
CONFERENCE ABSTRACT

Creating My Care Record: A participatory approach to digital care records for children and young people in Scotland

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Scotland's Independent Care Review (ICR) identified a need for innovative digital tools which can support how care experienced children and young people communicate, and give them greater ownership and control over their care records (1). Currently, care records may not always take a person-centred approach and viewing this can be traumatising to the individual (2) and does not capture a full and accurate account of their lives. Funded by the STV Children's Appeal and the Corra Foundation, Scotland's Digital Health & Care Innovation Centre (DHI) has partnered with statutory organisation Who Cares? Scotland (WC?S) and the Aberdeen City Council (ACC) to co-create new ideas for care records for young people.

Given the previous extensive consultation undertaken by the ICR with 5,500 care experienced individuals and those that support them, the project team decided to take a targeted approach to participation, overseen by an advisory group of expert professional stakeholders. Our research is design-led and trauma-informed, working with our advisory group to make sure that care-experienced participants are included in ways which are both supportive and empowering. We began with scoping interviews professionals to understand the context from their perspective. Next, we worked in partnership with WC?S to carry out three in-depth two-part interviews with care-experienced young people to map out the people, organisations and information that are important to them, and understand their experiences and views about information sharing and care records. At the same time, we carried out two focus groups with multidisciplinary professionals to learn more about how they use care records to support young people.

Using thematic analysis, we identified three overarching ways care records can support young people: reviewing information on their past, planning for the future, and sharing information with professionals about themselves. From this, we developed concepts for a timeline with varying levels of granularity, self-curated "story arcs", shared action lists, and an "About Me" profile. Working with ACC, we learned about the current infrastructure for recordkeeping and developed a technical model illustrating how a view focused on young people could be delivered in future.

We then validated low-fidelity prototypes of our ideas through follow-up interviews with our previous participants, and in two focus groups with care-experienced people 16 years and up. Their feedback showed that this type of model could be used to better support young people in care in the future. Next, we will continue working with ACC to develop a minimum viable product version of the service.

The findings and prototypes offer insights for the integrated care community about how care records can better meet the needs of care-experienced people by focusing on personal reflection without re-traumatisation, and promoting future achievement through respectful cooperation with professionals. Our innovative approach also offers insights into how to creatively engage young people in co-creating trauma-informed digital tools to integrate care.

(1)Independent Care Review. The Promise.; 2020. doi:10.1037/034322

(2)Who Cares? Scotland. Our Lives, Our Stories, Our Records: A Records Access Campaign.; 2019.