Recordkeeping and Relationships: Designing for Lifelong Information Rights

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ABSTRACT

We describe an approach for designing information infrastructure that addresses lifelong recordkeeping needs for those caught up in the child protection sector. The challenge is to enable people to exert their rights over information as it manifests and changes through time over generational timescales. We conducted a series of participatory design and prototyping workshops over an 18-month period, with a core group of eight academic and community researchers. Using Recordkeeping Informatics to inform critical, rightsbased, and trauma-sensitive systems design, we prototyped a distributed and participatory recordkeeping system that allows those with childhood protection experience to participate in their records. In this paper, we describe approaches we adapted for long-term participatory design in sensitive domains, and discuss the design artefacts we developed to capture the complexity of through-time information system design. We propose a set of design guidelines and discuss their implications for design work and systems.

Author Keywords

Recordkeeping Informatics; Recordkeeping Rights; Lifelong; Participatory Design; Trauma-informed

CSS Concepts

User-centered design, participatory design

INTRODUCTION

When designing information systems and user experiences, it is easy to forget that virtually every information system is also a recordkeeping system for someone, in some context, at some time [74] (p. 8). By recordkeeping system, we mean one that holds authoritative information that may provide memory, identity, evidentiality, and accountability beyond any immediate transactional context [47]. Information systems that lack such recordkeeping affordances often fail to uphold the rights in, and to, records and recordkeeping that underpin a raft of basic human rights [73]. As a consequence, such systems often disproportionately disenfranchise the

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most marginalized in society [65]. This disenfranchisement is exacerbated if the recordkeeping context involves traumatic experiences; as the making, keeping, and control of these most personal and private records are entwined with issues of power, trust, autonomy, surveillance, and accountability [42]. The challenge, then, is to understand how to design systems that enable people to exert their recordkeeping rights as they manifest and change through time.

One such context is the internationally problematic [31] child welfare and protection sector, which, in Australia, has been described as "poorly coordinated, inadequately resourced and often unable to protect children from significant physical, emotional or sexual abuse" [6] (p. 21). Of particular concern is ensuring that systems that remove children from their families into alternate care arrangements do not themselves cause harm. While workers and carers usually strive to provide the best care and support possible in difficult circumstances, institutional recordkeeping practices and systems can undermine these efforts. Inadequate recordkeeping can contribute to neglect and abuse with impacts often extending far beyond the immediate transactional context of childhood experiences [78]. System design in this context, needs to embody good recordkeeping informatics principles [74], to explicitly address the diachronic or through-time nature of such trauma and how it manifests in contingent and ever-changing ways in relation to the needs and rights of all participants in recordkeeping processes.

As part of a larger investigation into the lifelong identity, memory and accountability needs for those caught up in the Australian child welfare and protection sector, we have explored the design of a distributed and participatory Care recordkeeping system. This work progressed through a series of co-design workshops held over an 18-month period with young people with childhood Out-of-home Care experiences. Key design goals were enabling participation and supporting rights to identity, memory, accountability and privacy in the ongoing management, access, and use of Care records.

Importantly, the temporal dimension emerged as a critical factor in the design process as well as in the design outputs, and raises a number of design-related research questions. How do we account for potential trauma, diminished trust, and the upholding of the rights of the marginalized when

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designing information systems? What happens to design – both in its verb- and noun-senses of process, artefacts, outcomes, and instantiations – if one anticipates constant change in needs and impact over lifelong, and even multigenerational, timescales?

In moving from concept to generic design [77] and addressing these questions, this work makes several contributions: (i) we demonstrate the value of Recordkeeping Informatics to human-centered design, situating such work within critical, rights-based, and traumasensitive contexts; (ii) we present novel design artefacts that capture the complexity of diachronic information system design: and, (iii) we propose a set of generalized design guidelines along with some of their architectural and technical implications. While we do not claim a method contribution, present a detailed technical design, or report the evaluation of an instantiation, we do describe the design process and a number of generic design findings that arise directly from the diachronic and critical perspectives of this work.

BACKGROUND

Recordkeeping in the Care Sector

Out-of-home Care (capitalized to denote the ironic connotations of often uncaring treatment without typographically-heavy quotation marks – see [78]) is the contemporary term used in Australia to describe the living arrangements for children and young people unable to live in their parental home for a variety of reasons relating to child wellbeing or safety. Our concern is with the role and impact of childhood recordkeeping within the Care system.

We have long known that our life chances are underpinned by a strong sense of identity, social, emotional and physical wellbeing, and connectedness with the world from the earliest years [20]. There is also increasing awareness of the role that records and archives plays in developing and supporting this sense of self throughout our lives [14]. This extends beyond utilitarian or civic recordkeeping [9] to encompass intergenerational storytelling and sense making within the family context [40,76].

Consequently, in Australia, national standards for Care identify the rights of children and young people to have access to a complete and accurate history of their time in Care; the plans for their future; their health, education and other important official records; their family and community connections; memories of key events; and other records [20]. They also emphasize the need for children and young people to participate in the decision-making (and therefore recordkeeping) that impacts on their lives.

