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“I didn’t choose to write my life”: Trauma-informed values in the design of social care records

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Abstract: While there has been a recent interest in trauma-informed design approaches, there is still a need for further research on its use in participatory design (PD). This paper discusses the methodology of a values-driven, trauma-informed PD project which explored how social care records could be redesigned to meet the needs and aspirations of young people (YP). Care-experienced people have often lived through traumatic experiences closely associated with their experiences of care, resulting in a lack of trust in social care professionals. While foregrounding the views of care-experienced people, this project also engaged with professionals, revealing systemic tensions which needed to be navigated through the approach. We discuss application of the trauma-informed methodology and tensions that arose. Our work demonstrates how trauma-informed values and methods can be used during participatory research where groups may have conflicting goals, and how this can enrich the design process.

Keywords: care; trauma; ethics; tension

1. Introduction

Understanding how to undertake participatory design (PD) safely and ethically in sensitive contexts has become an increasing concern (Aldridge, 2014; Hodson et al., 2023; Lindberg, 2018; Raman & French, 2022). Trauma-informed practice used by health and care practitioners offers practical and ethical guidance for researchers and designers working in these contexts (National Trauma Transformation Programme, 2023). However, this area is relatively new and there is limited research to date discussing the application of these approaches within PD research (Dietkus, 2022). Within the context of health and care, power imbalances between staff and people who use services can create barriers for collaboration (Robert et al., 2022) and the potential for conflict. PD researchers in this context must therefore anticipate and mitigate these risks to avoid inadvertently increasing inequalities and to ensure the rights and agency of people with lived experience are prioritised (von Benzon & van Blerk, 2017).



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This paper discusses a trauma-informed PD project which explored how social care records could be redesigned to meet the needs and aspirations of young people (YP). Care records are an administrative tool which record a YP's time within the care system (CELCIS, 2022). This may include a chronology of life events, welfare reports, records of contacts between professionals and family members, legal documentation, assessments, and details of decisions taken (Aberdeen City Council et al., 2024). People with lived experience of care (PWLE) have often lived through trauma closely associated with their care experiences, resulting in a lack of trust and conflict with social care professionals (Aberdeen City Council, 2025; CELCIS, 2022; Pierre, 2022). While foregrounding the views of PWLE (including YP), this project also engaged with professionals, revealing systemic tensions around information power/poverty, professionals' duty of care, and differing concepts of truth and voice. Our resulting concepts show how care records can be made more equitable and collaborative, better supporting PWLE and YP. We explore the application of the trauma-informed methodology in navigating tension between participant groups and argue that it has led to more meaningful outcomes.

2. Background: PD for trauma and conflict

Recent research has questioned the ability of participatory research to achieve equitable, democratic engagement (Cozza et al., 2020). Ceding power to people with lived experience in the structuring of a PD project creates openness and increases their influence, but limits the researcher's ability to manage potential conflict (Bratteteig & Wagner, 2012), which can be harmful during sensitive research with marginalised and vulnerable groups (Aldridge, 2014; Lindberg, 2018). Iterative prototyping provides a visual manifestation of design decisions (Bratteteig & Wagner, 2012), supporting mutual understanding and empowering participants to challenge decisions. Where there is conflict within decision making, prototyping the different options supports participants to better understand the impact of decisions (Gulliksen et al., 2003) and enables negotiation.

Trauma-informed design practice is an emerging area for research of sensitive topics which is based on the trauma-informed practice guidelines used by health and care professionals (National Trauma Transformation Programme, 2023). These guidelines have been adapted by design researchers to understand best practice for supporting participants during engagements (e.g. Fathallah, 2024). However, trauma-informed approaches can be limited in that they are focused on the interests of individuals and don't give guidance for navigating conflicting interests. They have also been criticized as lacking methodological rigor (Birnbaum, 2019). Chayn, an organisation that works with survivors of domestic abuse, has defined trauma-informed design principles as follows (Hussain, 2021):

