Digital Equity for Peoples and Communities including Marginalised and Displaced

Research & Advocacy

Kathy Carbone  
UCLA

Sue McKemmish  
Monash University

Gregory Rolan  
Monash University
Introduction and Overview

Sue McKemmish
Imagine global digital equity: a world where

- discourses around data have shifted from commercial protection towards technologies for humanist self-actualisation

- Peoples who have been marginalised and displaced can establish and maintain rights in their data, information and records, as a crucial, but currently unmet, foundation for exercising their human rights
Envisage a world ...

- achieved through research in, and application of, rights-based design principles and innovative technologies

- where stakeholders in information are no longer viewed only as users, clients, or targeted demographic markets, but as active participants in their data

- a future where data is neither weaponised nor exploited, but considered as sovereign to individuals, families and communities.
What is data sovereignty?

• Typically defined in terms of data ownership in the context of legal jurisdictions and motivated by a desire for exclusive authority and control over data assets by institutions or state actors [1]

• Rights in data that support data autonomy are much broader supporting:
  • Self-determination
  • Identity
  • Memory
  • Cultural heritage
  • Evidence requirements
  • Accountability and transparency [2].

• Communities worldwide are demanding much more complex and nuanced approaches to data sovereignties
Why is data sovereignty a core concern?

• Human rights are articulated in international conventions and declarations, national instruments, and local regulation.

• The actualisation of all of these rights depends on data sovereignty, including control and access rights in data, information and records.

• An inability to exercise agency in our data affects us all, but it disproportionately impacts peoples who have been marginalised and displaced.
Their concerns are compounded by ...

• Embedded biases and values in software design which widen the digital divide.

• Information systems and networks that are becoming a root cause or exacerbating force of disenfranchisement from predictability, security, material wellbeing, and/or psychological welfare [3]

• Algorithmic decision-making that is emerging as a core plank in IS design but accountability and transparency are major problems[4]

• Outmoded forms of information governance which are largely ineffective in the digital world
Digital Equity Network

- Bringing together partner universities, civil society organisations and communities
- Meeting in Liverpool, July 2019
- Research and advocacy globally and locally to pursue digital equity in the context of human rights and social justice for refugees, Indigenous communities, children and the aged in Care, people living with disabilities, ....

- A partnership of Digital Equity Lab at Monash University and UCLA, UCL, Manitoba and Toronto Universities and..................., and their community partners
Refugee Rights in Records

• Globally, tens of millions of people are subject to some form of forced displacement [5].

• They lack access to and control over their data, resulting in:
  • inability to exercise their rights under the United Nations (UN) Convention and Protocol Relating to the Status of Refugees 1951/1967
  • denial of asylum claims
  • return of displaced individuals into dangerous spaces
  • statelessness
  • separation of and difficulties in reuniting families
  • heightened vulnerability for women and children [6].
Rights in Childhood Records

• In Australia, 1 in 32 children receive Child Protection Services, with almost 50,000 children (that is, almost 1 in every 100 children) in out-of-home Care – and ten times the number of Indigenous Australian children are in Care relative to their numbers in the general population [7].

• Globally many governmental inquiries highlight the failure of information and recordkeeping systems to meet their lifelong identity, memory, cultural, accountability and information accessibility needs [8–10].

• In Australia, the most recent Royal Commission into Institutional Responses to Child Sexual Abuse [11] emphasized the pressing need for the design of information and recordkeeping systems that enable children in Care to exercise the rights set out in the UN Convention on the Rights of the Child [12]: to know who they are, reconnect with family, practice culture, seek redress and bring perpetrators of abuse to justice.
References


References (cont.)