Even so, there is continuing evidence of a substantial lack of participation in Care planning processes and access to information [46]. As Care sector information systems move into the digital realm there is a real danger of encoding, and amplifying existing exclusions, biases and discrimination, without attending to the recordkeeping and information rights explicitly and implicitly articulated in child and other human rights instruments and policy [34]. This is despite recognition that active participation and proactive provision of rights are a protective factor for vulnerable people.

Access and Utility

While the family context ordinarily provides support for childhood recordkeeping [9] as well as literacies around the various uses of records, such support is usually not provided within the Care system. A lack of records, and of recordkeeping literacies, means that even proving one's identity may be problematic for some Care-leavers [52].

Designing for these needs is exacerbated by the complexity of the Care sector information systems landscape. There is a plethora of information silos and consortia that include government child protection departments; non-profit and commercial service organizations; individual carers; families and friends; the courts and justice systems; the police; the health system; government assistance programs; government civic functions (welfare, housing, registrars, transport etc.); educational institutions; service professionals; and emergent Care-sector information services [65]. Some record-holding consortia have developed private APIs for data exchange, while some others are pursuing aggregation strategies. There are myriad protocols for information access. This heterogeneity means that a central recordkeeping repository cannot satisfy all or most needs of the Care experienced any design solution must take the form of a distributed and interoperable network.

Apart from technical and jurisdictional challenges, these information silos have been designed for organizational use of Care-related transactional records. Consequently, recordkeeping access is fragmented and problematic for participant access [56]. When those separated from family have turned to records to make sense of those experiences, they have too-often found them "incomplete, insulting, incorrect, and incomprehensible" [54].

Many years of advocacy by the Care-leaver community (i.e. those no-longer in Care), have brought about a succession of government inquiries in Australia and other parts of the world [70]. Such inquiries have repeatedly demonstrated that past and present recordkeeping practice and infrastructure puts the rights of organizations, institutions and governments ahead of those of children and their adult selves. Recordkeeping for those who experience Care continues to be based on the administrative and reporting needs of organizations and government agencies rather than those of the child and their adult selves, despite policy rhetoric around child and person centered approaches [78].

Related work

Recordkeeping research relating to Care, trauma, or surveillance contexts has typically been observational, aimed at describing issues and linking them to recordkeeping theory. Research on community archiving as a mechanism whereby communities may gain control over records [28], has not generally approached issues of rights or trauma relating to institutional records. While there have been several studies of post-conflict or surveillance states that describe institutional arrangements that have been put in place to control access to sensitive records, rights to participate in ongoing recordkeeping processes have not been explored [5,32].

Research on archival imaginaries has explored the affect of gaps in the record relating to traumatic events [33], and some projects have also tackled archives in the Care sector directly. A study of the Scottish Care-leaver experience, in acknowledging the traumatic context of such inquiry, elected to not deal directly with Care-leavers but, instead, interviewed advocates and intermediaries [44]. The Memory-Identity-Rights in Records-Access (MIRRA) project is documenting the experience of Care recordkeeping in England [37].

Very little work has approached recordkeeping problems from a design perspective for transformational change [30]. As mentioned above, several recent human-centered design studies have investigated the value and sensitivity of intergenerational family stories [40,76]. There have also been inquiries into civic records in family contexts (albeit not from a recordkeeping perspective) [11], privacy in shared device contexts [1], and precarity of access [15]. The Trust and Technology project, exploring technologies for giving agency to Indigenous peoples over their state-held records, was conceived as a layer to existing archival systems [66]. That project, though limited by technological constraints, did highlight the complexities of working with communities and individuals in sensitive contexts.

In the Australian Care sector, the Who Am I project [71] lead to the development of the *Find and Connect Web Resource* [27] – a contextual network of information about institutions and their record-holdings. While pioneering in its exploration of trauma-sensitive recordkeeping, the *Find and Connect Web Resource* remains an index into existing recordkeeping systems and not a transformational design. Technical foundations for participatory recordkeeping design may be found in the investigation of dynamic descriptive recordkeeping metadata for interoperability [62], and functional modelling for participatory recordkeeping systems [63].

Value-sensitive design for information systems is now a well-established paradigm [29]. However, the acknowledgement of sensitivities to individual affect and potential trauma when conducting system design in contexts relating to childhood and family is only recently gaining attention in terms of power differentials and agency [51], empathy [81], and the need for long-term relationship building [82]. In particular, a rights-based perspective is often missing from these discourses.

CONTEXT

This research is part of a larger transdisciplinary program investigating the development of a national framework for recordkeeping in out-of-home Care. This work involves collaboration between academics in the information technology, history, social work, and education disciplines, as well as Care-leaver advocacy communities and Caresector system designers.