- **Safety:** keeping participants physically and mentally safe
- **Agency:** giving participants control over decision making
- **Equity:** making sure participants can participate equitably by being inclusive and accessible
- **Privacy:** keeping participants' personal information secure, respecting boundaries

- **Accountability:** staying open and accountable in decision making
- **Plurality:** respecting the whole person and not making assumptions
- **Power sharing:** working together with people with lived experience
- **Hope:** building hope for the future

Previous research has shown that PD can even be therapeutic for participants (Hirsch, 2020). As this is an emerging field, further work is needed to understand more about how such work may benefit participants in practice (Dietkus, 2022). On the other hand, sensitive research may also re-traumatise participants by reminding them of past traumatic experiences (Ahmadpour et al., 2023). Researchers must strike a delicate balance between including discussion of lived experience while still supporting participants. MC has previously argued that designers should make space for trauma and tension in sensitive contexts rather than seeking to eliminate it, proposing a concept of *design grief* (Cummings, 2024) as an alternative to *design optimism* (Kolko, 2013). This acknowledges that a focus on positive outcomes may not consider participants' own goals and emotions surrounding their experiences (Van der Kolk, 2014).

3. Case study: care records for young people

3.1 Context

"I didn't choose to write my life, social work did, and I don't even have the information the social worker wrote." - Participant

Care records are increasingly being seen as a biography of the past (Donnelley, 2010), and can play an important role in PWLE's "self-determination and participation, identity, connection to family, community and culture, evidence, memory, transparency, and accountability" (Golding et al., 2021). However, only professionals have regular access (Aberdeen City Council, 2025). While legislation gives everyone the right to request a copy of their records via a subject access request (SAR), organisations aren't required to comply where it may cause harm (Scottish Children's Reporter Administration, 2024), meaning that access is at the professional's discretion. Records may also contain judgmental language, hurtful opinions, confusing legal terminology, inaccuracies and incomplete accounts (Aberdeen City Council et al., 2024), which can be devastating to the PWLE who reads them (CELCIS, 2022; Pierre, 2022). Scotland's Independent Care Review (ICR) identified a need for digital tools which can support children and YP to communicate and give them greater ownership, access, and control over their care records (Independent Care Review, 2020). The project described in this paper follows on from the ICR and explores how digital care records could be redesigned for the use of YP in care. The project team brought together PD researchers, interaction designers, a health and care technologist and a leader in social work innovation, alongside social work professionals from a local authority as development and implementation partners. Many of the professionals involved, including a member of the project team, are care-experienced. The discussion of the case study will focus on the development of the trauma-informed methodology through input from professionals and PWLE, and our learnings from this.

3.2 Trauma-informed, values-driven research design

The project began with the formation of an Expert Advisory Group (EAG) made up of professionals across a range of statutory and third sector organisations, some of whom were PWLE. The role of the EAG was to advise on the research design and project direction (Figure 1). At the first meeting of the EAG, we did an activity using trauma-informed principles (Hussain, 2021) to discuss what the project should achieve (Figure 2). This activity helped us identify priority areas, scope, and guiding values.



Figure 1: Overview of the research design.



Figure 2: Setting project direction based on trauma-informed values.

Alongside this, we did a series of 1-1 scoping interviews with EAG members. These early conversations were crucial for the researchers to prepare for the later participant interviews,

and to link lived experience to project goals. From the beginning, our EAG was adamant that participation should focus on PWLE. In Phase 1, we did two formal focus groups with professionals to gather their requirements, and in Phases 2-3 we also did three informal workshops with different groups of professionals. These were kept deliberately light touch to ensure that professional voices didn’t overshadow PWLE.

3.3 Recruitment of PWLE

Our EAG felt that the care-experienced community in Scotland had become fatigued from over-research during the ICR, so we did targeted engagement. Participant recruitment was done our project partner, Who Cares? Scotland. Our recruitment materials included written and video project information (Figure 3) and a consent form. The video also included a brief clip from a PWLE professional stakeholder explaining the rationale for the project.