Recordkeeping Scenarios
Fictional Scenarios as scaffolding for thinking

- Workshop to begin thinking through development of a research agenda
- Focussing on supra-jurisdictional issues or those with application in all jurisdictions
- Fictional scenarios as a mechanism to spur imagination and thinking
- Instructions not to ‘solve’ the problems but to dig down into the component infrastructure that might be needed
Geographic displacement and climate change

Itabarik is a small pacific nation facing a devastating future with the predicted rise of sea levels due to climate change. A range of projects to proactively address this reality have been proposed to the Itabarik Governing Council. Amongst these are:

• A project to create a data embassy for Itabarik which will back up the digital transactions of Itabarik citizens and services, modelled on the Estonian data embassy. Yet to be specified in depth, it is clear that this will involve identification of a sympathetic partner country, establishing appropriate data and cyber security controls

• Proactive documentation of the landscape and culture of Itabarik with the intention of establishing a virtual representation of the islands for use by a diasporic and geographically displaced population which is anticipated in the future, featuring capability for the community to contribute their own stories, photos, records etc

• A citizen science project to collect and store details of sea levels, temperature, rainfall around the island

• Prioritised digitisation of existing analogue records and planning for a virtual digital archive, to be housed in the data embassy, initially focussing on records relating to individual Itabarik citizens facing geographic displacement.
Refugees and Stateless People
Indigenous community recordkeeping and knowledge systems
Framework for Refugee Rights in Records

Kathy M. Carbone
Anne J. Gilliland
Refugee Rights in Records (R3) Initiative

• An international multidisciplinary, multi-stakeholder research collaboration that is pursuing various research projects addressing a range of records/data concerns related to the global grand challenge of forced displacement and mass migration due to:
  • Conflict and persecution
  • Climate change and environmental disasters

• Overall goal: to identify how humanitarian-centered recordkeeping interventions in the arenas of recordkeeping systems and practices, technologies, law and policy might assist refugees and their descendants across time and geographies

  • https://informationasevidence.org/refugee-rights-in-records
Investigating Refugee Rights in Records
The US/Mexico border

- People who are being detained for illegal entry into the United States sit in one of the cages at a facility in McAllen, Texas on Sunday, June 17, 2018
  - Photo: U.S. Customs and Border Protection and the Associated Press
70.8 million forcibly displaced, more than any time since World War II:
  • 25.9 million refugees
  • 41.3 million internally displaced
  • 3.5 million asylum-seekers

Every minute: 25 people were forced to flee their homes
Every day: 37,000 people were displaced

The number of people who are refugees, asylum seekers, or internally displaced: 1 in 108 (ten years ago it was 1 in 160)

https://www.unhcr.org/figures-at-a-glance.html
https://www.unhcr.org/globaltrends2018/
Displacement and documentation

- Documentation is central to and threaded through every facet of the life of a refugee

- Official documentation is predominantly created by or through an interaction with an authority or agent other than the refugee
Required, privileged, and invoked records

During asylum interviews, hearings and other refugee processes, many kinds of records, both contemporary and historical records, are required and invoked, everything from centuries old land records to bio-based records:

- birth, marriage and death certificates
- travel and transit documents
- police, security or intelligence records
- property and tax records
- education and health records (including medical records indicating injuries sustained as a result of persecution or conflict)
- records of prior employment and military service
- biometric and surveillance records created in camps and elsewhere
Required, privileged, and invoked records

Besides these official records, documentation can also include:

• personal testimonies
• photographs
• social media
• artefacts

provided by refugees to authorities
extracted from refugees by authorities
Access to trusted records in various forms, formats, and locations are essential:

Refugees need records from their past lives to secure their future lives

- To establish identity and age, familial relationships, ethnicity, nationality, status and health rights
- To document persecution or credible fear of persecution
- To obtain benefits, healthcare and education
- To be able to practice a trade or profession
- To ensure successful resettlement, integration or return
- To reclaim property or land or to claim reparations
- For generational claims to citizenship
Two-part research question

• What roles do records, as well as the data they contain and the recordkeeping purposes, systems and processes that produce and manage them, play in asserting, securing or denying fundamental human and other personal and data rights of internally displaced persons, asylum-seekers, refugees and others who have experienced forced displacement?

