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## Voice, agency, and equity: deep community collaboration in record-keeping research

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**Introduction.** This article presents the Rights in Records by Design project that seeks to address the structural, generational, and particularly egregious record-keeping issues associated with child protection and the out-of-home *care* sector. We provide various perspectives on our research approach that is geared to engage at individual, community, organisational and societal levels.

**Method.** The participatory design and conduct of the project involves all members of the project. We focus on the close and continuous collaboration during all phases of this project by not only domain experts from various disciplines, but also advocates and community members from affected communities. Research participants are involved in all aspects of the conduct of research from planning to the communication of results.

**Results.** We found that participatory and co-design approaches not only leads to richer knowledge generation and better design outcomes, but also to unexpected benefits resulting from the empowerment of participants. We also note difficulties in conducting participatory research within a traditional academic context.

**Conclusions.** This project demonstrates the importance of being given voice and being heard. In many ways, this project has served to create an empowering space to explore how constructing and using 'your own knowledge' can lead to a wide variety of personal, community, and sector transformations.

### Introduction

Issues of voice, agency and equity in records and record-keeping are increasingly motivating archival and record-keeping scholarship and practice. As understanding of records as complex representations of human activities has deepened, so too has awareness of the impacts of the power differentials embedded in existing archival and record-keeping frameworks, processes and systems ([Evans, McKemmish, Daniels, and McCarthy, 2015](#); [McKemmish, 1996](#); [Ross, McKemmish, and Faulkhead, 2006](#)). In Australia these concerns have been brought to our attention through the tireless advocacy of communities pointing out the lack of voice in and control over the institutional records that document their childhoods.

These communities include *Aboriginal and Torres Strait Islanders* (the Indigenous or First-Nations Australians. Note that the terms *Indigenous Australian* and *Aboriginal and Torres Strait Islander* are sometimes used interchangeably. Regardless, we acknowledge the diversity of Aboriginal and Torres Strait Islander peoples); those known as the *Stolen Generations* (Aboriginal and Torres Strait Islander children taken from their families as part of the ongoing colonial programme of cultural assimilation); *Former Child Migrants* (children deported from the UK to Australia, Canada, and Malta as part of UK child welfare practice); *Forgotten Australians* (an umbrella term for the estimated 500,000 children who spent some or all of their childhoods in institutions or outside a home setting in Australia during the 20th century); and those within child protection services or with a child welfare experience. Members of all of these communities have spoken of the ongoing impacts of institutional record-keeping on their identity and memory, their life chances and their struggle for accountability and redress ([Australia Parliament Senate Community Affairs References Committee, 2004](#); [Australia Parliament Senate Community Affairs References Committee, 2009](#); [Human Rights and Equal Opportunity Commission, 1997](#); [Royal Commission, 2017](#)).

'*Nothing about us without us*' is an increasing cry in the child welfare sector ([Golding, 2015](#)). Redressing past record-keeping legacies and building better frameworks for the future require coming to terms with participatory rights in records and record-keeping. A key research and design challenge is to develop record-keeping and archiving systems capable of acknowledging and handling the information rights of all stakeholders. There is a pressing need to develop systems that enable (often unwitting) participants to establish and exert their archival autonomy ([Evans, McKemmish, Daniels, and McCarthy, 2015](#)), to participate in societal memory with their own voice and with agency over the records in which they are represented, rather than being forever trapped as powerless *subjects* of records and record-keeping processes.

Critical questions regarding participation and agency also apply to the research and design activities investigating this challenge. It is clear that the continua of use and affect of records and record-keeping can only be comprehensively discerned through multi-stakeholder collaborations to collectively develop rich understandings of problem and potential solution spaces ([Rolan et al., 2018](#)). In particular, this will ensure that those individuals with living experience of the affect and consequences of record-keeping over long (even multi-generational) timeframes are not just the objects of study, but equitable participants in inclusive research and research design processes ([McKemmish, Burstein, Manaszewicz, Fisher, and Evans, 2012](#)). Not only is this due recognition of living experience and expertise, and rights to participate, but also has the potential to generate shared understandings which transcend the insights that would normally be gained from non-participatory academic research methods and traditional systems development projects. The '*radical potential*' of inclusive and participatory action research approaches to challenge and change '*ways of thinking, learning and being in the world, both among researchers and those members of communities with whom they collaborate*' ([Monk, 2010](#)).

