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# Codesigning rights-based recordkeeping for childhood out-of-home care

Joanne Evans and Rhiannon Abeling

Department of Human Centred Computing, Faculty of Information Technology, Monash University, Clayton, Australia

**ABSTRACT**
Decades of inquires in Australia and internationally into child welfare and protection systems have highlighted the importance of quality recordkeeping to the lifelong identity, memory and accountability needs for those who experience Alternative Care. Having learnt about the devastating impacts of poor recordkeeping and challenges in accessing records of childhood Care experiences, it is clear that transformative approaches are needed to tackle what Australia's Royal Commission into Institutional Responses to Childhood Sexual Abuse in December 2017 has labelled a 'systemic and enduring' problem. In this paper, we report on our involvement in a co-design team of recordkeeping researchers, Care leaver advocates, and digital technologists working together to develop a deep understanding of Care recordkeeping needs and realise them in the functionality of a digital prototype. Developed as a design provocation – a blueprint for participatory recordkeeping infrastructure – we will explain how it enables those currently cast as the client of services and 'subject' of records, to participate in their Care recordkeeping on equitable terms. We will discuss how having knowledge of, and appropriate say over, who has access to personal information and records can be re-imagined through digital technologies in support of lifelong rights to identity, privacy, autonomy and accountability.

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**KEYWORDS**
Alternate care; participatory recordkeeping; children's rights; co-design

## Introduction

A number of significant inquires in Australia and internationally over the past decades have highlighted the importance of quality recordkeeping to the lifelong identity, memory and accountability needs for children and young people that grow up in statutory child welfare and protection systems (Bak et al., 2017; Hamber & Lundy, 2020; Human Rights and Equal Opportunity Commission, 1997; Independent Care Review, 2020; Ireland. Commission to Inquire into Child Abuse, 2009; Royal Commission of Inquiry into Historical Abuse in State Care and in the Care of Faith-Based Institutions, 2020; Senate Community Affairs References Committee, 2001, 2004, 2009; Sköld et al., 2012). Having learnt about the devastating impacts of poor recordkeeping, and the challenges of accessing records of childhood experiences from these inquiries, it is clear that more needs to be done to tackle what the 2013–2017 Royal Commission into Institutional Responses to Childhood Sexual Abuse in

**CONTACT** Joanne Evans joanne.evans@monash.edu Department of Human Centred Computing, Faculty of Information Technology, Monash University, Clayton, Victoria 3800, Australia

Australia has categorised as 'systemic and enduring' problems (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017, p. 39). Records and recordkeeping are of course not the most visible or pressing problem with systems that manage the Alternative Care of children (UN General Assembly, 2009), but they often play a significant part in the negative impacts of these systems on the lives of Care experienced people (Evans et al., 2015; Golding, 2020; Hoyle et al., 2020; Humphreys & Kertesz, 2012; O'Neill et al., 2012; Wilson & Golding, 2016).

In this paper, we report on research into a rights-based approach to recordkeeping in Alternative Care systems. After establishing the background to the problem, we introduce ourselves and discuss our involvement in a co-design team of recordkeeping researchers, Care leaver advocates, and digital technologists, working together to develop a deep understanding of Care recordkeeping needs and create a participatory recordkeeping prototype. Developed as a design provocation – a blueprint of a participatory recordkeeping infrastructure – we will explain how the features and functionality of our prototype, enable those currently cast as the client of services and 'subject' of records, to participate in their Care recordkeeping on equitable terms. We will discuss how having knowledge of, and appropriate say over, who has access to personal information and Care records can be re-imagined through digital technologies. And then reflect on how this may better enable rights to identity, privacy and autonomy, support the development of sense of self and worth, and achieve better child safety and wellbeing outcomes. Our work illustrates the value of lived experience and design research in building deep understanding of systemic problems and developing transformational solutions.

## Background

Out-of-Home Care is the term used in Australia for short, medium or long term living arrangements for children and young people not able to live in their parental home due to safety and/or wellbeing concerns (Department of Families, Housing, Community Services and Indigenous Affairs, 2011). This is often abbreviated to 'care' and in this article we will use the protocol established by Wilson and Golding (2016) of using the capitalised Care to indicate the ironic connotation of an often uncaring system to avoid the continual use of quotation marks.

In Australia, while state government departments are responsible for investigating and prosecuting child neglect and abuse concerns, the provision of placement and other support services is outsourced to a range of organisations, mostly non-profit, but also some run on a for-profit basis (Fernandez, 2014; Higgins, 2011). A number of these organisations have a long history of providing children and family services, some pre-dating Australia's federation in 1901, with various degrees of investment and professionalisation in the management of their organisational recordkeeping and archives (Humphreys et al., 2014; Swain, 2014). The Australian Out-of-Home Care sector is thus a complex network of agencies, unfortunately characterised as 'poorly coordinated, inadequately resourced and often unable to protect children from significant physical, emotional or sexual abuse' (Bessant & Watts, 2016). As highlighted by the 2013–2017 Royal Commission into Institutional Responses to Childhood Sexual Abuse, recordkeeping in the sector is similarly complex, convoluted, lacking coordination, under resourced, inefficient and often ineffective (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017). Responding to what they heard in the private sessions with survivors of childhood sexual abuse, particularly in Care contexts, the Commissioners noted in their final report that

> Inadequate records and recordkeeping have contributed to delays in or failures to identify and respond to risks and incidents of child sexual abuse and have exacerbated distress and trauma for many survivors. Obstructive and unresponsive processes for accessing records have created further difficulties for survivors seeking information about their lives while in the care of institutions. (Royal Commission into Institutional Responses to Child Sexual Abuse, 2017, p. 9)

As well as the vital role of records and recordkeeping in good governance and accountability, previous inquiries, research and advocacy had also highlighted the importance of childhood records to identity, both officially and in supporting your sense of who you are, documenting childhood memories and connections to family, culture and community, and managing your health and wellbeing (Human Rights and Equal Opportunity Commission, 1997; Humphreys & Kertesz, 2012; Senate Community Affairs References Committee, 2001, 2004; Wilson & Golding, 2016).