Central to the program is the design of participatory infrastructure that facilitates lifelong utility of records concerning childhood out of home Care. We envision this infrastructure as a safe and secure distributed recordkeeping network, populated by children and young people, and by their caregivers, social workers, teachers, health professionals, communities, families, and so on. The goal of the research reported here is this design – in both the verb and noun senses: what architecture and affordances should the design embody, and how should such a design be pursued?

For this study, we have focused on the needs of young people, collaborating with a small group of five young Careleavers with a variety of Care experience: including foster, kinship, residential, and institutional placement (and often a mixture of these). Some had spent entire childhoods in Care, others less time. Some had had stable placements, while others had been moved around, resulting in more fragmented experiences. All of our co-researchers were advocates for children in Care and Care-leavers, having previously received training from a national Care sector youth advocacy body.

Together, we employed participatory research and design approaches to model the lifelong and participatory recordkeeping needs of children who experience out-ofhome Care. We aimed to move beyond incremental improvements to existing systems [17], and ask how we might design a rights-based recordkeeping infrastructure to facilitate real agency. Holding vital evidence of childhood events, experiences and decisions made by child protection authorities, such infrastructure should play a key role in nurturing identity, development and connectedness to family (however defined and configured), community and culture.

THEORETICAL FRAMING

Recordkeeping Informatics

The (single word) term *recordkeeping* is used to mean all of the activity of conceiving, creating, managing, and deriving utility from authoritative information or records in a continuum of use. *Recordkeeping Informatics*, therefore, is an information science that comprises the social practices of recordkeeping as well as the material manifestation of information systems infrastructure [63]. It includes consideration of data, metadata, and process modelling; standards and practice creation; and recordkeeping systems design, development, deployment, and integration. It is underpinned by Records Continuum theory [48] that, in turn, is closely tied to critical and postmodern conceptualizations of society and its recordkeeping [18].

The records continuum makes no distinction between 'active', transactional data and those ostensibly 'inactive' records, traditionally kept for a variety of historical purposes [48]. In particular, records continuum theory recognizes multiple participants, rights, and roles in records and recordkeeping; and the ever-expanding web of record-related stakeholder relationships that is 'always becoming'. The 'record-ness' of information is articulated in ever expanding *metadata* – cascading inscriptions that describe the history, context, and future of recorded information as it manifests through time. This diachronic conceptualization – similar to the dynamic complexity of access theory [61] – contrasts the fixed, end-product view of records that pervades most record-holding organizations and systems.

The most recognizable expression of the records continuum is the Records Continuum Model, shown in Figure 1. It contains four recordkeeping loci of analysis, or dimensions (*Create, Capture, Organize*, and *Pluralize*), which arise from consideration of distanciation from the circumstances of record creation; and four axes of recordkeeping concerns (*Identity, Evidentiality, Transactionality*, and *Recordkeeping Containers*). More recent models, such as the Participatory Recordkeeping Continuum Model [63], provide the basis for analyzing participatory agency in records and recordkeeping.

A continuum view of agency leads to conceptualizations of rights in records and recordkeeping – rights of participation; of access; of privacy, of disclosure, and so on. Not only are such rights embedded in jurisdictional legal instruments and processes [39], but they are enshrined at the highest levels of humanitarian declarations [35]. Nonetheless, contemporary recordkeeping (or, indeed, information) systems are not designed with such rights in mind. In order to better serve all participants in records, we need to remain mindful that information systems embody ethics and values [55]. As designers, we need to check our assumptions about the nature, purposes, manifestation, and ethical impact of the systems we design in the broader sociotechnical context.

Critical Approaches

Information infrastructure is value-laden, and inherently political. For example the definition or even the inclusion (or not) of a data element is a statement of allowable actions or viewpoints within a sociomaterial context [10]. Moreover, in many such systems we recognize vestiges of colonial structures that, even today, serve to restrain, pathologize, or even criminalize those deemed to be at the margins of society [65]. This is especially so in the child protection sector which intersects and overlaps with justice systems, leading to poorer outcomes for those with Care experience [79].

We must therefore examine our information systems infrastructure and the role that "recordkeeping plays in the exercise and abuse of power in society" [24].



Figure 1. The Records Continuum Model

In particular, we must question the assumptions and norms of conventional information system design even, or especially, when such design is termed client- or usercentered. Such designations often simply reinforce control of information by an institution, with all other participants deemed as 'clients' that are granted (or not) access to information [26].

Exactly the same issues of power and agency often arise during the design process itself and especially in research practice. For example, the language of designing is often defined in terms of professional activity, in which the 'real' knowledge gained from domain experts is often attributed to intermediary researchers (for example, see [83]). Such extractive information gathering often disenfranchises and further disempowers those who disclose their living experience (even where consent is explicitly sought as an upfront transaction) [25,68,79]. We prefer to think in terms of peer relationships with domain experts [22] and strive to critically examine our research practice to ensure we avoid slipping into a more extractive paradigm.