In this article we present the co-design activities of the Rights in Records by Design project as an example of participatory research exploring questions of voice, agency, equity and participation in record-keeping. We begin by providing a brief background to the record-keeping challenges in Australia's out-of-home *care* sector and outline the inclusive research approach the Rights in Records by Design project is taking to address them. We describe our co-design activities as we explore requirements for a system that would enable those with *care* experiences to access, manage and control their childhood records. This is followed by reflections by both the academic and community participants on the research and communications processes. We then conclude with the outcomes and implications for participatory research that we have identified at this stage of the project. Throughout this article, we explicitly employ the plurality of voices within the research team as a framing element, reflecting and reinforcing the co-design principles of the research.

## Record-keeping research and the *care* system

Out-of-home *care* (OOHC) is the contemporary term used in Australia to describe the temporary, medium-term, or long-term 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. Through several waves of reform, there has been a transition from children growing up under quite frightening and brutal conditions in children's homes, orphanages and other residential institutions, to being predominantly being placed into family-based *care* (e.g. foster or kinship *care*). There are some supervised group housing arrangements, known colloquially as *resi* (short for residential) units, which can too often increase safety risks for children and young people ([Commission for Children and Young People, 2015](#)). As explained by Wilson and Golding (2016), the capitalized form of the word, Care, is often used to denote the ironic connotations of uncaring treatment in a fragmented, fractured and under resourced system, without the typographically heavy-handedness of continually enclosing the word in quotation marks. In this article we will use the italicised version, *care*, for this purpose.

In the first decades of the 21st century, Australia's 'child welfare' systems morphed into 'child protection systems'. It remains a system open in 2015 to the same criticisms made in 1900 and in 1950, namely that it is poorly coordinated, inadequately resourced and often unable to protect children from significant physical, emotional or sexual abuse. ([Bessant and Watts, 2017](#))

Statistics from 30th of June 2018 indicate that nationally there are about 45,800 children and young people in the out-of-home *care* system, with almost 95% in family-based *care*, and over two thirds have been in *care* for longer than two years ([Australian Institute of Health and Welfare, 2019](#)). Despite a range of sector reforms and policy emphasis on helping families rather than removing children, the statistics show increasing rates of removal, longer periods of time in the *care* system and continued over-representation of Aboriginal and Torres Strait Islander children.

Our concern is with the role of record-keeping in the *care* system. Many years of advocacy by the *care*-leaver (those with a *care* experience, but no longer in *care*) community have highlighted the difficulties faced in finding and accessing records in their search for identity and memory, (re)connecting with family, holding the child-welfare system accountable, and seeking redress for abuse and neglect ([O'Neill, Selakovic, and Tropea, 2012](#)). The 2015-17 Australian Royal Commission into Institutional Responses to Child Sexual Abuse (RCIRCSA) is the latest in a long line of inquiries ([Swain, 2014](#)) to identify '*systemic and enduring*' record-keeping problems:

For those who grew up away from their families, the absence of the records of childhood that many people take for granted – for example, birth certificates, photographs, art works, school reports and medical histories – can have profound consequences. Some survivors were unable to obtain passports, while others had to apply for Australian citizenship as adults, despite the fact that they were born and raised in Australia. Without the childhood records and mementos that those who grow up with their families typically retain, survivors may feel lost, isolated and incomplete and that their childhoods were meaningless or insignificant. ([Royal Commission, 2017, Vol 8, p. 10](#))

While experiences of *care* are varied, many negative outcomes during or following *care* pertain to the deleterious effects of non-existent, poor, inaccurate, or malicious record-keeping, compounded by records access frameworks that reinforce a lack of power and agency by *care*-leavers. To find their records, *care*-leavers are required to negotiate an array of bewildering bureaucratic processes, and suffer from the complexity and inconsistent application of law and policy; the costs of access (for example, application fees and processing charges); and especially rigid thresholds for verifying identity, particularly pernicious given that one reason for requesting records in the first place may be to establish identity ([Royal Commission, 2017, Vol 8, p. 88](#)). The Royal Commission noted that despite reforms as a result of recommendations from prior inquiries many '*were still experiencing considerable difficulty and distress in accessing records*' ([Vol 8, p. 39](#)).

