All participants were white English. Three participants presented to the ED at night. Participants described an overall positive experience, identified opportunities for learning from a very distressing situation, and difficulties with specific methodologies. Table 1 presents the themes and subthemes from the thematic analysis.

### A Good Experience When Research Conducted in a Skilled and Kind Manner

*Research a positive experience and appropriate within a seeking-help context.* Participants said that taking part in research was an overall positive experience, even for those who had no previous experience of participating in research: *"I've never taken part in a study before so I'd say I've had a good experience"* (P14). They indicated that they would do so again if there is need and given the opportunity: "*I'd be quite prepared to help out in any way*" (P32) and appreciated the fact that research is needed: "*I thought it was a very good idea*" (P32).

Some participants stated that they presented to the ED to get support during their crisis and taking part in research was in line with that situation: *"it [participating] was fine, I really was, it was like… at that time you weren't… you just want to be helped and that's what you're there for"* (P22).

*Professionally done, comfortable and caring.* Drawing upon their interactions with the researcher, participants stated that the research was conducted in a skilled way: "*you weren't intruding or anything it was just… professional"* (P22), and with a considerate approach: "*the way it was, you know asked, I felt comfortable"* (P02). Participants explained how their good experience was also influenced by being fully informed and the fact that the researcher reiterated that their participation was voluntary: "*it was approached in the correct sort of way, I didn't feel like I was forced in to having to do that. It was approached like, it's up to you, it's purely my choice sort of thing"* (P35).

Participants appreciated that it was not easy to talk about their experience, and that specific care was required for discussing such a sensitive topic: "*I think you've handled it really well actually, it's not an easy thing to talk about"* (P24). Another aspect participants identified as part of the 'professional' and sensitive approach used by the researcher, was checking often that they felt comfortable and happy to continue: *"It was very open, and I was asked if I was ok with everything, numerous times as well. It wasn't just once, you were making sure that I was fully ok with it"* (P35).

### Benefits of Participation: Difficulty versus Necessity to Get 'True Picture'

*Personal and wider benefits of participation.* Helping other people who might find themselves in a similar crisis, by sharing their views and experiences was cited as one of the reasons for participating: "I *just hope I can help someone, doing this can help somebody else. That's why I agreed to it, because I thought if I'm going through it somebody else will obviously go through it and if this helps"* (P22). They explained that by participating in the study they may contribute to improving access to mental health services and quality of care: "*I'm hoping that I can help others I guess, and I'll do anything I can to try and aid this study if it improves services and care for other people"* (P11). Participants acknowledged their unique position as experts by experience: "*If people don't put themselves on the line to give insights to people, they can't progress to try to do something to stop things happening again"* (P28); along with making something positive from their own distress by benefiting others: "*I'm glad I can help, you know, through the sort of the trauma of what's happening to me*" (P11); *"it's kind of nice to put the situation to some kind*

**Table 1.** Themes and Sub-Themes.

| Themes | Sub-Themes |
|---|---|
| A good experience when research conducted in a skilled and kind manner | - Research a positive experience and appropriate within a seeking-help context<br>- Professionally done, comfortable and caring |
| Benefits of participation: Difficulty versus necessity to get 'true picture' | - Personal and wider benefits of participation<br>- Tension between reliving distress and conveying a true picture of distress |
| Unobtrusive video-recording good for capturing interaction and not a barrier to disclosing | - Cameras: Initial nervousness but forgot about them and opened up<br>- Video-recordings: a better learning tool<br>- Questionnaires not representative of changing emotional state |

*of…use or hopeful benefit, possibly … which is a slightly positive spin on a pretty negative situation"* (P37).

Apart from the indirect benefits that their participation might bring about, participants also expressed personal positive experiences, such as feeling better after talking to the researcher: "*it's been a good thing because I've been able to speak to someone else about how I'm feeling and the more people I can speak about how I'm actually feeling the better"* (P29).

Participants were offered a monetary payment to compensate them for their time and effort. Two participants gave feedback (unprompted), stating that how money was used: *"I caught the bus home with the money you gave me"* (P09), whilst the other participants felt uncomfortable with the payment:

> "the hospital staff had looked after me, and then I was almost given £30, so it maybe would have been nice to have the option or 'would you like to donate it to the hospital?' or just back into research" (P02).

*Tension between reliving distress and conveying a true picture of distress.* In some instances, participants found it difficult when the conversation delved further into their experiences surrounding the crisis, but stated this was not severe and appreciated that talking to people when in crisis or soon after, is the only way to to get a true representation of the crisis:

> "*I was quite distressed actually talking about it to you, I think you went more in depth about it didn't you? The questions you asked? … I think it might have been nice if you'd have said that you wanted to deeply look into what happens and how …Where that was going to lead to, yeah. I would've said that it added to my distress… you can only be asked those kinds of questions in the moment to get the true picture of it, can't you? Because if you'd spoken to me three days later or two days later it will have changed won't it, so I can see the value of you doing it at the time*" (P16).