While there is now a mountain of testimonies, inquiry reports and research articles describing the systemic problems with Care recordkeeping systems, there is less investigation of systemic solutions. While access to past records has improved through government funding of a network of support services for Stolen Generations, Forgotten Australians, Former Child Migrants and other (older) Care Leaver communities, problems with records and recordkeeping persist (Golding, 2020). In a survey of more recent Care Leavers by the CREATE Foundation[1] carried out in 2018, less than half of the two thirds of respondents who had sought access to their records had received them, and only just over a third found the process easy and supportive (McDowall, 2022, pp. 35–36). Comments regarding missing records, the poor quality of information, frustration at redacted information and pejorative language echo the frustrations of previous Care experienced generations. Similarly systemic inquiries by the Victorian Commissioner for Children and Young People into Care experiences around the same time found serious deficiencies with care and transition planning records, with the majority not featuring any indication of consultation with the child or young person (Commission for Children and Young People, 2019, 2020).

We believe that incremental reform of a recordkeeping infrastructure designed around organisational ownership and control cannot address the systemic and enduring nature of Care recordkeeping problems. Our position is that we need systems designed around the rights of Care experienced children, young people and adults to identity, memory, accountability and participation in the recordkeeping that impact on their lives (Rolan et al., 2018). Our research is therefore aligned with those articulating the need for more radical systems transformation in order to address the power differentials, discrimination and disadvantage embedded in existing Care systems (Braithwaite, 2021). We particularly welcome those calling for Alternative Care systems to be run (and resourced) based on a public health model, for which we believe a transformed participatory recordkeeping infrastructure would be essential (AIFS, 2014; Driscoll, 2020). Our research is therefore aimed at contributing to the conceptualisation of a future digital information and recordkeeping infrastructure in support of a well-balanced, inter-connected, child protection ecosystem. Designed and built on rights-based, strengths-based, trauma-informed and culturally safe practice principles to facilitate healthy and productive working relationships with parents, families, carers, communities, and agencies, it should enable children and young people to grow up in safe, secure, loving and caring Alternative Care environments.

## Author introductions

We adopt the self-reflexivity approach used by Sexton and Sen (2018) to tell the story of our research collaboration. This reflects our approach to participatory research and design where we have sought to each bring our whole selves to address the emotionally charged topic of Care recordkeeping and break down, as much as we can, traditional academic distinctions between researcher and researched. An important part of our collaboration has been open and respectful discussion of asymmetries in our work and life experiences, and recognition of associated power and privileges as part of building the affinity, trust and mutual learning environment of a participatory action research project (Reason & Bradbury, 2008).

### *Introducing Joanne*

I'm an archival and recordkeeping scholar in the Faculty of IT at Monash University in Australia. I first became aware of the issues with Care recordkeeping when I worked as an archival systems developer at the University of Melbourne in the late-2000s. It was in a meeting with colleagues at the eScholarship Research Centre, as they embarked on work to document the complex network of record holding organisations in Victoria as part of the Who am I? Project in response to recommendations relating to records from the Forgotten Australian report (Senate Community Affairs References Committee, 2004). In the spirit of the participatory action research approach adopted by this project (Humphreys et al., 2014), my colleague began the meeting reading the words of Frank Golding, a Ward of the State in the 1940–1950s, a highly regarded Care experienced advocate and then Vice President of Care Leavers Australasia Network (CLAN) on receiving a letter that his mother had written to him as a young boy in the Ballarat Orphanage with sections blacked out by the heavy hand of redaction for 'privacy' reasons (Golding, 2010). My colleague also shared the words he had written about the years of bureaucratic obfuscation he had encountered in trying to locate records about his childhood.

It was a moment that I remember so well, changing both the tenor of the meeting, but also significantly impacting my thinking and approach to archival systems design. It taught me the value of listening – really listening – in order to appreciate and learn from the voice of living/lived experience (including the living experience being another astute insight from a presentation by Frank at a 2019 Symposium at UCL in London for the MIRRA Project that his childhood Care experiences are not just part of his lived past, but also his present and future). I walked back to my desk resolved to be part of designing systems to reduce rather than add to recordkeeping bureaucracies. I also remember subsequent discussions with my colleagues trying to represent the complex networks of records custody, ownership and access in our database (Evans, 2014; McCarthy & Evans, 2012; O'Neill et al., 2012), and thinking that if I was struggling as an experienced data modeller and recordkeeping professional to make sense of it, then those with less experience, expertise, opportunity and 'insider' knowledge would be up against it in locating records relating to their childhood.

Fast-forward to now and through my privileged position as a university researcher and educator, I've managed to attract research funding for a series of projects to investigate and address Care recordkeeping challenges. The approach has been to look at combining participatory research and participatory design approaches to imagine and investigate what a participatory recordkeeping infrastructure for Out-of-Home Care might look like (Evans et al., 2021).