These experiences are symptomatic of the power imbalances embedded in existing record-keeping frameworks, processes and systems. These have been constructed primarily to support the business and administrative needs of the government agencies and other organisations in the *care* sector. Case records are written about clients by workers and are owned and controlled by the organisations for which they work. Children and young people are the mere subject of the records, and have little or no rights or agency in record-keeping processes. The consequence is ongoing inability to meet the identity, memory and accountability needs of those with childhood *care* experiences. A shift to a participatory record-keeping paradigm is needed to acknowledge the rights of those with *care* experiences in the records and record-keeping that documents their childhoods ([Evans, McKemmish, and Rolan, 2017](#); [Gilliland and McKemmish, 2014](#); [Rolan, 2017](#)). It requires socio-technological transformation of existing record-keeping infrastructure, designed for a different age, different values, and a different technological paradigm, and which has put the rights of organisations and institutions ahead of those of children, young people and their adult selves.

Whilst much of the research into the *care* system has not concerned record-keeping directly, research is frequently undertaken using the very records that are often denied to those documented within them ([Wilson and Golding, 2016](#)). Its conduct, from a social services perspective of investigating policy, practice and/or outcomes, can often seem to serve research interests without meaningfully addressing the concerns of those studied ([Wilson, Mendes, and Golding, 2018](#)). It tends to reflect the power imbalances in traditional research approaches, where researchers extract knowledge from *participants* who then have no control over how it is contextualised, communicated, or applied. Control over information is often signed away at the moment of giving consent to participation in research activities. However, the anonymity that is ostensibly for the protection of participants, also denies their voice and agency. The researcher becomes the cited expert through the relaying of the words and experiences of the anonymous participants.

Both *care* system record-keeping itself and record-keeping research in the sector are therefore bound up in structures of institutional power and social inequality that, historically play out for individuals caught up in the *care* system with detrimental effects. Both of these aspects need to be tackled '*to transform the way that archival and record-keeping systems connect and communicate and are threaded into the community, organisational and social fabrics*' ([Evans et al., 2015, p. 358](#)).

## Participatory research and co-design

Participatory research is an umbrella term for a school of approaches sharing a core philosophy of inclusivity. It recognises the right of those who are intended to be the beneficiaries, users, and stakeholders of research to participate in all research processes, from conception to design to the doing and to dissemination. It also recognises the value and benefits of such an approach in generating knowledge and understanding and affecting change, summed up in the following quote from two of its leading advocates:

Participation in inquiry means that we stop working with people as 'subjects' (which, in actuality means to hold them as objects of our gaze) ... Instead we build relationship as co-researchers. Researching with people means that they are engaged as full persons, and the exploration is based directly on their understanding of their own action and experience, rather than filtered through an outsider's perspective. Participation is also political, asserting people's right and ability to have a say in the decisions which affect them and claim to generate knowledge about them. And, in addition to producing knowledge and action directly useful to a group of people, it can also empower them at a second and deeper level to see that they are capable of constructing and using their own knowledge. ([Reason and Bradbury, 2001, p. 9](#))

This is a fundamental contrast to research approaches which feature transient engagement with, and extraction of knowledge from, subjects of research, even when couched in terms of consultation, collaboration, or participation ([Evans, 2018](#)). Often experienced by Indigenous communities, such *helicopter* research benefits the researcher and research organisations without necessarily leading to meaningful improvements for participants ([Braun, Browne, Ka'opua, Kim, and Mokuau, 2014](#)). An extractive research paradigm is one manifestation of token forms of *participation* ([Arnstein, 1969](#)) that can negatively impact participants. Such research can squander limited resources, particularly if the participants are the subject of repeated investigation. Expectations that are raised and not met can exacerbate perceptions of alienation and disillusionment. Even more injurious is where information extracted from participants is exploited, or worse, used against participants' best interests. Finally, involvement in the research itself can cause conflict within communities or expose participants to danger from outside sources ([Chambers, 2006](#)).