One participant stated that when the conversation became too intense and specific about their suicide attempt, they felt they couldn't talk about it: *"I can remember as soon as you hit the suicide … I was like no, no I'm not going to do this now, like I can't do this now, just because I was shutting you down"* (P17). Similarly, the role of the researcher questioning was challenged, as they are not a 'therapist', however again acknowledging the necessity: *"I just felt like it wanted to all come out but wasn't the time because you were not there as a therapist are, so…I can't see that it could have been done any other way"* (P16).

## *Unobtrusive Video-Recording Good for Capturing Interaction and Not a Barrier to Disclosing*

*Cameras: Initial nervousness but forgot about them and opened up.* Many participants commented on the acceptability of being video recorded during their psychosocial assessment. They were aware of the cameras but did not pay attention to them during the assessment: "*I forgot they were there to be honest. I mean I noticed them straight away as soon as I walked in, the GoPros …it was just I forgot they were there and talked naturally*" (P11). They also commented on the small size of the cameras, which meant they were not visually intrusive: "*I initially thought there was going to be these big cameras in and they were so small…You couldn't really see them they were so small. I just kind of almost forgot they were there. So they were non-intrusive"* (P07).

Participants state that being aware to being video-recorded, had no influence on their interaction with the clinician and did not affect what the said or did: *"I feel like I still opened up as much as I would have if they (cameras) weren't there*" (P01). Similarly, participants said the cameras did not make them feel suspicious or distrustful: "I didn't feel like… you know like I was being watched or anything" (P02).

*Video-recordings: A better learning tool.* Some people commented on the benefits of video as a research tool and the rich kind of data this provides: *"I was really interested from the video, what my body language was saying, because I felt like I was all over the place, I'm not sure"* (P17). They suggested that it could be a good learning tool for mental health professionals: "*If someone sees it then they'll learn something*

*won't they? [People] are training at least?"* (P09), or as an example of people who are in crisis: *"I wouldn't mind you showing it on a programme of people who are suffering"* (P09).

*Questionnaires not representative of emotional state.* The data collection also included participants completing questionnaires after their psychosocial assessment. They suggested that, compared to being interviewed, questionnaires reduced their experience to scores with generic questions: "*the questions do come across as a bit distant and that's just the way they're phrased"* (P24), and were sometimes unclear: "*I mean sometimes I found some of the questions… not difficult to answer … just weren't clear what the question was asking, sometimes a bit difficult"* (P15). There was also the impact of 'rating' one's experience when in crisis, and what this might entail in terms of representing one's 'real' emotional state:

> "[interview] was obviously a much longer process than circling numbers, but I definitely felt like that was much more of an honest portrayal of how I was feeling, whereas those numbers were maybe a misrepresentation, or not the full picture at least" (P10).

Rating their experience also created concerns in terms of the impact this might on perceptions of legitimacy:

> "there was a list of statements and I had to I think label… I had to circle the numbers between one and four…I just felt that that questionnaire, I don't know because I felt like I was circling a lot of ones and twos which kind of made me very… I don't know, it made me diminish my… it made me not take my problem seriously after that because I thought if I'm scoring so low, do I actually have issues worth talking about" (P10).

## Discussion

In this paper we explored subjective experiences of participating in research with people presenting to the ED with self-harm/suicidality. In line with other research our findings suggest that 'high risk' research with participants who are considered vulnerable, is experienced by participants as overwhelmingly beneficial. This included personal benefits after their participation (Alexander et al., 2018; Pessin et al., 2008), including feeling better for having talked about their experience (Newman et al., 2006) and the feeling of contributing to the improvement of services and using their distress to help others have a better experience and care (Newman et al., 2006).

In line with other research with people who are suicidal (Labott et al., 2013; Littlewood et al., 2019), participants who provided feedback on the participation, stated that any concerns they had about participation were short-term and did not cause harm. None of the participants changed their mind regarding their participation in the study (consent was re-confirmed and no participant withdrew from the study). With respect to video-recording, the two participants who were initially apprehensive about the idea of being video-recorded, said they were satisfied they decided to participate despite their initial worry and this did not result to a negative experience (Biddle et al., 2013; Gibbs et al., 2018).

Research that involves people in acute distress inevitably raises ethical questions. In this study, people participated soon after harming themselves through e.g., overdoses or when they were feeling suicidal, and in addition, the research tool place in a stressful setting – in the ED whilst particpants were waiting to meet with a mental health professional and soon after their psychosocial assessment. Findings from other suicide-related research also found that participation in research was not associated with increased distress or suicidal thoughts (Blades et al., 2018). Carrying out research sensitively (Pessin et al., 2008) can minimise the possibility of further distress. Aspects and questions participants identified as positive, e.g., checking often if they are comfortable and happy to continue, were suggested by our PPI group, demonstrating the importance of a PPI perspective on self-harm and suicide research (Littlewood et al., 2019) and specifically early engagement in the research process and recognition of their contributions (Hawke et al., 2020). Specifically, some participants in this study stated that the researcher had a considered approach. This included providing clear information about the research aims and process and checking often and during different stages of the study their continued willingness to participate and whether they were okay to continue talking about a specific topic. When researchers ask for intimacy and self-reflection (Birch & Miller, 2000) they inevitably create a therapeutic setting. Similarly in this study participants stated that they felt able to talk to the interviewer and were listened to. This has important implications for training (Birch & Miller, 2000) as well as the analytic process of interviews. Although a 'therapeutic' research interview can be seen as a successful one by the researcher, usually interviews (including this study) are not followed up, which raises important questions regarding the wellbeing of some interviewees, who although may had a positive encounter, there may be (additional) distress once the interview has ended. It may be beneficial for future studies to include an optional follow-up meeting with a therapist as part of the process so that participants feel safe, or even offering longer term support (Mitchell & Irvine, 2008).