## *Introducing Rhiannon*

I am a Care Experienced Advocate and working as a Research Associate on the Rights in Records by Design Project. I experienced my world crumble around me when I entered the out of home Care system. Like many others, I was separated from my family, placed into the homes of people I didn't know, and moved around from placement to placement, changing schools, areas, agencies, workers with little to no warning or explanation (McDowall, 2018). I experienced what it was like to lose everything when taken into the Care system – not just personal belongings but your identity. You become a number on top of a case file, a statistic or piece of data (Humphreys & Kertesz, 2012; O'Neill et al., 2012; Wilson & Golding, 2016). Looking after you becomes someone's job and their source of income.

When I was a teenager, I participated in a workshop about young people in Care and their legal rights. This was the first time I found out that we could have a voice, and that we could advocate to make changes for not just ourselves but for others who have, are and would go through what we have (Equit & Purtell, 2022). After the workshop I put my hand up to be a voice for Care leavers and I trained to become a young consultant with the CREATE Foundation – the peak body advocating for kids in care and young Care leavers in Australia. CREATE's development programmes and promotion of advocacy by young people with Care experiences gave us not just voice, but also safe spaces for expressing our views, audiences to listen to what we had to say and mechanisms for encouraging them to act upon our ideas and concerns, in line with emerging models of participatory rights for children (Lundy, 2007).

After completing my training, I started assisting in training new child protection and social workers, speaking to politicians, speaking to students in universities, speaking to the media, giving presentations about my Care experience and what needed to change so that no one would have to go through what myself and many others had had to go through. Fast forward to now and through my particular interest in Care recordkeeping, I have been working with Joanne on her Recordkeeping and Rights of the Child research programme since 2017, when I was involved with designing a session for the *Setting the Record Straight for the Rights of the Child Summit*.

## *Recordkeeping and Rights of the Child Research Program*

Funding from the Australian Research Council (ARC) for a Future Fellowship in 2015 enabled the establishment and development of the Recordkeeping and Rights of the Child Research Program in the Faculty of IT at Monash University. The aim is to investigate how to transform Care recordkeeping to better recognise, respect and enact multiple rights in records. The strategic vision of the programme was established through the *Setting the Record Straight for the Rights of the Child Summit*, held over 2 days in May 2017 in Melbourne, Australia (Evans, 2017b; Reed et al., 2017). Specifically designed to centre the voices of those with lived/living experience, it brought together community advocates, researchers and a range of recordkeeping and Care sector professionals to discuss how to address Care recordkeeping challenges. Day 1 was focused on listening and learning about the issues with Care recordkeeping and archiving systems from past, present and professional perspectives, while on day 2 the emphasis shifted to imagining a better future. Together attendees discussed the attributes of a more equitable and inclusive recordkeeping infrastructure, and then considered what would be needed to turn that vision into a reality.

A strategic vision of a National Framework for Recordkeeping for Childhood Out-of-Home Care resulted from the Summit. It enlarges on the Recordkeeping Principles for Child Safe Organisations, that subsequently came out of the Royal Commission into Institutional Responses to Child Sexual Abuse Final Report (2017, pp. 22–23) with the concepts of Rights-based Recordkeeping and Lifelong Living Archives as key components of a participatory infrastructure for managing the Care records of yesterday, today and tomorrow, across all jurisdictions (Evans et al., 2021). It is a bold and optimistic idea – reflecting that major transformations are ultimately needed to address the power asymmetries in existing Care recordkeeping processes and systems. The strategy also envisioned achieving this National Framework through interconnected action & advocacy and research & development agendas utilising participatory approaches to transform recordkeeping in order to deliver better outcomes for Care experienced children, young people and adults.

Since the Summit, our focus has been on progressing the research and development agenda of the strategic plan, through the ARC Discovery Project, Rights in Records by Design. This brought together a trans-disciplinary research team – across Monash University, Federation University and with Care experienced community advocates, like Rhiannon – to further develop, model and prototype rights-based approaches to Care recordkeeping. Australian Out-of-Home Care standards identify the rights of children and young people to have access to a complete and accurate history of their time in care and other records to support and nurture their sense of identity, security, and connectedness with the world (Department of Families, Housing, Community Services and Indigenous Affairs, 2011). They also emphasise rights to participate in the decision-making that impacts on their lives, which for us must include the formation and use of their Care archive. Hence the aim of this project was to explore ways for designing these rights into Care recordkeeping systems.

The Recordkeeping and Rights of the Child Research Program reflects a human-centred, participatory design ethos (IDEO.org, 2015; Lewis et al., 2020), drawing on the principles of creativity, participation, open-minded, and open-hearted design thinking to iteratively understand the complex problem of Care recordkeeping, imagine new possibilities and design potential