As described above, extractive research is common for those with *care* experiences and is all the more egregious because of the power imbalance relating to records ([Wilson et al., 2018](#)). In the light of this, it is incumbent upon researchers to recognise their position of real power and consider how to engage in a sensitive manner. Such engagement is not easy and it may indeed be sometimes simpler to avoid uncomfortable interactions in sensitive research domains (for example, see [MacNeil, Duff, Dotiwalla, and Zuchniak, 2018](#)). However, we argue that the ethical and intellectual demands of research make it obligatory to tackle the cultural shifts

necessary within the academic community to give voice to those experiencing marginalisation through the use of a participatory approach to investigate requirements for participatory record-keeping.

We are therefore interested in moving beyond documenting concerns towards finding solutions to record-keeping problems through applying pragmatic research methodologies such as design science ([Gregor and Hevner, 2013](#)) in a participatory manner ([Evans, 2017](#)). This involves the use of co-design methods to bring those with *care* experiences into the design space and surface issues, rights, stakeholders, and, most importantly, values that may be otherwise hidden from a here-and-now, transactional viewpoint.

Co-design, while currently an over-used buzz word for any consultation process, is a way by which a range of living and professional expertise can be harnessed to address complex social challenges. Like participatory research it seeks to involve those impacted by systems and services in re-design efforts, engaging with their deep experience of the systems and services and their insight and creativity into what may make them better. As with participation more generally, co-design is not just another word for consultation, requirements gathering, or usability testing, in user experience design. Co-design is a deeply collaborative process comprising reflective, iterative phases that bring together a range of experiences and expertises and move from creatively exploring, defining, and redefining the problem through to identifying, prototyping and implementing potential solutions. As with participatory research, it is about the right to have voice and agency in design processes, and for recognition of expertise in an individual's own living experience.

Some key features of co-design are that it uses creative methods to create an equal relationship between a range of stakeholders; it respects the experiences and views of everyone connected to the issue; and it captures these experiences, then shares, analyses, debates and uses them as a foundation for inspiring new ideas and responses to challenges. ([Szebeko and Tan, 2010](#)). Co-design results in building capacity and coalitions among communities, creating a strong sense of ownership of the many ideas that result.

## The Rights in Records by Design project

The Rights in Records by Design project is an Australian Research Council Discovery Project investigating the design of systems to support the record-keeping rights of people who experience childhood out-of-home *care*. Conceived as a transdisciplinary project, its chief investigators are drawn from information technology, history, social work, and education disciplines, with *care*-experienced community advocates an integral part of the research team. Through an inclusive research and participatory design approach, the project team aims to develop a model distributed and participatory record-keeping system to enable those with *care* experiences to participate in the creation of their records and exert their rights to identity, memory, accountability and privacy in the ongoing management, access, and use of their records. We aim to challenge institutional record-keeping and research paradigms that result in records '*dominated by the viewpoint of those in power, the decision makers*' ([Brownlee-Chapman et al., 2017](#)).

Running in parallel with other research activities, a small co-design team has been established made up of two academic record-keeping researchers (Greg Rolan and Joanne Evans), and five young *care*-leaver advocates (Rhiannon Abeling, Aedan Brittain, Elizabeth Constable, Matthew Kelemen, and Ella Roberts) with past or present involvement with the CREATE Foundation (the national consumer body representing the voices of children and young people with out-of-home *care* experiences). Through CREATE they have undergone extensive training, linking their *care* experience to learning more about the *care* system and developing advocacy, leadership, and public speaking skills. As young consultants they have used their stories and experiences to work with Commissioners for Children and Young People, Department Secretaries, Ministers and chief executives of representative bodies and non-government agencies and to advocate for positive changes in the sector.

The co-design team came together in a series of eight four-hour workshops in the latter half of 2018, with a number of aims:

- to learn about experiences and aspirations when it comes to records and record-keeping in general, and in particular with respect to the *care* system;
- to imagine rights-based, person-centred, participatory record-keeping and lifelong living archives for childhood out-of-home *care*;
- to develop a set of design communication objects (e.g. personas, design principles, trajectories, storyboards) to convey requirements into digital prototyping; and,
- to build advocacy and co-researcher relationships between participants.