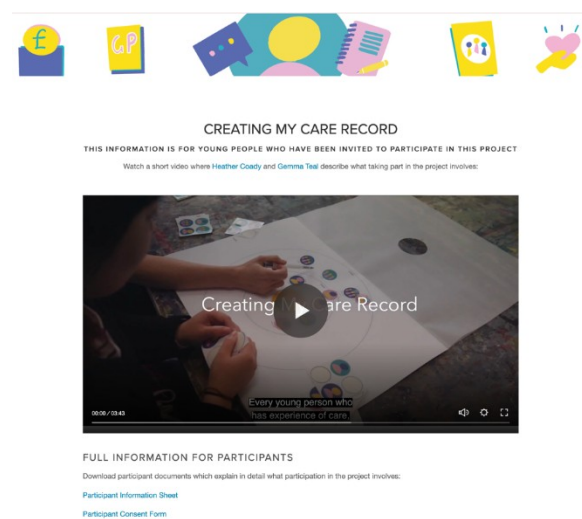


Figure 3: Recruitment website for participants, featuring a video explaining the research.

While the project focused on designing for YP, participants also included older PWLE who had already accessed their care records and therefore had a broader perspective. The youngest participants in the project were in secondary school, while the oldest participant was already a grandparent. The table below summarises the engagements and participant numbers by phase. 1-1 interview participants are the same across all phases.

Table 1: Lived experience participatory engagements with Who Cares? Scotland.

	Format	Age range	Number of participants	Duration
Phase 1	semi-structured interview (part 1)	16-25	3 (1 per interview)	1 hr
	1-1 semi-structured interview (part 2)	16-25	3 (1 per interview)	1 hr
Phase 2	1-1 semi-structured interviews	16-25	3 (1 per interview)	1 hr
	16+ group workshop	16 and up	6	1.5 hrs
	<16 group workshop	12-15	6	1.5 hrs
Phase 3	1-1 semi-structured interviews	16-25	2 (1 per interview)	1 hr
	Aged 16+ group workshop	16 and up	4	1.5 hrs

3.4 Lived experience interviews (Phase 1)

In Phase 1 we conducted two-part interviews with care-experienced YP to understand their experiences with their care records and how they wanted to use and share information about themselves. Our approach followed trauma-responsive research guidance and was reviewed by our EAG to ensure materials were as sensitive as possible. Based on the learnings from our initial scoping interviews, we determined that it was important to have someone other than the researchers in the room to stand in solidarity with them while discussing their experiences. We therefore invited them to bring any trusted person of their choice (although they weren't required to). Researchers worked in pairs to support each other, meaning that there was a maximum of 4 people present.

We designed a bespoke paper-based tool to facilitate exploration of people, information and record keeping (Figure 4), inspired by a tool developed for a previous project (Teal et al., 2017). The YP worked together with the researcher and their trusted person to complete the mapping activity. At the end of the second session, we asked participants to review the map and reflect on their contribution as a final consent checkpoint.

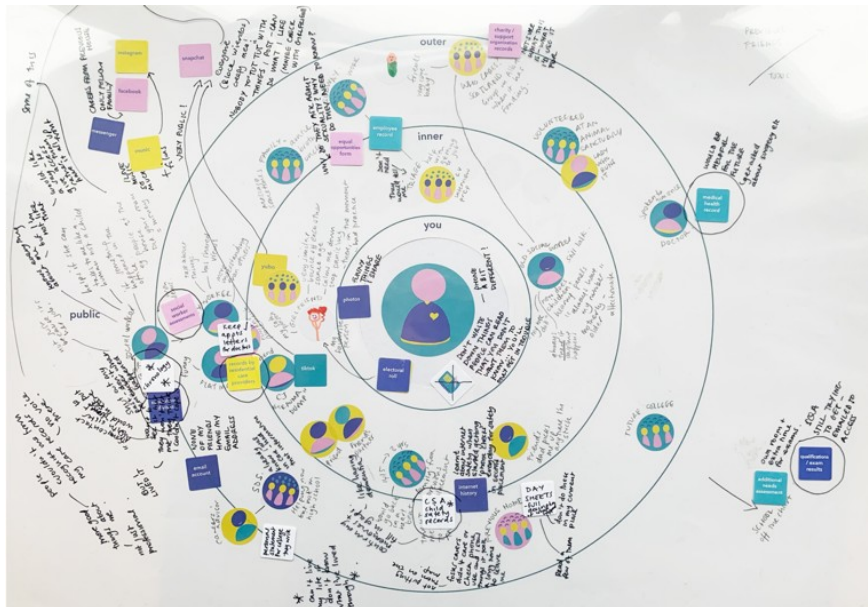


Figure 4: A completed paper/acetate interview map with layers visible.