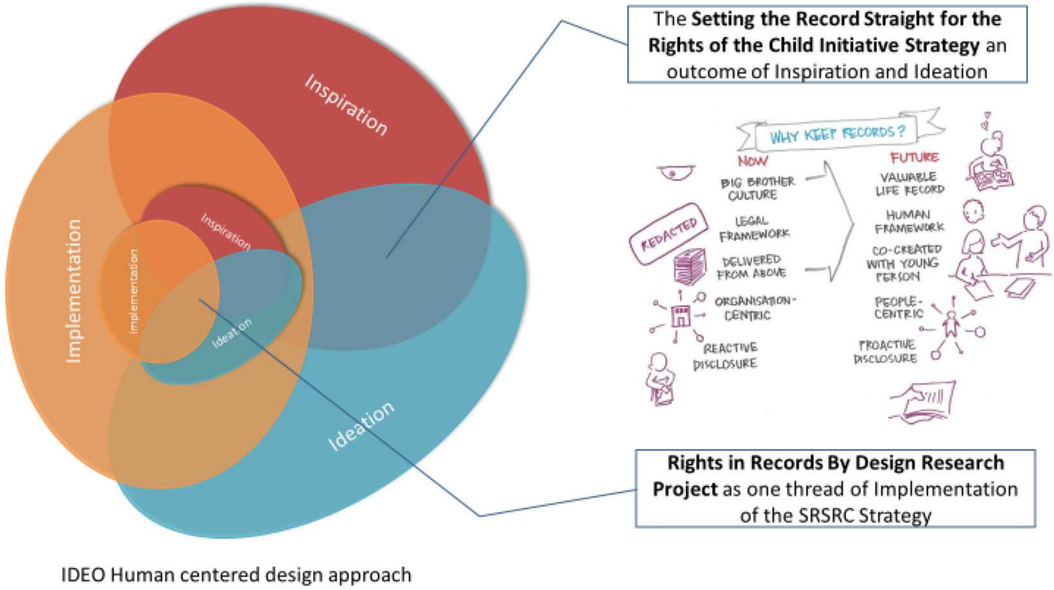


**Figure 1.** Human centred, participatory design approach of the Recordkeeping and Rights of the Child Research Program.

solutions. As illustrated in Figure 1, while the Summit envisaged this on a sector scale in establishing a shared strategic vision, in the Rights in Records by Design Project we have looked to implement a thread of that strategy through applying participatory research and design methodologies to the development of a recordkeeping infrastructure to recognise, respect and enact multiple rights in Care recordkeeping.

## *Participatory recordkeeping prototype*

The focus of this paper is on the technical prototyping of the Lifelong Living Archives component of the National Framework for Recordkeeping for Childhood Out-of-Home Care in order to realise recordkeeping rights through systems design. It complemented other research in the Rights in Records by Design Project into the development of a Charter of Lifelong Rights in Childhood Recordkeeping in Out-of-Home Care (Golding et al., 2021). With existing Care systems based around singular, organisational ownership and control of records and recordkeeping, this research aimed to explore the features and functions of a digital system in which 'subjects' of Care records might have equal rights to access them, contribute to them and challenge and correct them as needed.

## *Co-design research*

As with an increasing number of research and practice initiatives, foregrounding the voice and agency of lived/living experience was an essential aspect of this design research (Schelbe & Geiger, 2022), and like others, we arrived at co-design as a methodology for enabling this (Black et al., 2023; Victorian Council of Social Service, 2015). At its best, co-design recognises and embraces the value of living/lived experience and expertise, facilitates community empowerment in addressing complex social challenges and enables positive change of both the processes and objects of design (Zamenopoulos & Alexiou, 2018). At its worst it is just the application of the latest buzz word to tokenistic consultation processes or traditional extractive research methods (Burkett, 2013; National Centre for Action on Child Sexual Abuse, 2023). Effective co-design will seek to acknowledge and address power differentials and where possible attempt to equalise relationships

(Farr, 2018). This is a particular challenge in the academic space where it can be difficult to deliver on co-design principles within the structures and strictures of the academy and its embedded privileging of the knowledge and skills of academic researchers.

Our research design was also informed by our adoption of a participatory action research approach, aimed at fostering co-research relationships with participants and bringing together action and reflection with theory and practice (Reason & Bradbury, 2008). Reflective of our positioning as recordkeeping and information systems researchers we additionally utilised systems design as a method of knowledge production (Evans, 2017a; Gregor & Hevner, 2013; McKemmish et al., 2012). Our systems design approach has also been influenced by value-sensitive design principles, with overt consideration of stakeholder values and social structures, e.g. policy, law, regulation, organisational practices and cultures, at play in design and solution spaces (Friedman & Hendry, 2019). This is perhaps a different, but complementary pathway, to the emerging application of co-design, co-production and peer support to practice initiatives in the Care sector, where the focus is on enacting rights of participation within services (Equit & Purtell, 2022) or for research that co-designs resources with lived experience participants to directly apply in practice environments (Black et al., 2023).

## *Our co-design research*

Details of our co-design approach have been published elsewhere illustrating how voice, agency and equity issues were considered across a range of research processes, along with how we worked to create an empowering space for exploring Care recordkeeping problem and solution spaces (Rolan et al., 2019, 2020). Rhiannon played a key role here in being employed as a Care experienced Research Assistant, helping us to form the co-research and co-design team by reaching out to other Care experienced advocates interested in addressing Care records and recordkeeping challenges, as well as advising on the design of the co-design activities. Over an eighteen-month period in 2018–2019, we conducted two sets of workshops – 8 in the first and 12 in the second – deep diving into Care records experiences, digital systems infrastructures and digital design considerations – laughing and learning from each other along the way.

In the first series of workshops we focused on articulating the systems problem. We discussed how being in out-of-home Care for any period of time means having records about your childhood distributed over a whole host of systems. It also subjects a child and their family's behaviour to extensive scrutiny and documentation, with many, many, people and different kinds of professionals involved in making decisions about the young lives in their care. To capture this, we created what we called our Trajectory document as a design artefact to represent the myriad of Care events, transitions, living contexts, and interpersonal relationships, together with their associated formal and informal records and recordkeeping processes. As we developed this document, we discussed how we might imagine better and more child-centred recordkeeping, that could enable the records to play a positive role in nurturing and developing one's sense of self, feeling connected to family, carers and community, and ensuring decision making and actions by all the different organisations in the system are at all times considering best interests' principles, and enabling active participation. In the second series of workshops, we used an agile systems development approach to turn our shared knowledge into a rights-based, participatory recordkeeping prototype.