Each workshop focussed on a different aspect of the design problem, but with the common concern of exploring the way particular records manifest during *care* and beyond. Mutual learning has seen the academic researchers gain a deeper understanding of *care* records and the impacts a lack of voice and agency in them has over young lives, with the *care*-leaver advocates gaining insight into the design of record-keeping and digital information systems. The team has collectively established ground-rules, selected activities, and discussed outputs. We have shared family stories and we have also laughed a lot.

During these workshops, the question of the communication of results was raised. One suggestion was the 2018 RAILS: [Research Applications, Information and Library Studies](#) conference with its theme of Engaging Research: Collaboration and Community that recognised the need for '*efforts across disciplinary boundaries, which calls for new approaches and questions within information and library studies, and archival science*'. The opportunity to present at RAILS was enthusiastically embraced as a way to communicate to an information studies research audience our learning about, and reflections on, participatory record-keeping research. Because it was being held at Monash University in Melbourne, where the team is based, it presented an opportunity (in the absence of an extensive travel budget in the grant) for a research audience to hear directly from community co-researchers, rather than the usual '*ventriloquism*' ([Sexton and Sen, 2018](#)). Together we developed the script and slides for the presentation and, drawing on *care* advocacy experiences, designed a role-playing exercise with audience participation as a feature. The session aimed not just to talk about voice and agency in research, but to actually demonstrate it.

In the following sections we further develop the presentation script as a reflection on the participatory research process and the understanding of record-keeping needs for *care* experiences coming out of the workshops. Developing the conference presentation and this subsequent paper has been an opportunity '*to embrace processes of co-reflection as a means of addressing and, where possible, transforming asymmetries in position and privilege between participants*' ([Sexton and Sen, 2018, p. 884](#)). It also illustrates the mutual learning and understanding of problem and solution spaces unfolding in our co-research and co-design processes ([Brownlee-Chapman et al., 2017](#)).

## Establishing the participatory research space

*Perspectives: Greg, Joanne and Rhiannon*

An understanding of the affective nature of records relating to childhood *care* experiences informed our approach to the design of the workshops. We needed to create an environment in which we could discuss the ways in which sensitive and personal information about children and young people in difficult and vulnerable situations should be handled. As record-keeping researchers, we are aware of symbolic power, not only of records but also of institutions, institutional architecture, and of the academy. Being continually mindful of how we were to wield that power was vitally important, as we cannot escape it. We needed to make the research space welcoming and do our homework regarding the needs and experiences of the *care* advocates that we wanted to work with.

Aware of what we didn't know, we engaged Rhiannon as a research assistant to help us develop the plan for the workshops. Our first task together was to work on making the ethics documentation (call for participants, explanatory statement, consent form, and so on) better meet the needs of both the Monash University Human Research Ethics Committee and the potential participants. It was an interesting negotiation as we progressed the documents from standard officious academic communiques to something featuring warmer and plainer language to better inform potential participants of what would be involved. This negotiation continued into the first workshop when we made time to discuss consent as a process and asked for further feedback on the language we used on the documentation.

Another key activity at the start of the initial workshop was collective establishment of ground rules for collaboration. Joanne's suggestion to use an archive box as a metaphor for the group's rules of engagement was quickly accepted. As we agreed on what behaviour was to be in or out of the box, the contents of the archive box represented those attitudes that we would want to preserve, nurture, and protect throughout our work. Mindful that one of the things we needed to discourage was the propensity of the academics in the group to use record-keeping and research jargon, we spent a bit of time discussing how it could be called out. We came up with

the idea of an academic jargon scoreboard where we could be red-carded (to borrow a sports metaphor) and asked to explain what we meant whenever we used a term or phrase that wasn't universally understood. It made the use of inclusive language and learning fun; a challenge for us to not get caught out and a challenge for the others to catch us out.

Making the physical space for the workshops welcoming was also considered important. Knowing that it can be difficult to navigate to meeting rooms on university campuses, Greg ensured that the way to the workshop room was well signposted. The team commented on the helpfulness of those signs in making those coming to meet us for the first time know that they were in the right place. It also proved to be an important precedent as we found ourselves rarely meeting in the same space twice given the limitations on meeting room availability during busy times in the semester. It might seem like a small point but it was part of the development of trust in our co-research and co-design relationship.