Our information sheet included support resources (helplines and services) which might be useful for them, and this information was highlighted to them during the session. We ensured they had a printed information sheet when they left the session and highlighted the section with these resources. Participants were also offered optional aftercare, such as a phone call from the recruiter to discuss the session. Only one participant was scheduled per day. Following the session, debriefs were scheduled between the two researchers and they were also given the option to work from home. The audio recordings of the sessions were transcribed, combined with interviewer fieldnotes, and thematically analysed. Our initial analysis was presented and discussed in a meeting of the EAG to validate our interpretation and add a layer of additional insight based on their expertise in the context.

3.5 Scenario-based, iterative prototyping (Phases 2-3)

Phases 2 and 3 focused on iterative development and validation of the technical designs through group workshops and follow-up engagement with our initial interviewees. Each phase began with scenario-based prototyping based on the findings from the previous phase. Our decision to use scenario-based design (Carroll, 2000) rather than direct codesign was based on: 1) the complexity of the care records system, and 2) the lack of familiarity most PWLE have with their records. The following extract from one of the 16+ group workshops demonstrates the differing levels of knowledge and complexity of navigating one's records, and how this can be interwoven with trauma. Participant 1 hadn't seen their records, but Participant 2 had accessed their records via an SAR.

Participant 1: "...Does this [record] include pictures? ...[I]f the polis [*sic*] take pictures... Would that be in there?"

Participant 2: "It depends on what the polis took pictures of. If it was you breaking—of you being arrested or something?"

Participant 1: "No, just like—bruises and stuff like that."

Participant 2: "Right, if it's bruises like that, then that's obviously—probably going to be in the police file rather than the social work file."

Participant 1: "Aye, sorry, I just don't know what's in the care file as a whole. So, that's why I'm asking..."

Researcher: "...That's fine. So... multi-agency stuff...being able to see stuff from other agencies, like police..., that is something that has come up that people would like to be able to see."

Participant 1: "Aye, I just wasn't sure. Because there'd be...points where like something might've happened in the house at night. And then I would go to school, and then they'd be like, 'You're going to your carers after school.' ... And then they would come into school and take pictures or whatever. But it was a social worker that did it, do you know what I mean? And that's why I was asking. So, I dinnae know how that would go into something like that."

The format for all engagements was the same in each phase. Participants for the group workshops were recruited by Who Cares? Scotland from existing advocacy groups, meaning that most of the participants knew each other and felt comfortable with each other. Workshops were kept informal, with pizza and fidget toys on the table. Participants were free to move around and could leave at any time. There was an attached lounge area where they could sit if they wanted a break. Staff members who were known to the participants were on site to greet them and remained nearby to offer support if needed. In Phase 2 we tried a group workshop with YP currently in care aged 12-15 years, but this was dropped for Phase 3 as we found they had almost no awareness of their care records. This made it difficult for them to anticipate their needs and give feedback on the developed prototypes, although their participation was still valuable to raise their awareness.

In Phase 2 we used more conceptual prototypes, while in Phase 3 we worked with the City of Aberdeen to develop realistic prototypes based on their actual records systems (Figure 5).

This allowed us to explore how closely our concepts could be implemented using real-world data.