## *Our participatory recordkeeping prototype*

The result is MySSy – a research prototype of a personal recordkeeping system for a Care experienced child, young person or adult to access and have control over their distributed Care records network. The name is an abbreviation of My System with an added S for the different kinds of adjectives that could be applied to it – Safe, Supporting, Self, Sharing, Secure – so we could pronounce it as 'Missy'. Perhaps not the most creative and inspiring name but one that we could at least all

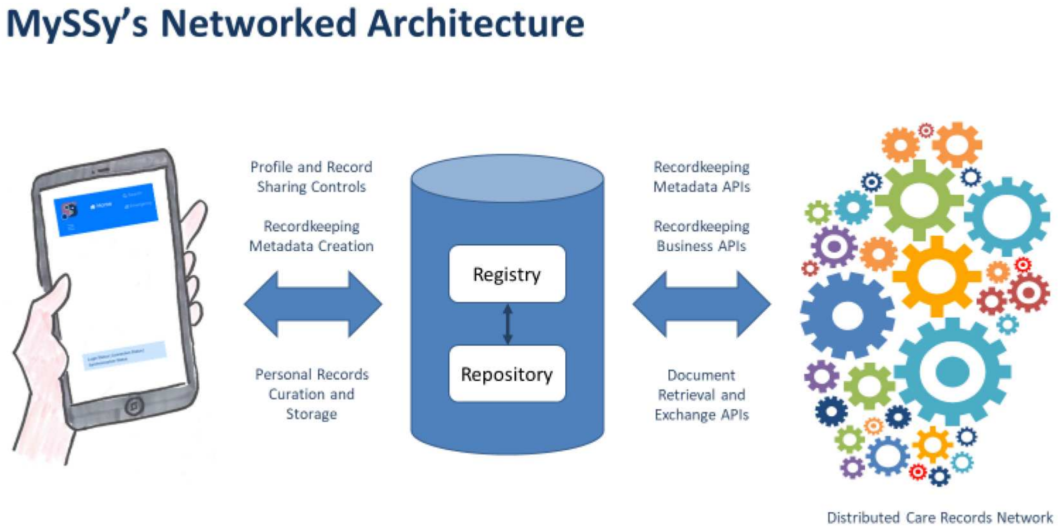
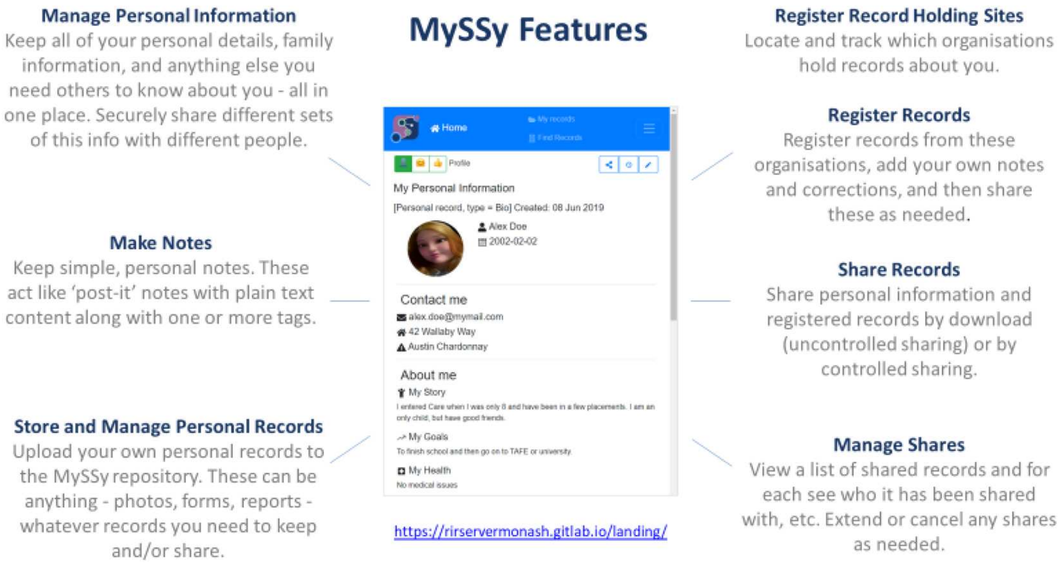


**Figure 2.** MySSy's networked architecture.

somewhat agree on. With personal archive apps, like KicBox[2] and Caring Life,[3] emerging in Australia for children and young people in Care as we undertook this research, we imagined MySSy as more than just an app for storing copies of records but instead as an architecture for an independent personal recordkeeping registry – a gateway to the records of a Care experienced person held across a myriad of organisational recordkeeping systems, as illustrated in Figure 2.

Figure 3 provides an overview of the key features we have designed into MySSy for exerting participatory recordkeeping rights. We have decided to use the second person pronoun, you, to introduce and describe these features as we want a reader to consider how MySSy might enable participation in recordkeeping from the perspective of a Care experienced person. On the left of



MySSy Features

**Manage Personal Information**
Keep all of your personal details, family information, and anything else you need others to know about you - all in one place. Securely share different sets of this info with different people.

**Make Notes**
Keep simple, personal notes. These act like 'post-it' notes with plain text content along with one or more tags.

**Store and Manage Personal Records**
Upload your own personal records to the MySSy repository. These can be anything - photos, forms, reports - whatever records you need to keep and/or share.