Trauma Sensitivity

In the child protection sector, deleterious effects of instability and disruption arising from family separation are common, as "the loss of identity and connection with family is one of the most traumatic and distressing outcomes from a life lived in institutional care" [3] (p. 253). Such trauma is due, in part, to institutional practices based on a deficit and needy child; high turnover of staff and often constant churn in placement arrangements; the sector's alignment and overlap with the adversarial justice system; and a risk-averse, transactional approach to childhood Care [46,53,65,80]. As a result, those with Care experience often "mis-trust authority figures, have low literacy levels, lack confidence and self-esteem, and will experience great apprehension when approaching a service provider" [56].

Moreover, recordkeeping systems and practices remain a symbol of institutional power [9]. The reproduction of

surveillance and institutional control over personal and private information [78] continues as Care-leavers approach institutions for their records. For example, Swain writes of the "emotions and unmet expectations involved in records access" [71] (p. 7) and quotes Dominick Capra who argues "In traumatic memory the past is not simply history as over and done with. It lives on experientially and haunts and possesses the self or the community."

Thus the very existence of records, as well as the processes and systems for their access, may be reminders of a time spent under institutional control, while the content of such records may trigger long repressed memories. "Page after page ... that [file] there reminded me that I was once upon a time society's reject ... it reminded me of all the loneliness, of all the horror and shame that I carried with me my whole life." [56] (p. 30).

TRANSFORMATIVE DESIGN

Design Workshops

We adopted a participatory research approach, featuring the use of co-design methods to bring together lived and professional expertises. 'Participation' is an overloaded term [2]. In the design context, it can often be taken to mean consultation with users in requirements gathering, or usability testing activities; with 'participatory design' a synonym for user-centered or user-experience design [72]. We take a more inclusive view, striving to build relationships of trust and mutuality as we explore the design space of recordkeeping rights and needs. For example, we avoid the language of 'user' with its tendency to cast people as passive and powerless in system design and implementation processes. Moreover, we distinguish between co-design as short encounters for requirements elicitation or usability testing, and this deeper activity, diachronic in both process and output.

The project underwent university ethics approval, with granular consent sought at every workshop – and continually reviewed. The ethics instruments (invitations, explanatory statement, consent forms etc.) were designed with Careleaver input. While we produced some joint publications, participants were given the opportunity to review academic outputs. The research data comprised workshop worksheets, researcher notes, audio recordings, versions of design outputs, feedback on prototype iterations, sprint tracking records, and source control logs.

We conducted two sets of workshops over an eighteenmonth period in 2018/19. In the first set of eight workshops, the two academic and five Care-leaver participants focused on developing common mental models of Care records, recordkeeping, and systems design. By sharing records and recordkeeping experiences, we established that the work was valuable for all participants and that we could create a welcoming, safe and trusted working environment [64]. An initial focus of these workshops was the development, and refinement of a trajectory of childhood Care experience (described below) that articulated Care relationships, activities, processes, transition points, and other events. Insight from our community participants at this stage was invaluable as they were able to give a 'street-level' perspective [43] on Care practice and systems that contrasted with institutional policy and workflow documentation.

In subsequent workshops, we then 'deep dived' into elements of the trajectory as prioritized by our community co-researchers. We mapped individual, activities, situations, transitions, events, and relationships from the trajectory to the associated recordkeeping and records, with attention to ongoing recordkeeping needs through time. This analysis was informed by department and other administrative documentation, as well as a wide range of grey literature such as reviews and reports. While we understood the transactional importance of the records from an administrative perspective, it was the 'street level' perspective of our young co-designers that provided insight into the meaning and affect of the records and recordkeeping as it occurs 'in the moment' and subsequently through their lives. They were able to draw upon real examples and suggested mechanisms for participatory recordkeeping that could lessen rather than add to bureaucratic burdens, as well as ameliorate the tendency in child protection systems to pathologize normal childhood behavior.

This mutual learning enabled us all to gain a deeper understanding of Care records, the impacts of a lack of voice and agency in records and recordkeeping, and possibilities for system transformation. At the same time, our community co-researchers gained insight into the fundamentals of recordkeeping and digital information system design. For example, while they were familiar with some existing government services, it was important that they understood the actual architectures of existing systems and their implications for privacy, control, and data sharing.

The second phase of the project comprised an agile effort to develop an infrastructure prototype. While two academic researchers performed all programming and implementation activities, all eight participants collectively determined features and affordances based on the trajectory analysis. We used the twelve workshops for sprint walkthroughs and feature/bug backlog management. Although we spent much time discussing affordances for rights-based, participatory recordkeeping, our main concern was not on the user interface but on the underpinning infrastructure. In contrast to a focus on interface concerns, we discussed 'under the hood' design and architectural decisions that would allow for participation in the creation of Care records, their management through time, and the specification of recordkeeping and other controls.

Participatory design approach and tools

Configuring the workshops

We were very sensitive to the symbolic power of the research context and the potentially alienating research experiences that our participants may have previously experienced. To that end, we wanted to create a safe and welcoming space for our workshops where all members of the research team were able to share personal and family stories, memories, records, and recordkeeping experiences.