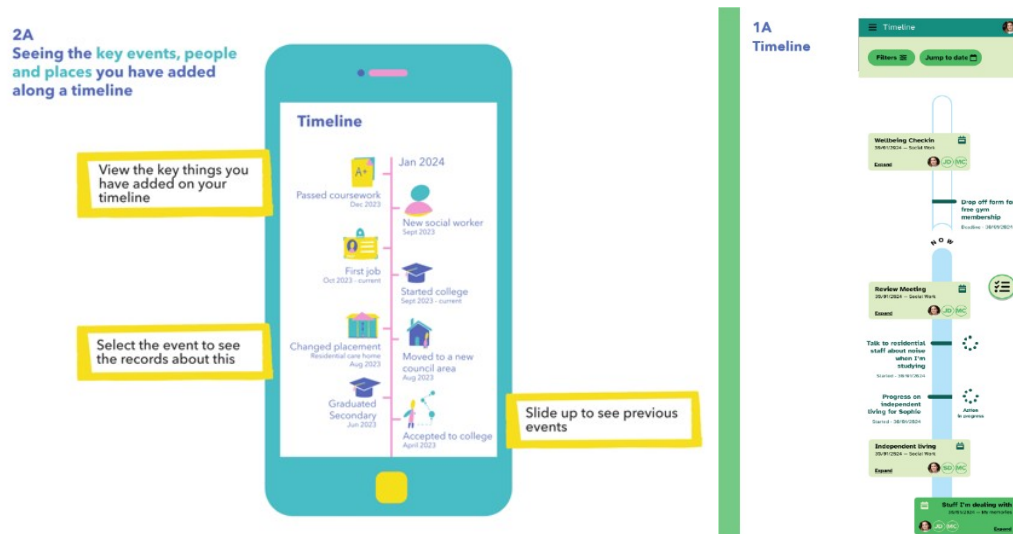


Figure 5: Iterative prototypes of the timeline from Phase 2 (left) and Phase 3 (right)

In the workshops, we presented the prototype designs on laptops and printed A4 cards, moving between formats based on what was comfortable for the participant. We wanted to convey to participants that the concepts were just a starting point to allow exploration and trigger their imagination, by ensuring they didn't feel too realistic (Bratteteig & Wagner, 2012). Each concept was presented in multiple ways to demonstrate flexibility in implementation, and we recorded the participants' ideas directly onto the printed cards.

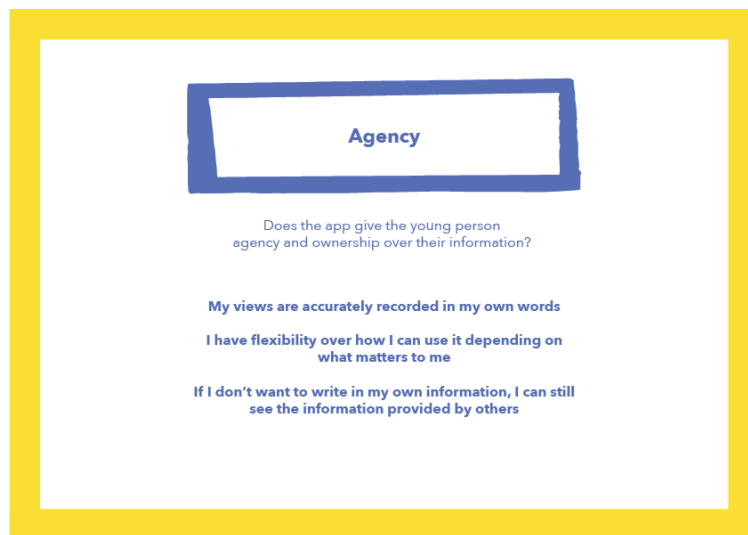


Figure 6: Trauma-informed, rights-based value for a digital care record for young people.

In Phase 3, we also did a validation exercise where participants were shown the trauma-informed, rights-based values we had identified with expert stakeholders at the start of the project (Figure 6). Participants were asked to give feedback on whether they thought we had achieved these. The transcribed recordings from all engagements were again analysed using thematic analysis. Finally, a full analysis was done of the combined transcripts across all

phases using thematic coding. The themes were discussed and refined between the researchers.