To meet as co-researchers rather than researchers and subjects, we also needed to show that the time and expertise of participants was valued with appropriate remuneration. Joanne's Future Fellowship (the Australian Research Council's programme for funding high-impact researchers) grant had a budget for this, but a key issue for the future is how the university and government research funding administrative processes could be improved to explicitly cater for the remuneration of research participants. It was a lesson in how the inflexibility of university bureaucracy can make participatory research difficult because the relationships sought with community participants fall outside of traditional assumptions of research roles. As researchers our role is to advocate for the better support of participatory research within universities and to make the case to funding bodies as to why appropriate remuneration for participants is an essential part of research budgets ([Bergold and Thomas, 2012](#)).

Our workshop plan reflected the space of mutual learning that we wished to create. We wanted to learn about record-keeping needs, but also share our knowledge of record-keeping and information technology systems, so that we could come to joint understandings of the problems and together imagine better solutions. Constructed as a dialog we planned to move from the *what is* of current record-keeping systems in the *care* sector to *what could and should be* if designed from the *care*-experienced person perspective.

*Perspectives: Matt, Ella, Liz and Aedan*

Greg, Joanne and Rhiannon created a welcoming and comfortable space in which we felt able to share our views on *care* system record-keeping. We have appreciated the open ended nature of the discussions, rather than just being the subject of an interview or a survey. This gives us voice, a chance to get our viewpoint into the design of future systems. We are advocates for better *care* experiences and have passion for this work. It is not just a job: this is what we are living. We probably would get involved in this project even without payment. But it is good that our work is recognised and that our expertise is valued.

We can't stress one point too much: how important it is not to be treated as a research subject and have experience extracted as research data. We are actual people; not just a number on a case file, a name on a court docket, or a data point in a research model. This is what participatory research is about: treating us as equal and valued research partners. It has been great to have input and say in the project and involvement in other parts of the research journey, not just the bit where we are asked questions. In so doing we have learnt a lot about academic research processes and why they are constructed the way they are.

We have spent a bit of time discussing the language of the *care* system as well as records, archives, and information technology, making sure that everyone understands what is being said. Maybe we all now use less jargon. Or maybe we understand it better. Either way, communication is not a problem. Along the way we have learnt about record-keeping, its language, purpose and principles, so we have a clearer picture of its complexities. It has also been interesting to learn more about the configuration of information technology systems, and the role of metadata in understanding how privacy and security could work. We now appreciate how *accessible in one place* does not have to mean a central database. This understanding of the back-end is important when you've mostly dealt with the front-end of government systems like Centrelink (the Australian government social services agency) and MyGov (the Australian government services Web portal). We have also worked through how we would like to use and maintain records, both during *care* and after; curation activities that Greg has nicknamed *tending the garden*.

*Perspectives: Greg and Joanne*

Reflecting on some of the down sides, we should have been better at maintaining momentum of the workshops. Too often our busy schedules (not only other research streams within the Rights in Records by Design project, but other academic work as well) have got in the way of workshop scheduling. Perhaps we could have sought ways of meeting more intensively and providing more feedback in-between the workshop sessions. In our next round of workshops we hope we can better pace the co-design process. These scheduling and workload constraints underscore that the reality that, in having control of the resources and setting the agendas, we are the ones calling the shots in terms of activity planning. While the project has a participatory research ethos, pragmatic considerations impact on how that actually plays out. Challenges of participatory research processes include dealing with instances of inclusion and exclusion, along with sustaining relationships through the ebb and flow not just of research cycles, but also of people's lives.

Similarly, because of the complexity of the problem domain, at times we have found ourselves on tangents, discussing other initiatives in the sector, mechanisms for advocacy, or even pathways into higher education. Some of these diversions have yielded areas of exploration and insights that could not have been anticipated while others have been less productive. How to better maintain focus is something we need to consider for the remainder of the research project.

## Care system record-keeping

*Perspectives: all*

Together through our workshops we have come to a better understanding of the record-keeping activities and systems of the *care* system in Victoria, from all the different types of records, notes, reports and so on that are kept by the government department responsible for child protection (including material not documented on departmental workflows or policy guidelines), and the differences between the department and agency (non-government organisations responsible for delivering out-of-home *care* placements and other programmes) records. Advice has been shared, for example, about knowing where to ask for records and which records to ask for, and experiences around costs, and redaction of material discussed.