Viewing consent as a process, rather than a one-time transaction, we constantly revisited our jointly established protocols as our working relationship deepened. We also tried to remunerate community research participants in recognition of their contribution and expertise – either through casual employment as research assistants (n=1), or honorarium payments (n=4).

Recordkeeping 'hats'

We employed an approach similar to DeBono's 'Six thinking hats' technique [19] for ensuring we continually considered various recordkeeping perspectives. However, rather than general attitudinal postures, our seven 'hats' (actually cards that were held up) represented concerns informed by recordkeeping informatics and the records continuum in particular: *Evidence*, *Identity*, *Memory*, *Accountability*, *Stakeholders*, *Story*, and *Time*. It was the responsibility of the person with each 'hat' to ensure that the particular recordkeeping concern was being considered during discussion. The roles were regularly redistributed to ensure that no single person was unduly saddled with a particular perspective. In this way, we strived to ensure that, in the excitement of design, no particular concern was privileged over others, and that no concern fell through the cracks.

Use of Language

Bringing together researchers from different disciplines or with varied life experiences inevitably introduces problems of language, communication, and sensemaking. While some projects elect to identify problem jargon and establish acceptable translations [12], we instead elected to 'lean in' and explain our varied vocabularies. Reflection on our use of language enabled us to move beyond clashes of technical nomenclature in order to develop shared mental models of Care and recordkeeping.

To this end, we instituted a protocol whereby anyone could interrupt a discussion by holding up a red card (a la the sports metaphor) and ask for explanation of a particular term or phrase. Following the explanation and agreement on meaning, the term was written up on a display for that purpose. We maintained a tally of individuals' 'red-card' counts. This had the effect of improving reflection on the use of language and even individuals 'red-carding' themselves when introducing new terminology.

PARTICIPATORY DESIGN OUTCOMES

As a diachronic and infrastructural design exercise, our challenge was to find ways of articulating the complexity of recordkeeping in the Care sector. We developed several design outputs for this purpose.



Figure 2. Segment of Trajectory document

Design artefacts

Conventional design artefacts such as user stories or UML models appeared too synchronic (moment in time) and transactional to capture the through-time nature of the recordkeeping problem. Instead, we adapted some of these and developed others as design artefacts that proved to be useful for this diachronic mapping and sensemaking. These outputs include a Care recordkeeping trajectory and maps, and our use of deep archetypes or personas.

Trajectory

One of the earliest artefacts developed was what we referred to as the *Trajectory*. This document, a segment of which is shown in Figure 2, was derived from various child protection manuals and court processes, and supplemented by participants with direct experience in child protection as children and/or parents.

It comprised a visual representation of interpersonal relationships and living contexts, together with the possible events and transitions that could take place within a Care experience - from first involvement with child protection services, through placement in out-of-home Care, to leaving Care (and, perhaps, re-entering, as is often the case). For each of these, we identified the creation, capture, organization and pluralization of records and candidate stakeholders in these activities. This articulation of the Care sector recordkeeping landscape was more comprehensive than any government or NGO organizational perspective and included informal and other records that did not appear on any formal process documentation. The Trajectory was displayed at subsequent workshops and amended as required. Trajectory elements were used to frame the 'deep-dive' workshop activities from that point on and formed the basis of other outputs.

Developmental Map

The Trajectory provided a transactional view of records creation, but did not explain how the records could be used through time. The next workshop step was the mapping of each record type against its stakeholders and various age groups to analyze how records and recordkeeping could manifest at each of these life stages. For this purpose, we used the stages *Infant* (0-3), *Young child* (3-6), *Child* (7-11), *Adolescent/Teen* (12-17), *Young Adult* (18-20), and *Adult* (21+). However, life is more complex than can be specified through simple age ranges and there are other contextual dimensions to the sensemaking of records. More research is needed to define developmental stages in relation to recordkeeping and other literacies, for such analysis. Nevertheless, this mapping suggested, at a basic level, how recordkeeping could manifest diachronically.

Deep Personas

The last artefact of interest is the way we developed and used Personas or Archetypes. Personas are a well-known design tool, employed to define system users, their characteristics, and goals. However, while useful, they may lead to design pitfalls due to oversimplification and stereotyping [45].

Moreover, personas are typically created and used in a transactional manner – i.e. created with just enough background to contextualize their needs at the point of action with the system. This was certainly the case in the publically available personas previously created in Child protection contexts (for example, [4,16]). In our case, we wanted to avoid these pitfalls, while expanding from backstory to a more comprehensive life story that we could contextualize against the trajectory and developmental map. Additionally, research ethics constraints prevented us from using real childhood stories or set of records as test data. We therefore needed to reconstruct meaningful childhood personas from an amalgam of factors that change through time as well as to reconstruct a set of Care-related (and court, education, heath, personal, and so on) records to use as prototype data.