Despite the evidence of the benefits of research with acutely distressed populations, barriers include hurdles in gaining ethical approval, stating concerns about potential harm to participants (Biddle et al., 2013; Carter, et al., 2020). However, denying the opportunity to vulnerable people to participate has been found to be 'overly protective' (Biddle et al., 2013). This is not limited to ethics committees, as sometimes health care professionals who may be concerned about over-burdening their patients when in crisis, assume they would not want to participate (Loades et al., 2019; Ross

& Cornbleet, 2003) and unwittingly limit the right of individuals to participate in research (Maillet et al., 2017; von Benzon & van Blerk, 2017).

The use of video recordings as a means of observation in health-care research introduces another level of concern to sponsors and ethics committees as well as stakeholders. Although video-recordings of doctor-patient interactions have been used for education and training of health professionals (Parry et al., 2016) it has been underutilised for research purposes. Similarly to Parry et al. (2016), we also found that concerns that video-recording might harm healthcare delivery are not supported and participants reported that they did not feel their interaction with the clinicians was hindered by the presence of cameras. In line with other research in medical consultations (Penner et al., 2007) participants very quickly became accustomed to the presence of the two very small cameras and reported that although aware of the cameras, this did not affect disclosure of personal accounts of suicidality. Observing interactions without a researcher present using unobtrusive equipment eliminates observer effects, such as participant reactions to researchers and equipment (Penner et al., 2007). Therefore, in contrast to concerns and accounts of consultations being affected by filming (Hargreaves & Peppiatt, 2001), participants emphasised the cameras did not deter them from speaking freely. Themessl-Huber et al. (2008) found that people who had previously participated in research that used video, regarded video-recording more acceptable than those who did not, therefore showing that often it may be the idea about being videoed that can be negative, rather than the actual experience. Similarly in this study, some participants said that any initial apprehension did not translate to a negative experience.

Finally, participants talked about difficulties when they were administered the questionnaires and their preference for the video-recording and interview. This might be due to the context in which the research took place, a challenging ED environment, when people are distressed. They preferred the open-ended interview questions versus the very structured and often difficult to understand questionnaire questions. Methods that are flexible and sensitive to people's emotional state can be better incorporated into the setting and experience of seeking or receiving therapeutic support.

Whilst incentives to research are generally viewed necessary and positively, researchers should consider potential concerns of either undue influence (Crane and Broome, 2017), or as one participant in this study suggested, other options such as donations to charity should be available, as the monetary 'thank you' payment made them feel uncomfortable.

### *Limitations and Further Research*

Participants were not asked to comment specifically of issues of confidentiality and questions about participation were at the end of an interview that covered other topics, therefore perhaps limiting the amount of time participants wanted to talk about this topic. We do not know if this was because they were given comprehensive information on anonymisation, access and use of all data, or because they were not specifically asked about this. There may also be selection bias as patients who agreed to participate and be interviewed are likely to be more positive and hence not necessarily representative of the wider patient population. Participants in this study were asked about their overall participation and being video-recorded and, unprompted, they commented on the use of questionnaires versus qualitative methods, such as the interview and video recording. People needing an interpreter were not eligible as it was not possible to know in advance which interpreter (language) would be needed as people were approached and recruited within an hour of presented to the ED. The study did not have resources available (study not funded) for having several interpreters on stand-by. All participants recruited were white English, and we cannot conclude if this was due to recruitment bias (not recruiting non-English speaking people) or due to a non-racially and ethnically diverse recruitment area. The same researcher conducted all data collection in the study (including the interviews) which may be a conflict of interest, e.g., obtaining feedback on own conduct, and although participants were critical of some aspects of the process (e.g., questionnaires) it may have been difficult for some participants to give negative feedback.

## Conclusion

The benefits of conducting research with distressed individuals in healthcare settings are numerous. Transparent, comprehensive and participant-led research methods and processes can help address valid ethical questions and concerns. Video-recording as a data collection method is found to be acceptable by patient participants and viewed as good method to capture experience. Participants also suggested that video-recording and interviews are preferable as a method in this setting to questionnaires. Research that provides evidence of the acceptability of research topics and methods can reassure potential participants, address difficulties and improve the data collection process. This work can encourage clinicians, sponsors and ethics committees who may be protective of vulnerable participants to allow and encourage such populations to engage with research. Researchers should consider also the importance of sharing research findings with the participants so they can see the results of their participation.

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## Data Availability

Research data supporting this publication are provided within this paper. Due to ethical concerns, further research data are not publicly available.

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## Supplementary Material

Supplementary material for this article is available online.

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