3.6 Tension and conflict

The project identified ethical conflicts related to information power/poverty caused by the differing levels of access to care information. Although care records are theoretically owned by the individual, they will normally not be able to gain access to their records until adulthood. Conversely, professionals get access to a YP's record as soon as they have been included in their care and will usually review them immediately to ensure they are aware of any support needs. PWLE felt that the information in their care records belonged to them and shouldn't be looked at without their permission:

"...[S]ee when I went into care...my foster carer, she told me...they said to her, 'read through all her reports', why? ...It felt like a pure invasion of privacy...it's just a bit unfair, you hardly know me, yet you are getting to find out every little thing about my life."

Some participants told us that they felt professionals held this knowledge over them as a form of control:

"...[T]hey have told me that they have everything since I was put on a compulsory supervision order when I was two. So, my whole life will be on there... [Residential Unit Manager] was like, 'Yeah, I know you', and I was like, 'No, the fuck you don't', 'Yes, I have everything on you', like in a creepy way..."

On the other hand, PWLE told us that it could also be uncomfortable when professionals tried to be considerate by not looking at their records, because this might result in them having to recount a traumatic event.

There was also a lack of agreement over how much information YP should be able to view if they did have access. Many people enter care from a young age: wanting to understand what had happened to them and why was by far the most common goal. In our analysis, we identified 75 separate quotes relating to this theme. However, viewing this information can also be re-traumatising:

"I requested some information...I was just looking for one particular thing, and I had to go through everything to find that one and then I read things that I really didn't want to read, and didn't know, and shouldn't have read."

As a result, professionals may sometimes discourage YP from accessing their records if they feel that they aren't ready or lack appropriate support, which was frustrating to PWLE. At the same time, older PWLE (ages 25+) who had seen their records also discussed the need for a duty of care because they were aware of the risks:

"...And obviously as the child grows, they should get full access. ... [T]hey shouldn't get to see as children because they should be kept as innocent as possible. ...There's going to be stuff about the instance when they got taken into care, what happened that night, why they got into care. There's going to be...violence..."

However, not all PWLE viewed the past negatively. Some participants said that reflecting on past events built hope for the future by showing them and others what they had overcome. In this sense, trauma could be a source of both pain and personal strength.

4. Discussion

4.1 Reflections on the trauma-informed approach

To aid other researchers, we would like to share aspects of the methodology which worked well and could be adopted elsewhere:

- **Stakeholders with lived experience:** The involvement of professional stakeholders who were care-experienced showed how important it is to include PWLE in early research design (Boilevin et al., 2019). This insight wasn't restricted to direct feedback. For example, during the scoping interviews, a professional stakeholder was recounting an emotional experience. At that point, another care-experienced stakeholder stepped into the conversation to show solidarity. This led to the idea of having a trusted person at the interviews. In a sense, the EAG involvement also became another form of PD in co-designing the research approach.
- **Values at the core:** Using trauma-informed values helped to set shared goals and language for the project team and provided greater clarity during the validation stage. By revisiting these in the final phase of the project, we were able to identify gaps in the research by seeing where needs weren't being met. In future, we would like to do values-based evaluation at more stages during the project.
- **Trusted person at 1-1 interviews:** The presence of the trusted person enriched the findings by revealing different aspects of the participants' lives and allowed researchers to witness how they liked to be supported. Over time, all participants independently chose to stop bringing their trusted person, demonstrating a sense of trust and familiarity with the researchers.
- **Visual mapping tools:** The interview mapping tool in Phase 1 allowed us to draw on lived experience without requiring participants to describe traumatic past experiences. This also worked well to mediate the conversation between the participant and the researcher as focus could be directed on the tool rather than the individual, like the proxies used by Amadpour et al. (2023). We would argue that our interview maps were the first care record prototype made collaboratively with the YP, exploring: what they would like to see, how they would like to share and secure their information, and generating scenarios of use without requiring detailed knowledge of the records system. In addition, the visual data stories ensured the participants' voices remained in the visuals when shown to other

stakeholders (Barley & Russell, 2019) rather than being filtered through the PD researchers.