To start with, we analyzed the Trajectory and Developmental Map to derive a set of 'dimensions' that could be used to describe/explain a Care experience as well as inform recordkeeping needs or behaviors. These dimensions were *Physical Environment; Relationships; Role Models; Literacies; Exposure to Trauma; Health & wellbeing; Carerelated legal matters; Justice-related legal matters; Educational Opportunities & Engagement; and Access to Technology.* A specific workshop was held to identify the extremes of experience in each dimension as well as any significant points within. An example dimension worksheet is shown in Figure 3.

We then created personas with childhoods based in terms of these dimensions. We completed a detailed historical timeline –from the first interaction with Child protection Services, through to finally leaving Care – with vignettes, events, and intervention points that were consistent with these dimensions; such as the reasons for Care in the first place; placement moves; incidents; achievements and setbacks; relationship establishment and breakdown; interests; and so on. The result was not only a rich basis for creating sets of records, but also a mechanism to understand the use of our system throughout childhood and beyond.



Figure 3. Example persona Dimension Worksheet

This invaluable tool provided an authentic view into the diachronic complexity of the Care and post-Care experience. An unexpected and emergent aspect of this complexity was the sensitivity of various life junctures to changes in recordkeeping practice. The detail and realism of the deep personas, mapped out an objective manner, enabled ideation of alternative life pathways in a way that individual reflection on personal lives could not. As we worked through alternate scenarios for the deep personas, it became apparent that an intervention here or an instance of 'being heard' there could potentially make a huge difference in the life chances and direction of the individual.

One example was the incident reporting mandated by departmental policy, currently manifesting as being 'written up' in a 'ledger of transgressions' – often with downstream justice system implications. A reconceptualization of this recordkeeping as a participatory process could become opportunities for connection and learning with mentors. 'Sun-setting' of such records could also lead to better Care outcomes in the absence of perpetual records of surveillance.

Proof-of-concept Prototype

Rather than dovetail with the emergent complexities of the current Care-sector information landscape, we focused on defining architectural affordances and the minimum interoperability needed between legacy systems and the proposed infrastructure. This resulted in a loosely coupled, three-tier architecture, which formed the basis of our prototype. This is not an aggregation repository of records,

but a platform for the management of records that, in most instances, are held elsewhere.

At the core of this architecture is a personal recordkeeping registry decoupled from the plurality of legacy record-holding systems. This registry is based on an activity modelling paradigm [62,63] that represents a fundamental shift from traditional recordkeeping modelling concerned with 'doers, deeds and documents' [38]. It leads to a complex knowledge graph of activities, participants, mandates, and representations and can facilitate the continuum-oriented capture, (re)organization, and pluralization of records under the control of those recorded. The registry also serves as a point of creation and ongoing management for other personal records that the design team found problematic in the Care context – such as personal biographical information that constantly needs to be reproduced due to the siloed nature of organizational information systems.

We also arrived at a personalizable, cross-platform, and offline-enabled browser-based web-based client, decoupled from the registry server. Such a design choice provides accessibility to those with only a personal mobile phone or access to a shared computer or borrowed device. However, this introduces a tension between flexibility and differences in modern browser functionality across a variety of potential runtime platforms. Additionally, operating in unsecured or hostile environments, or with shared or borrowed devices, poses the need for robust authentication processes: login, logout, and timeouts; meticulous clearing of local data; credential recovery [8,41,58]; multi-factor verification; and unexpected usage detection.

The precariousness and transience of many Care-experiences means that the client also needs to be able to work offline – albeit with (considerably) reduced functionality – such as when there is poor mobile or wireless reception or depleted phone credit for data services. Apart from complicating authentication processes, this also affects recordkeeping integrity across transitions between complex authentication/network states.

The designed recordkeeping system therefore comprises the independent registry and client components which are the missing elements of a truly pluralized recordkeeping landscape; a necessary 'third place' given contemporary portals and interfaces only provide invited access to records organized and pluralized from organizational perspectives.

Findings

Our participatory methodology was iterative, exploratory, and reflective [50], and, at times, difficult to describe [59]. However, we found ourselves returning to a small set of design factors foreshadowed by recordkeeping informatics (and continuum theory in particular), a critical posture, and trauma sensitivity. The design work itself, together with the resultant artefacts, reinforced and clarified these factors that we now consider to be a set of Strong Concepts [36] for the design of diachronic, trauma-sensitive systems. We propose these as generalized guidelines for the design process itself as well as foundations for resulting recordkeeping design artefacts and products.

Concept 1: Diachronic Contingency

This reflects the design process and outputs being context dependent and rooted in movement through time, and the need to make this movement and change explicit in all facets of the work. In acknowledging this dynamic temporality, we shift from 'snapshot' views of the design, problem, and solution domains, to an ever-changing, through-time framing. Perspectives, needs, responses, and issues, that wax and wane through time, need to be reflected in research and design processes and captured in design artefacts.