As the records continuum model ([McKemish, 2017](#)) and the participatory record-keeping continuum model ([Rolan, 2017](#)) indicate, there is a diversity of perspectives, values, and needs in record-keeping, which we found even within our small group. But we have been able to marshal the pluralities of both professional and living experience to confront these, and move from rights in records and record-keeping as an ideal towards a coherent systematisation of rights. We have mapped the complexity of trajectories through the *care* system and beyond, along with the associated record-keeping requirements. This will feed into the next phase of workshops when we look at the prototyping of a childhood record-keeping system for the *care* experienced.

It has become really clear that, while everyone has a different experience of records and record-keeping, it is the people at the centre of the records who are most important. record-keeping should be providing continuity of evidence and memory throughout the disruption of childhood due to *care* interventions. Discussing various experiences of *care* records has exposed some of the manifest unfairness in the system, which can continue to reverberate when a person is no longer in *care*. Put bluntly, the department is not acting '*as a good parent would*' when it comes to record-keeping and so records are not playing the role that they could in a child's '*physical, intellectual, emotional and spiritual development*' ([Children, Youth, and Families Act 2005](#)).

From diving together into legislation and policy impacts on record-keeping practice, we now have a greater appreciation of the complexity of regulations within the *care* sector. We also have an understanding of the difficulty of changing laws and government regulations. This learning has given us a chance to see other perspectives. It has helped us develop empathy for others working in the *care* system. We can see that they may be trapped in a less-than-ideal system, implementing regulations or policies not of their choosing.

This lets us move from thinking of *care* workers, *carers*, administrators, record-holders, and others that embody the system as *the enemy*, to trying to understand how we might jointly advocate for change. For example, we can feel for administrators dealing with limitations of systems that poorly document records, or those that have to review records of *care* and redact details from them to conform to risk-adverse interpretations of privacy legislation. This brought home to us how difficult it is to change the existing predesigned framework, and where this research may fit in breaking free of some of those constraints. What has become clear are

the ways in which good record-keeping could drive better, proactive practice and, ultimately, community change. Likewise we now understand the competing rights of different stakeholders, but it is also clear that we need to voice and fight for the record-keeping rights of children and young people in the *care* system.

## The RAILS conference presentation

*Perspectives: Rhiannon, Matt, Ella, Liz and Aedan*

In developing the RAILS: Research Applications, Information and Library Studies 2018 conference presentation, we felt that it was important to demonstrate the barriers we experience in trying to obtain *care* records. We thought that a short role-play would be best, with each of us taking on roles of various institutional and bureaucratic service providers. A volunteer from the audience was selected to play an unemployed, essentially homeless eighteen-year old who had recently transitioned from years of living in residential *care*. Their task was to obtain records as proof of having been in *care* for accessing youth allowance payments, as well as to answer a number of personal questions about what happened in their childhood.

The volunteer began with the department but was quickly referred to its Freedom of Information Unit (as this is the legislatively-mandated method for accessing *care* records in Victoria, Australia) who first required proof of identity. For most people, this would be straightforward. But without a driver's licence or, even in some cases, a birth certificate, this can be difficult. The volunteer was then directed to Centrelink (the Australian government's social services agency) at which obtaining a certified identity document was shown to be a complex and fraught activity in its own right.

Back at the freedom of information unit, the next hurdle was to create a request with '*as much detail as possible, such as the type of document, the date produced and its agency reference number*' ([Department of Health and Human Services Victoria, 2018](#)). Trying to find out what records may exist can lead to circular enquiries with referrals from department to department. Finally, after speaking with friends, other *care*-leavers, and finding the *leaving-care-hotline*, the volunteer was able to work out what to ask for, and after finding out how to provide proof of hardship in order to have the freedom of information application fees waived, was able to receive some records. We used actual case-file records that we enlarged to A3 size to show the audience. The records ranged from having individual names redacted, to being completely blank. We used these to pose questions to the volunteer and to the audience in general about the process and quality of response.