• How can we ensure that records, as well as the data they contain and the recordkeeping purposes, systems and processes that produce and manage them, do not prevent internally displaced persons, asylum-seekers, refugees and others who have experienced forced displacement from asserting and securing their human and other personal and data rights?
Data collection and analysis

Analysis of:

• 19 key international human, civil, and information/data rights instruments
• ICA Draft—Basic Principles on the Role of Archivists and Records Managers in Support of Human Rights
• Cases and stories reported in English and Arabic language news media
• NGO reports, and
• personal narratives
25 rights grouped under 9 rubrics

**Rubrics:**

1. Rights to have a record created
2. Rights to know
3. Rights regarding records expertise
4. Cultural, self-identity and family rights in records
5. Right to respond and to annotate (right to rectification)
6. Refusal and deletion rights
7. Access, reproduction and dissemination rights
8. Consultation rights
9. Personal recordkeeping rights
The Framework for Refugee Rights in Records

• Argues that:
  • enabling and activating human and personal rights laid out in key conventions and other internationally recognized instruments are significantly impeded without similar recognition of rights in and to records

• Aligns with:
  • growing national and international concerns about data protection and privacy for vulnerable populations
The Framework for Refugee Rights in Records

• Provides:
  • new mandates for recordkeeping systems design and archives

• Requires:
  • taking into account humanitarian and human rights needs for access to and a voice in the control over how records are managed, but also needs to secure and manage records for future accountability and research purposes
  • rethinking retention decisions regarding case files and “routine” records containing personal data
  • reprioritization and rethinking of how documentation is stored, described, digitized, made available, authenticated and adjudicated
Rubric 3: Rights regarding records expertise

- The right to request and be provided with a records advocate or expert in legal and bureaucratic processes who could help with locating, introducing and challenging records.

- The right to have a records expert testify as to the historical and bureaucratic circumstances surrounding the creation, management and reliability of records about oneself that are introduced in adjudications and other actions.

- The right to be provided with the index terms or other metadata necessary for searching and retrieving records about oneself.

- The right to be able to read and understand records about oneself or about one's own case.
Rubric 7: Access, reproduction and dissemination rights

• The right to access records about oneself, including those that are still otherwise subject to legal or other closure periods.

• The right to access one’s record according to one's own literacy and modality.

• The right to guaranteed safe, secure, timely and low or no-cost access to relevant records about oneself upon request.

• The right to receive copies of records about oneself, and to specify the form and format of those records, or else to be given a clear explanation as to why one may not.

• The right to transmit or share records about oneself.
Rubric 8: Consultation rights

• The right to be consulted regarding how, where and when records about oneself are preserved or archived, made available for archival research, or disposed of.

• The right to be consulted when and why another party, including family members, requests access to a record about oneself.
Rubric 9: Personal recordkeeping rights

• The right to a safe and secure personal recordkeeping place or space to preserve, manage, transport, and access records and authentic copies of records about oneself in and over time.
Complexities, contingencies, complications, contestations

Some rights may be incommensurate with each other:

• individual and familial rights in the same record

• the rights of an individual and the rights of others with a legitimate reason to have similar rights in particular records

• legal standing or understandings do not align between documents that are dependent on each other
Complexities, contingencies, complications, contestations

Other rights might:

- raise significant national or personal security concerns
- support the ability of perpetrators and other 'bad guys' to protect themselves to the detriment of those who are less powerful or victims
- be at odds with one or more existing human, civil or data instruments, statements, or policies
Some specific recordkeeping and archives (research and practice) challenges arising
• Are archives collecting/preserving/digitizing the necessary materials?

• How can we help locations without robust archival infrastructure to manage needed records or digitize and make trusted digital copies available?

• How can we help or incentivize archives in countries in conflict or subject to hostile regimes to provide extra-national digital access to their records by records subjects and their descendants?
• How do we integrate relevant records and data located across multiple institutions and countries? (the recent debacle with the reunification under court order of separated children and parents at the US southern border was in no small measure due to poor recordkeeping processes by border authorities and lack of ability to work across different agency systems)

• How do we describe holdings in (scalable) ways so that asylum seekers, refugees, and aid workers can find relevant records? Related records? Alternative sources of needed data?

• How do we ensure that our data or digitized records are trusted by legal and other authorities outside our jurisdictions?