- **Fidget toys during engagement:** The use of fidget toys was suggested by one of the participants from Phase 1, and every one of our sessions from Phase 2 onwards had snacks and fidget toys on the table. These proved useful in many ways: we used them as an icebreaker, a distraction to move focus away from participants when they were feeling stressed, and as gifts that participants could take with them after the session. Although a minor change, they had a positive impact on the social dynamic and were commented on positively by all the participants.

4.2 Approach to positivity

Previous work has discussed how the use of negative emotions can be used to enrich design outputs (Fokkinga & Desmet, 2013). The methodology adopted an open-ended stance to allow both positive and negative emotions to emerge, without focusing on trying to “fix” problems: what MC has previously described as *design grief* (Cummings, 2024). In creating the digital prototypes, we tried to stay true to participants’ experiences and interpretations of events. For example, participants commonly talked about conflict with professionals, so the prototypes included features and content which illustrated this tension. This could be quite provocative when shown to professional stakeholders, and including this content resulted in some interesting discussions which greatly enriched the findings (discussed further in the following section).

We were surprised to discover that some of the participants viewed their past experiences in a positive way, for example as a source of strength. This demonstrates the importance of allowing for differing viewpoints, even within the same cohort (Munson, 2022). *Design grief* paired well with asset-based approaches (Broadley, 2020) in supporting discussion of *future hope* (Hussain, 2021), and their ideas for how new forms of care records could support them and build more equitable relationships with professionals. A positive emphasis could also help build rapport: in our initial mapping interviews, researchers felt that the second part of the interviews were easier to facilitate because the interview design had built up capacity to support the YP to share their ideas about new forms of care records, which was empowering and ended the engagement on a positive note.

4.3 Surfacing tensions

When we started the project, there was an assumption that everyone would agree with the project goals of giving YP access to and control over their own records. On paper, this seemed to align well with the recommendations made by the ICR and the strategic work being done across Scotland to achieve this (Independent Care Review, 2020). The project team was surprised to discover that some professionals were strongly opposed to the ideas we proposed. Giving YP open access to their record was seen as particularly dangerous due to professionals’ duty of care. The people who were most opposed were those who had supported PWLE through the SAR process (Scottish Children’s Reporter Administration, 2024), because they knew how delicate and complex this process could be. Older PWLE who had accessed their care records were also more cautious for this reason. One professional

gave an example of a YP who had been sexually abused when they were very young but had no memory of it. Although it was in their record, the YP hadn't been told about it. In this kind of situation, it is unclear ethically whether giving someone knowledge of these events would be beneficial or not.

Professionals who worked with the technical systems were also unwilling to give open access to some information (e.g. gender or date of birth). From a systems perspective, professionals need to ensure the information is accurate as it could be used for all kinds of official purposes, such as eligibility criteria. Some of our wider stakeholders who had been initially supportive became more wary as the project progressed and the implications of giving YP this level of access became clear. This shows a tension between the goals of person-centred care and system needs.

Ultimately, we viewed this as a positive outcome from the project, since it unearthed some of the real-world conflicts which would need to be resolved for this type of system to be implemented. However, it also showed some of the limitations of the approach. A trauma-informed methodology is designed for protecting the needs of an individual or small group: it is less clear how to apply it when you have multiple groups (or participants within the same group) whose needs and perspectives are in conflict. Further work could be done to explore how this should be addressed within trauma-informed design research, for example using conflict resolution frameworks.

5. Conclusions and future work

Through the case study, we have discussed how we navigated ethically complex research through the application of trauma-informed values and principles. This also surfaced some tensions, which ultimately led to more meaningful design outcomes. We argue that these approaches can support PD researchers to ensure that people who have traumatic lived experiences associated with statutory services can safely and meaningfully participate in their redesign. It also underlines the importance of adopting an open-ended approach to design research of sensitive topics.

Future work within this context will explore how we can resolve some of these tensions to safely deliver tools which meet the ambitions of the YP and keep the original aims of the project at the fore. In the next stage, we plan to undertake a real-world trial of the prototyped system to further validate it and understand how it needs to be adapted to meet statutory requirements.

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