Much of the audience was justifiably surprised at the complexity and difficulty of records access. We stressed that this was a small slice of the access problem as record-holders include not only government child protection departments, but also a range of non-profit and commercial organisations providing *care* services; individual *carers* and other professionals; families and friends; the courts; the police; the health system; government assistance programmes; and educational institutions and professionals. Feedback we received after the presentation was that the role-play really brought home the difficulties and frustrations often experienced in trying to access an individual's records of *care* (and made a pleasant break from the usual PowerPoint talks). We hope it had the audience thinking about the relationship they will have with stakeholders in their next research project.

Our reflection is that in developing the conference presentation, and in the project more generally, we are given voice, a chance to speak and get our viewpoint across about research and about the design of future record-keeping systems in the *care* sector. We are more than research data and not just *care* statistics. Working on the project has also helped us think about our work and lives in a bigger context. We feel validated and encouraged to follow our dreams, passion, and develop our future possibilities.

## Conclusion

Our co-design workshops have been a process of education for all of us. We have shared our knowledge about *care*, research, record-keeping, and system design, and have a greater appreciation of the complexities we need to factor into our research and advocacy work. We have been forced to confront the complexities and inhomogeneity of diverse experiences of out-of-home *care* as we attempt to break away from the lowest-common-denominator of current systems thinking in the child protection and welfare sector. The workshops have made it clear that we need to be designing record-keeping systems that support identity, memory, evidentiality, and accountability requirements beyond the immediate transactional context. We must take a through-time, or diachronic perspective, identifying the needs of all participants from a variety of disciplinary perspectives and their manifestation across space and over time. Through this participatory research and co-design process, we have obtained a rich understanding of the problem and solution spaces, with insights that surprised and challenged us. This knowledge positions us to commence the iterative prototyping of components of a lifelong living archive framework (a childhood record-keeping system that serves changing needs over multi-generational timescales) in the next round of workshops

In designing such a system, we are able to identify, not just its immediate transactionality but also its longer term, social and societal impacts. This often tacit and experiential knowledge can only be comprehended through collaboration, rather than consultation, to develop deep and rich understanding of problem and solution spaces. The research is based directly on the understanding of participants' own experience, rather than extracted through arm's-length requirements elicitation. Our research findings, and the design outcomes are all far richer – as foreshadowed in the earlier quote by Reason and Bradbury (2001).

However, beyond the research findings and the recognition, attribution, and application of generated knowledge is the impact on individuals and the community. Whenever we talk about out-of-home *care* we are rarely far from the political. It is difficult to engage in the sector without being reminded of the immediate and day-to-day impact records and record-keeping have on those with *care* experience. There have been several unexpected consequences of facilitating the ability of participants to have a voice in both the knowledge generation and its application.

The first was in relation to *care* system advocacy. Our aim in conducting this research is for transformational change. However, our own advocacy and activism ([Evans, McKemmish, Daniels, and McCarthy, 2015](#)) as well as that of our community participants is not core to the design activities of the research. Even so, it was pleasantly surprising to see how the knowledge generated in the project is not only furthering the design but also reinforcing other *care*-practice advocacy activities by the project team members. Since the aim of the research is for change in the sector, this is a double benefit of the participatory approach.

Also unexpected were the reflections about increased empathy for workers, *carers*, and bureaucrats caught up in the *care* system that emerged as we developed the conference presentation. While it may be easy to demonise those who embody the child protection and welfare sector (particularly for those who experienced poor treatment in care), this project has demonstrated that knowledge about complexity and a systems view can bring about changes in interpersonal perspectives. Most importantly, though, we did not expect to hear of the individual empowerment in terms of personal aspirations and validation from being part of the co-research and design team.

Conducting participatory research in this way has had its challenges (in dealing with faculty, ethics boards, and funding sources that are not configured for this approach) but we are convinced of its need and significance. We have greater understanding of the importance of being given voice and being heard. In many ways, this project has served to create an empowering space to explore how constructing and using *your own knowledge* can lead to a wide variety of personal, community, and sector transformation.

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**Matthew Kelemen** draws from his out-of-home-care lived experience and exposure to advocate to achieve a higher quality of life for all youth, careers, and workers in the Child welfare sector.

**Ella Roberts** became part of the rights to records group because she had experienced the instability in the care sector, and wants to push for reform and consistent support for young people experiencing disadvantage.

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