• How do displaced people know how and where to locate and access records?

• How do people with no fixed address, little or no ability to travel, and no money access records? How to provide records to them?
What are the human costs of not doing these things?
We are currently soliciting responses to the Framework: https://informationasevidence.org/framework (send responses to kcarbone@ucla.edu)

Thank you
Rights in Records by Design
Recordkeeping and Rights

- Recordkeeping systems provide memory, identity, evidentiality, and accountability beyond any immediate transactional context.
- Often fail to uphold the rights in, and to, records and recordkeeping that underpin a raft of basic human rights.
- Disproportionately serve to disenfranchise the most marginalized in society.
- Disenfranchisement exacerbated if the recordkeeping context involves traumatic experiences.
Shift from subject to agent

I want to tell a different story. It’s about how Aboriginal people can be the authors of our stories and not the passive and powerless subjects of stories told and written by others. It is the role of government and others, including archivists and recordkeepers, to position themselves to enable Aboriginal and Torres Strait Islanders to move from passive and powerless subjects to active participatory agents. I hope my insights assist in pushing towards an archive and recordkeeping system that facilitates the active participation of Aboriginal and Torres Strait Island peoples.

(Then Aboriginal and Torres Strait Islander Social Justice Commissioner Mick Gooda speaking at the Monash AIHR Workshop, 12 October 2010)
Our Project
Out-of-Home Care

An estimated 500,000 Australians have experienced out-of-home Care as children.

More than 80 state and federal enquiries have been held into the circumstances and provision of out-of-home Care.

Each enquiry identified systemic problems in recordkeeping infrastructure that affect the lives of Care-leavers.

Recommendations remain largely un-implemented due to limitations with existing standards and systems.
Rights in Records by Design

• Child protection and welfare recordkeeping

• 3-year transdisciplinary research IT, History, Social work, Education, & Community members

• Co-design of lifelong living archive for those with childhood Care experience
Rights in Records by Design

- Childhood Recordkeeping Rights Charter
  Mandate & warrants for rights and obligations

- Historical Justice
  Children, incarceration, recordkeeping systems as 'weapons of affect'

- Early Childhood Education
  Philosophy & Sociology of the child, recordkeeping literacy

- National Framework for Childhood Recordkeeping for OOH
  Technical, policy, & governance systems

- Lifelong Living Archives
  Co-designed, person-centred

- Recordkeeping Informatics for OOH
  Trajectory & case-file analysis

- Culturally Safe Recordkeeping and Archiving Places
  Colonial constructs of Indigeneity, child removal

- Imagined Archives
  New knowledge about archives through art
ENFORCING RIGHTS... 
★ TO REMEMBER
★ TO FORGET
★ TO REQUEST/AMEND
★ TO PARTICIPATE
★ TO THE TRUTH
★ TO FAMILY

NOW I UNDERSTAND MY GRANDMOTHER...

IT'S IMPORTANT TO ME THAT MY RECORDS REMAIN PART OF HISTORY
AND THAT I'M ALLOWED TO AMEND AND ANNOTATE THEM.

WHO GETS TO SEE MY DATA?

BUT WHAT IF DHHS USE THAT INFORMATION AGAINST YOUNG PARENTS?

THE ORGANISATION DOESN'T OWN THE RECORDS - THEY'RE MINE!

IT'S ABOUT ME - IF ANYONE SHOULD BE ABLE TO ACCESS IT, IT'S ME

YOU DON'T HAVE TO ACCEPT THE RECORD - IT'S ONE PERSON'S OPINION OF YOUR CHILDHOOD

ONE DAY 100 CASE FILES SHOWED UP ON MY DOOR.