My Personal Information

[Personal record, type = Bio] Created: 08 Jun 2019

Alex Doe
2002-02-02

Contact me
alex.doe@mymail.com
42 Wallaby Way
Austin Chardonnay

About me

My Story
I entered Care when I was only 8 and have been in a few placements. I am an only child, but have good friends.

My Goals
To finish school and then go on to TAFE or university.

My Health
No medical issues

https://rirservermonash.gitlab.io/landing/

**Register Record Holding Sites**
Locate and track which organisations hold records about you.

**Register Records**
Register records from these organisations, add your own notes and corrections, and then share these as needed.

**Share Records**
Share personal information and registered records by download (uncontrolled sharing) or by controlled sharing.

**Manage Shares**
View a list of shared records and for each see who it has been shared with, etc. Extend or cancel any shares as needed.

**Figure 3.** Features of MySSy for exerting participatory recordkeeping rights.

Figure 3 are the features for creating and managing your own personal records, and on the right those for finding and accessing the Care records that others create about you.

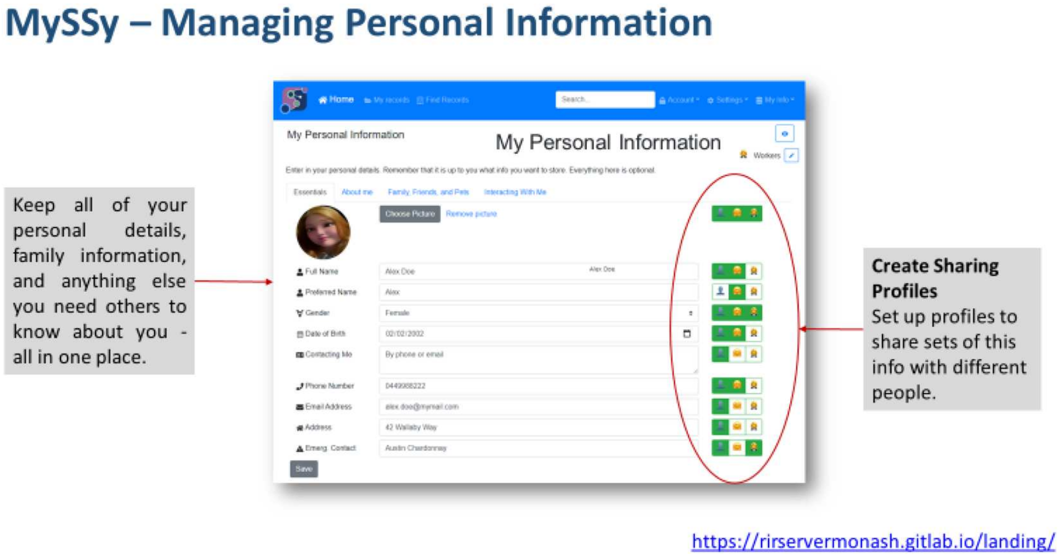
For the co-design team, bringing the functionality for managing personal information and other Care records together in the one system is very important. Firstly, it overcomes the problems with having to negotiate a bewildering array of organisational systems and access processes to track where information and records about you are held. Instead rights to have control over personal information and to access records are embedded into the system and enabled via a systems interface, rather than having to be individually and repeatedly fought for. Secondly, it allows for control and oversight of how personal information and records are shared and used by others. This turns information sharing into something that is done with you, rather than for and about you, which is essential in order to move from being a passive subject of records, to an active participant in their creation, management and use.

We will now step through each of these key recordkeeping features of MySSy in a little more detail, highlighting the lived/living knowledge and experience that has influenced their design.

## *MySSy – managing personal information*

From a Care-experience perspective, having functionality to capture and manage personal information in MySSy is very important. We had many discussions in our co-design workshops of the tendency for workers to see the children and young people they have responsibility for through the prism of their case files rather than as living, breathing, unique and developing individuals. We talked about how the basic personal information captured in case files can often be wrong and out of date. We also noted that it tends to capture most often the negative aspects of young lives. We also discussed how vulnerable it feels to have personal information shared with strangers, with no knowledge or say in what is disclosed, to whom and when. To combat this, we spent a lot of time discussing and designing MySSy's personal information management features.

As the screenshot In Figure 4 shows, here is where a Care experienced person's key personal information can be in a single safe place, ensuring that it is up to date and correct, acting as a single reliable source of truth. We discussed the need to capture the key information that matters to a child or young person in the Care system – your story, your goals, your likes, your dislikes, your



MySSy – Managing Personal Information

Keep all of your personal details, family information, and anything else you need others to know about you - all in one place.

Create Sharing Profiles
Set up profiles to share sets of this info with different people.