Concept 2: Individuality

Every child and young person's experience in Care is unique. When designing in and for a large sweep of time, we need to eschew conceptualizations of a generic 'user' or even clusters of 'normal' behavior. Instead, we must embrace the individuality of each participant - when conducting design, as well as in the recordkeeping facilitated by the designed system. Both age and differences in experiences - in this case, the trajectory through and, perhaps, beyond Care - can lead to vastly different sensitivities and responses to particular circumstances, events, and information in the context of ongoing recordkeeping. Similarly such experiences manifest both as variation in foundational, digital, recordkeeping, and other literacies, as well as in the range of living expertise that is brought to bear upon the problem domain. All of these inform requirements for lifelong recordkeeping and require affordances that pay particular attention to 'edge' cases.

Concept 3: Transience

These needs and capabilities as they manifest through time may result in dipping in and out of engagement with recordkeeping (and, indeed, activities such as research) throughout one's life. Often, the precariousness of Care and post-Care life [46,53] can undermine the availability or continuity of devices, connectivity, and time for engagement. Communal or adversarial living circumstances can affect privacy and security when devices may be shared or stolen, or behaviors subject to various forms of surveillance and control. Assumptions about continuity of service provision, access, and engagement need to be continuously questioned.

Concept 4: Child/person Centredness

Child/person centeredness in design necessitates a shift from the organization/client framing of systems to one that consciously privileges the primary participants' perspectives. We must constantly challenge relationships and power structures in the problem/solution spaces, as well as in design process. When designing, it may be necessary to push back against well-intentioned perspectives and system paradigms that serve to maintain the status quo.

Concept 5: Activity focus

The major implication from a diachronic orientation is the shift from things to activities as units of analysis. Design

moves from being a means-to-an-end to becoming an end in itself; how we get there (and what happens along the way) is as important as design outputs themselves. Similarly, recordkeeping systems shift from repositories of artefacts to dynamic spaces in which recordkeeping-related interaction takes place. Designs need to (re)present activities or events that give rise to information being recorded as well as the associated network of stakeholders. This is an iterative process, as changes in perspective or time may illuminate additional stakeholders and/or perspectives that were unknown at the time of the originating activity.

Concept 6: Complexity

Dealing with ever-shifting networks of people, perspectives, and activities is complex - in terms of research design; the participatory design itself; and any design outputs. By acknowledging and embracing this complexity, we necessarily move from a closed-world assumption [57] of absolute truths, to an open-world perspective of pluralities and sensemaking. As Clay Shirky argues, "the semantics here are in the users, not in the systems" [69], and this has major implications for pluralistic design. Both designing and designed affordances need to accommodate conflict, ambiguity, and uncertainty.

Concept 7: Trust & Agency

We identified a wide range of real-world challenges to people with Care experience, including variations in educational, digital, recordkeeping, and civic literacies; challenging social, safety, and socioeconomic contexts; experiential concerns about privacy and control, and transient and ever-changing access to platforms and data networks;. All of these can engender low expectations of trust and agency in relation to systems, institutions, and formal contexts. A key factor in this work, then, is finding ways to establish and maintain trust, and ensure individual agency – particularly in contexts that involve the recording or sharing of traumatic experiences.

DISCUSSION

These concepts, while individually significant, interact and reinforce each other to provide a foundation for rights-based and trauma-sensitive design.

Implications for participatory design

Adhering to these guidelines during the participatory design process was at time challenging due to personal constraints as well as academic conventions, timing, and research strictures. Yet, we all found the experience a significant departure from previous research and other institutional interactions. Our participants' reflections on the empowering effect of this principled design process are described elsewhere [64].

It is impossible to separate one's stories, sensitivities, and aspirations from design contributions – even if they are never explicitly communicated outside of the design context. This requires a great deal of *trust* in individuals as well as the design process – especially for those who previously have been in positions of vulnerability. This underscores the

importance of *diachronic* approaches. We built in project time for participants to come to appreciate the problem domain from other perspectives; to establish trust; to develop a level of candid rapport that enables understanding of the depth, range, and subtleties of the living experience of others; and to reflect on the implications of all this ambiguity, and uncertainty in their own lives. It also meant overcoming impediments to participation [13] and stereotypes of researchers and research borne of previous treatment as 'subjects' in non-participatory research [60].

Through collectively developing the design program, we acknowledged all participants' experiences, literacies, and expertise, finding surprising resonances in our family stories and institutional experience. We reflected on the manner in which the participatory design workshops were conducted; the suitability and affect of materials and methods introduced; and questioned assumptions about research outcomes and communications. From an academic perspective, it is easy to fall into patterns of speaking for others and so it is necessary to take pains to avoid such ventriloquism [68], even when developing more technical communications (e.g. this paper).

This privileging and understanding of *individuality* was complicated by the real-world events that affected engagement over time. As well as academic calls on our time, individuals were dealing with illness, pregnancy, marriage, legal matters, study, and a variety of domestic and employment issues. We strived to find flexible ways of carrying the research forward, while adapting to the sometime, *transient* nature of engagement.