BUT THEY DIDN'T GIVE ME ANY ANSWERS
Charter of Childhood Recordkeeping Rights

```
YOUR RIGHTS
- The right to know who you are
  - Know where you belong, your family, your community, your country
  - Express or practice your culture, religion, language

- The right to remember
  - Remember
  - Be remembered
  - Forget
  - Be forgotten

- The right to hold accountable
  - Hold accountable
  - Call to account

YOUR RECORDKEEPING RIGHTS
- The right to create your own records, life history
- The right to decide what is recorded about you in organisational systems
- The right to access records
- The right to intervene in the record (right of reply/set the record straight)
- The right to determine how long to keep records, and in what form

IDENTITY RIGHTS
- Self-determination
- Autonomy
- Agency
- Historical Justice

PARTICIPATION RIGHTS
- Wellbeing
- Being Safe
- Rights to Privacy & Safe Recordkeeping

ACCESS RIGHTS
- Lifelong access to records about your childhood
- Have a say in intergenerational access

MEMORY RIGHTS
- Remember
- Be remembered
- Forget
- Be forgotten

ACCOUNTABILITY RIGHTS
- Hold accountable
- Call to account

PROACTIVE DISCLOSURE RIGHTS
- Know where records about you are held
- Understand the type(s) of information held about you
- Be informed of when and why others are given access to your records
- Consent to use of your records by others
- Know when and why records about you are destroyed

Sue McKimmish, Frank Golding, Nina Lewis and Joanne Evans

MONASH University
UCLA
```
Update Essential Information Record - Alex Jones

Enter the details of this record. Remember that it is up to you what info you want to change. Everything here is optional.

**Original Label**: Essential Information Record - Alex Jones

- **My Label**: My label

**Original Date**: Invalid date

- **My Date**: 23/04/2010
- **My Date Accuracy**: This exact day

**Original Description**: Started in first two weeks of placement (at the same time C&PP is being developed). All members of care team contribute information they each know that should be shared. Update whenever new information obtained and check that it is still up to date at least 6 monthly. Enables important factual information to be kept and shared in the best interests of the child/young person.

- **My Description**: My description

- **My Notes**: This is not exactly right. I distinctly remember...

**Tags**:

- Add new tag

Copy stored on system, originally from Department of Health

---

MONASH University

UCLA
Artefact Modelling
Activity Modelling...
The Digital Equity Network
Digital Equity

• Equity for all in new and emerging digital information systems

and

• Equity for those who do not participate within the digital sphere
Example:

UN: Global study on children deprived of liberty (2019)

The consultation process identified the importance of hearing directly from children about their lived experiences. They reported that their rights were not protected, including [...] being denied access to information…”

106. States are strongly encouraged to establish an appropriate system of data collection at the national level, involving all relevant ministries and other State agencies, coordinated by a focal point. Whenever possible, data on children should be obtained directly from them in accordance with the principle of informed consent and self-identification. When necessary, such information should be supplemented by data concerning their parents or primary caregivers.
7 Topics

1. Information needs of marginalised and displaced peoples
2. Cultural dimensions of trans-national information ecologies
3. Relationships between information rights and human rights
4. Co-design of trauma-sensitive recordkeeping systems
5. Information technologies that facilitate data sovereignties
6. Empowerment of communities through data-driven technologies
7. Equitable, transparent, and accountable governance frameworks
Topic 1: Information Needs

• Lifelong and rights-based

• Information, identity, memory, cultural heritage, evidence, accountability, ...

• Human rights, social justice and post-conflict contexts
Topic 2: Cultural Dimensions

• Complex trans-national information ecologies
• Including translation strategies to mitigate against language colonisation.
Topic 3: Records and Rights

- How a platform of information rights could support enabling and actualizing human rights
- Data, Information, Records
- Recognition of rights in and to data, information and records themselves as fundamental human rights
Topic 4: Trauma Sensitivity

- Data, information and records frameworks, reference models, infrastructures, systems and technologies
- Co-design
- People-centred values and principles
Topic 5: Technological Innovation

• Design of smart and secure information technologies
• Enable exercise of data sovereignties and rights in data, information and records
• Provide crucial underpinning for the actualisation of human rights;
Topic 6 Empowering Communities

• People-centred, culturally appropriate technologies
• Active participants
Topic 7: Governance

• Equitable
• Transparent
• Accountable
• Governance frameworks for technologically-enabled data, information, and recordkeeping systems;