My Personal Information

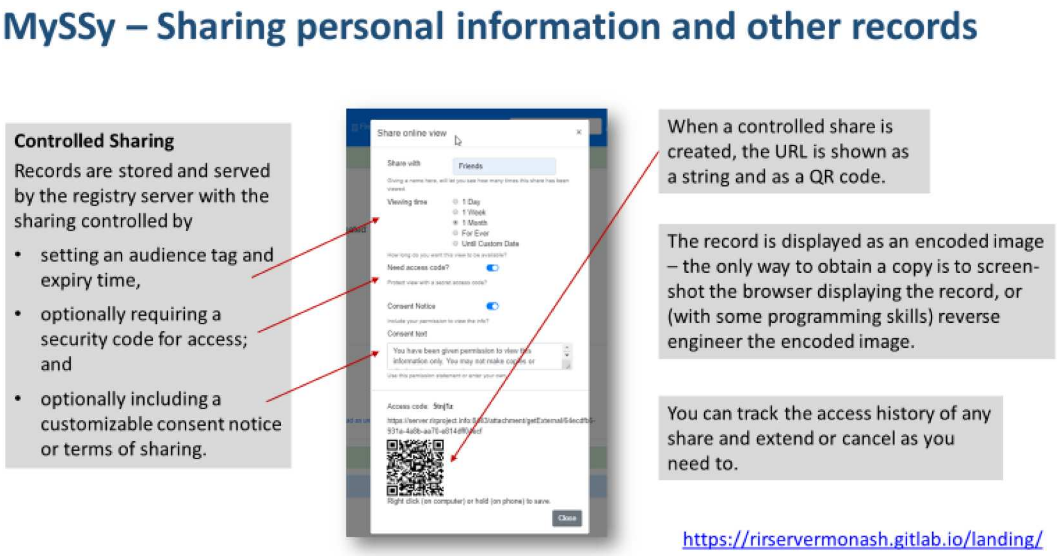
My Personal Information

Enter in your personal details. Remember that it is up to you what info you want to store. Everything here is optional.

Full Name: Alex Doe
Preferred Name: Alex
Gender: Female
Date of Birth: 02/02/2002
Contacting Me: By phone or email
Phone Number: 0449988222
Email Address: alex.doe@mymail.com
Address: 42 Wallaby Way
Emerg. Contact: Austin Chardonnay

https://rirservermonash.gitlab.io/landing/

**Figure 4.** Managing personal information in MySSy.



MySSy – Sharing personal information and other records

**Controlled Sharing**
Records are stored and served by the registry server with the sharing controlled by

- setting an audience tag and expiry time,
- optionally requiring a security code for access; and
- optionally including a customizable consent notice or terms of sharing.

Share online view

Share with: Friends

Viewing time
○ 1 Day
○ 1 Week
● 1 Month
○ For Ever
○ Until Custom Date

Need access code? ●

Consent Notice ●

Consent text: You have been given permission to view this information only. You may not make copies or

Access code: 5trnj1x

Right click (on computer) or hold (on phone) to save.

When a controlled share is created, the URL is shown as a string and as a QR code.

The record is displayed as an encoded image – the only way to obtain a copy is to screen-shot the browser displaying the record, or (with some programming skills) reverse engineer the encoded image.

You can track the access history of any share and extend or cancel as you need to.

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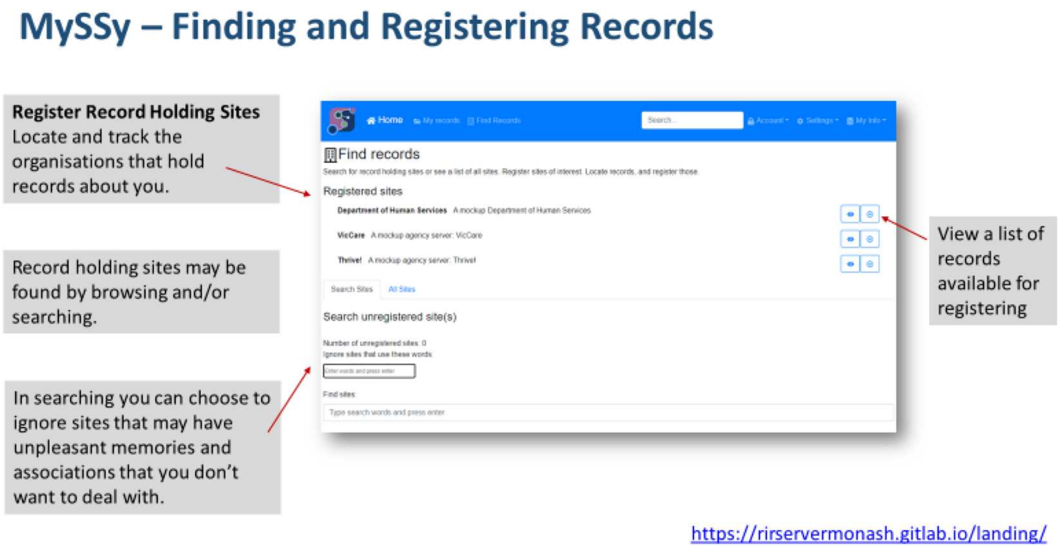
**Figure 5.** Sharing personal information and other records in MySSy.

family and friend networks, etc., noting also how best to interact with you – what might be triggering, what might help to keep you calm, etc.

### *MySSy – sharing personal information and other records*

That led to us designing functionality for sharing this personal information as a record as illustrated in Figures 5 and 6. This means that instead of wondering who is accessing your personal information and other records and for what purposes, you can participate and have a say in who sees, what and when. Controlled sharing allows for records in MySSy to be shared in, as the name suggests, a controlled manner. For each share you can specify the audience, a time limit, security controls and a



MySSy – Finding and Registering Records

**Register Record Holding Sites**
Locate and track the organisations that hold records about you.

Record holding sites may be found by browsing and/or searching.

In searching you can choose to ignore sites that may have unpleasant memories and associations that you don't want to deal with.

Find records

Search for record holding sites or see a list of all sites. Register sites of interest. Locate records, and register those.

Registered sites

**Department of Human Services** A mockup Department of Human Services

**VicCare** A mockup agency server: VicCare

**Thrive!** A mockup agency server: Thrive!

Search unregistered site(s)

Number of unregistered sites: 0

Ignore sites that use these words:

Find sites:

View a list of records available for registering

https://rirservermonash.gitlab.io/landing/

**Figure 6.** Managing personal information in MySSy.

customisable consent notice. This then generates a URL and QR code that can be used to access the record as an encoded image. You can then use the access history features to see when it is accessed and extend/cancel any shares as needed.