Simple things like customized signposting to the (ever changing) on-campus workshop locations; providing food as a social leveler; inviting participants to bring children if experiencing childcare problems; establishing multiple communications channels (email, Slack, and phone/text) all served to break down the institutional research façade and enable us to approach engagement as equals in research with individual needs and contributions.

Implications for systems

A focus on *child/person-centeredness* directly challenges existing power structures in order to support a wide range of human rights - including recordkeeping rights – that relate to self-determination, identity and expression. This *complexity* impacts architecture; interoperability, process, and quality standards; and interface affordances. If individuals require the highest degree of agency in the recordkeeping activities that will pervade their life, then information control hierarchies and processes need to be re-imagined.

Such affordances need to make explicit this *temporality* and a plurality of *individual* perspectives that may change *diachronically*. People may not engage with childhood records for years, until they need to, when such records may become crucial evidence and memory going forward. For example, survivors of childhood sexual abuse often do not report it for several decades [67] (vol. 4, p. 9). Similarly, changes need to be tracked and/or be reversible across multiple, networked systems; consent and authorizations should be revocable; histories and audit trails of activity should be transparent; and so on. These are necessary to ensure the persistence of functionality through time over generational timescales. Moreover, regardless of recordkeeping infrastructure, interfaces and affordances may need to be aligned with childhood and adolescent developmental stages.

Similarly, *trustworthy* systems must be transparent in terms of what the system does and does not do [75] (p. 51). System affordances need to make explicit what *agency* all participants in the recordkeeping possess, and the limits of such assurances. We need to question norms of static and unitary information ownership as well as assumptions and expectations of system behavior. This leads to the openworld design that better deals with ambiguities, pluralities and sensemaking rather than singular views of 'truth'. A simple technical example of this can be found in ideas of fixity around dates and records. In many cases, recordkeeping dates are modelled as if they are singular, known with uniform accuracy and precision, immutable, and uncontested. This is simply not so – and further confounded by a plurality of candidate dating schemes and dates.

An additional consideration for such a loosely coupled architecture is the management of identity, and authentication - particularly given the diachronic and transient nature of participation. How do you ensure authentication through decadal timescales, unstable technology access, and shifts in technology? This is related to questions of control and agency by participants over records held elsewhere. A registry goes a long way to fulfilling requirements for memory, identity, evidentiality, sensemaking, and so on. However, considerations of complexity and agency suggest that, ultimately, control over records will be negotiated. This, of course, relies upon agreed activity modelling, which, while forming the basis of the registry server, is not completely exposed to, or by, contemporary systems. More research is needed to understand how these could be systematized in an interoperable manner within a heterogeneous network.

Recent web technology advancements provide an offline runtime and persistent local storage capabilities for web-apps [21] which, in turn, require synchronization of user data. Existing mechanisms for handling offline-online authentication/synchronization [7] make assumptions about architectures and network connectivity. Our context is a new take on this problem; particularly as some user data also dictates the behavior of the entire web-app.

Trust & Agency, Individuality, and *Diachronic Contingency* direct impact on affordances for information sharing. Individual responsibility for downloading, storing and sharing copies of records can be fraught, as circumstances may change over time, and information once shared is

difficult to revoke. It is easy to lose control over who has access and how records may be used – even if one understands the nuances of information and system behaviors. What appeared as a seemingly 'simple' interface issue is actually a manifestation of underpinning concepts.

We created a second sharing mechanism whereby sets of view of records, created on the client, could be served to different audiences in a controlled, view-only manner from the registry server. We elected to maintain both sharing mechanisms but spent effort in the UI design to make clear the risks and benefits of each approach. Such affordances provide a good example of addressing the *individual privacy*, *agency*, and *literacies* needs of record participants while maintaining *child/person-centeredness* without the paternalistic control so often found in information systems.

LIMITATIONS

In this investigation, we sought to address contemporary Care-sector recordkeeping systems design. However, by working with young Care-leavers rather than children currently in Care, we acknowledge that our study represents young adult perspectives. It therefore does not deal with developmental age dimensions of recordkeeping systems and interface design. In addition, while we recognize the colonized nature of the child welfare sector [49], this study did not explore the intersectionality of ethnicity, socioeconomic status, or indigeneity and its manifestation in Care-sector recordkeeping systems design. There are thus further opportunities for research to address these limitations.

CONCLUSION

This project has demonstrated how the application of recordkeeping informatics and participatory approaches inform the design of lifelong information systems. In particular, rights-based approaches completely change the dynamics of information infrastructure for truly personcentered systems. Through this work, we identified a set of strong concepts as guidelines for such long-term design – in terms of both the design process and the design outputs themselves. We contend that these guidelines are generalisable to other domains as they provide a foundation for rights-based and trauma-sensitive design. They result in richer knowledge generation and better design outcomes, as well as leading to design tools, artefacts, architectural characteristics and affordances that support such work.

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