MySSy reflects being given a say over how and when personal information and other records are shared in your best interests, with the functionality to actively participate in your records network. We talked a lot about when such control is needed and when it would have less importance. Would every Care experienced person want to micro-manage this sharing all the time? No, not necessarily, so It has been designed as latent functionality – there if and when needed. We discussed how it might help to build trust in your Care circle and once that trust was established, in feeling safe and secure then it would not need to be utilised.

We also talked long and hard about how exercising such autonomy over your sensitive personal information and records comes with the need for an awareness that there might be consequences that you would have to deal with depending on your choices. We had a number of discussions about the heightened recordkeeping and Care system literacies that are needed when you grow up under the auspices of child protection. Participation rights means that part of implementing MySSy would require also investing in helping kids in care to develop the knowledge and skills for keeping sensitive personal information safe and secure – indeed 'as a good parent would'[4] with their own child.

### *MySSy – finding and registering records*

We have designed the MySSy Find Records interface for locating records about a child or young person's time in Care. It is a model of how rights to proactive disclosure can be realised. The idea is that when a Care experienced person activates MySSy, they can immediately see which organisations have records about their time in Care, and can then choose how and when to go about accessing them.

The interface we have designed also reflects how finding out about and accessing records is a very emotional experience. Hence, it is vital to have a degree of control over the process. We had lots of robust discussions about different approaches and preferences – how some might want to have a complete list of their records from the start, while others might want to have controls over which sites and records they are shown. The Find Records interface allows for sites to be 'hidden' that may have unpleasant and distressing associations and memories. These can then be reactivated when/if/as needed.

After finding out what organisations hold records a list of what is available from each site, can be viewed. This would come with various filtering and sorting options, with our prototype implementing date filtering as just one example. The records to register into your MySSy can then be selected, either individually or in bulk. Once registered, you can then add your own description and other notes, along with using the sharing profiles functionality to specify who you might wish to share this records metadata with. Hence, it is a way in which rights of reply to records could be implemented.

## Discussion and conclusion

MySSy is more than just another digital app. It is a design provocation: tools of, and for, the imagining of distributed, rights-based, participatory recordkeeping networks. With a records registry at its heart it imagines giving a child, young person or adult Care leaver visibility and control over their records network. It is a blueprint for a networked information infrastructure to enable rights to participate in recordkeeping to be enacted. Both its design and its (co-)designing demonstrates the value of pursuing participatory approaches to reach a deeper understanding of the needs of children, young people and the adults they become, at the centre of child protection systems and explore their realisation in a digital system (Steiner, 2021).

One of the benefits of co-designing in a research environment was having the freedom to explore 'what if' rather than being tied to fitting in with 'what is'. However, this is also a limitation, as the challenge now is in communicating our research prototype to practice audiences to influence their thinking about the design of their processes and systems. A practical problem is how to do that after project funding has been exhausted, and members of our co-design team have moved on. Sustaining the prototype on the ARDC Nectar Research Cloud has also raised issues with platform updates over which we have no control requiring detailed technical troubleshooting. This has been frustrating, but also illuminating as we have come to appreciate that promulgating the conceptualisation of MySSy is what matters rather than maintaining the particular instance of MySSy developed in our research.

MySSy's design has major technical implications for recordkeeping systems in the Care sector and for refiguring relationships around active, informed and supported participation. It challenges the Care sector to consider how the rights rhetoric in legislation, policy and standards might be translated into digital capabilities, establishing the need to invest in the development of integration mechanisms, including technical interoperability standards, APIs (application programming interfaces between software systems) for records sharing and appropriate security protocols. This may be a challenge for the Care sector, not used to driving digital innovation, but instead relying on the use of commercial systems and tools or working with (or often around) organisation bound systems that reflect managerial needs rather than supporting relational social work practice (Devlieghere et al., 2020; Haider, 2021).

Our research illustrates how the Care sector might go beyond the usual 'fast paper' automation of processes, documents and forms towards exploring how digital technologies might be used to positively reshape power and relationships in Care systems. We believe we have to have these conversations, if we are to enable those with Care experiences to equitably participate in the recordkeeping that documents their childhoods and resonates throughout their lives. Developing future digital systems that embody voice, agency and equity are vital to ensuring the rights of Care experienced children, young people and adults to identity, memory and accountability and to grow up in a caring system.

## Notes

1. CREATE Foundation is Australia's national consumer body representing the voices of children and young people with an out-of-home care experience.
2. https://www.qld.gov.au/youth/support-services/young-people-in-care/kicbox
3. https://about.caringlife.com/
4. The Victorian Children, Youth and Families Act 2005, section 174 (b), requires a Secretary in placing a child to 'must make provision for the physical, intellectual, emotional and spiritual development of the child in the same way as a good parent would'.

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## Notes on contributors

***Joanne Evans*** is an archival and recordkeeping researcher and educator in the Faculty of Information Technology, Monash University. Her research aims to address the lifelong identity, memory and accountability needs of childhood out of home care. This involves the exploration of participatory design and research strategies to develop dynamic evidence and memory management frameworks, processes and systems supportive of multiple rights in records and recordkeeping.

***Rhiannon Abeling*** is a Research Assistant on the ARC Discovery Project, Rights in Records by Design, in the Faculty of IT at Monash University, where she is able to use her Care and Care advocacy experience to help imagine and design improved recordkeeping systems. She is keen to be part of helping to move out-of-home Care systems forward, ensuring a better tomorrow for all those involved.

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