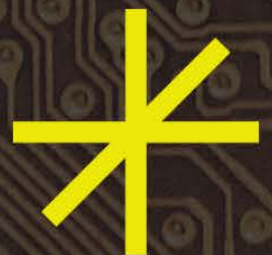


DESIGNING FOR CHANGE

DATA AND
DISADVANTAGE
PROJECT

EXECUTIVE REPORT



Australian
National
University

School of
Cybernetics



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National
University

Designing for Change: Data and Disadvantage Project Executive Report

Cultivating reflexivity through systems
visibility, for purposeful data decision
making

Funding

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KEY TERMS

Capta

Some academics within the digital humanities have argued for the necessity to refer to data especially humanistic data as ‘capta’. This idea draws from the insight that the word ‘data’ is derived from the Latin *dare* which means ‘to give’. Rob Kitchin and others have argued that although the pervasive attitude to data is something that is simply given, the practical reality is that data often taken and therefore rarely neutral but embedded with decisions and values and cultural factors¹. It is argued that the term ‘capta’ should be used instead since capta is derived from the Latin *capere*, meaning to take. So capta seeks to describe those data ‘units that have been selected and harvested from the sum of all potential data.’² While ‘data’ can represent all that is knowable about things such as a person, Kitchin and others have argued that capta should frame what is selectively captured through measurement like surveys, polls etc³. We use it in this report in the sense that approaching socially relevant data as capta invites data professionals to embrace their role in giving meaning to datasets.

Circular causality in causally closed systems

Within system dynamics, a definition of a system entails that it is causally closed. This means all causal influences within a defined system will feedback on themselves leading to various forms of recursive action. This process of causal influences feeding back on themselves is referred to as a causal loop, causal feedback loop or an instance of circular causality.

Closed and open systems

The terms closed and open systems have been co-opted into systems research from thermodynamics concepts in physics. In this thermodynamics sense, closed and open refer to the ability of a given system to exchange energy and/or matter with its environment. If a given system can exchange both energy and matter with its environment, it is referred to as an open system while it is defined as a closed system if it only exchanges energy.

Data decision-makers and data workers and professionals

In this report, we have used the broad term “data decision makers” deliberately, to nominate individuals working with or within data assets, and who decide how, who, when, and why data gets used and for what purpose. Those decisions about data can happen at management level as well as at entry levels. Throughout the report, we also use the term ‘data decision-makers’ and ‘data workers’ and ‘data professionals’ interchangeably; we also make references to more specific data decision-maker roles, such as data custodian, researcher, analyst, and the like. All data decision-makers work within data systems.

Data driven and data informed

When organisations are using or planning to use data, they must decide on a data-driven or data-informed approach or both. A data-driven approach to decision making seeks guidance for actions from model results that are continuously updating and are adaptive to changes. A data-

¹ Melody Lynch, “Data Lives: How Data Are Made and Shape Our World,” *The AAG Review of Books* 10, no. 2 (April 3, 2022): 20–21, <https://doi.org/10.1080/2325548X.2022.2036546>.

² Rob Kitchin and Martin Dodge, *Code/Space: Software and Everyday Life* (The MIT Press, 2011), 261, <https://doi.org/10.7551/mitpress/9780262042482.001.0001>.

³ Kitchin and Dodge, 261.

informed approach to decision-making seeks to use the results of data models as a supplement to other types of advice that is seen to be critical to the decision-making process⁴.

Data integration and data linking

The goal of data integration is ‘to offer uniform access to a set of autonomous [i.e. independent] and heterogeneous data sources’.⁵ That is, data integration seeks to provide ways in which disparate and diverse data sets can be usefully linked or cross-indexed, so that despite having different variables and parameters, they can be used to provide a richer picture of or answer to any given situation or question.

In 2010, government in Australia agreed upon principles for data integration across agencies for statistical and research projects. They also agreed on guidelines for putting in place governance and institutional arrangements. Appointed/authorised data integrators head efforts to integrate government data sets and are also responsible for data ethics.

Data integration remains fraught with challenges, with efforts affected by the following technical and legal considerations:

- Hardware platforms
- database implementation
- query languages and templates
- data structures and schemas
- complex and/or distributed data ownership and maintenance
- legislative requirements and protections

Data systems/assets

Within this report, we take the term *data system/asset* to describe the personnel, organisations, services, technical tools, infrastructures, and platforms that generate, collate, administer, and use various types of datasets including census, econometric and administrative datasets.

In the Australian context, public research or statistical institutes are key players in the data system, with demographic (census) and econometric data being a substantive backbone on and against which other data sets can be established and/or compared. Both kinds of data sets have been especially pertinent to disadvantage studies because of the way in which disadvantage has been historically understood and measured as synonymous with poverty (lack of resources, especially monetary income) among particular social groups. Bodies such as the Australian

⁴ Anne Fleur van Veenstra and Bas Kotterink, “Data-Driven Policy Making: The Policy Lab Approach,” in *Electronic Participation*, ed. Peter Parycek et al., *Lecture Notes in Computer Science* (Cham: Springer International Publishing, 2017), 100–111, https://doi.org/10.1007/978-3-319-64322-9_9.

⁵ AnHai Doan, *Principles of Data Integration*, 1st edition (Waltham, Mass: Morgan Kaufmann, 2012), 6.

Institute of Health and Welfare,⁶ the Australian Institute of Family Studies,⁷ and the Australian Bureau of Statistics have primary responsibility for data gathering and reporting.⁸⁹

Further, services administrators from federal government agencies as well as jurisdictions are often stewards of large administration data sets gathered in the process of delivering public services. The administrators collect, manage, and use this data to record/track and assess service provision.

More information can be found at <https://www.oaic.gov.au/>.

Human flourishing

By human flourishing, we mean that each person considers their life to be good when evaluated across “happiness and life satisfaction, health, both mental and physical, meaning and purpose, character and virtue and close social relationships.”¹⁰ We conceive of these indicators as being influenced by various systems through which a person navigates their life course. On this conception, flourishing is intimately connected to the well-functioning of technical, social and environmental systems for supporting life, such that disadvantage is largely understood as the *consequences* of an absence of human flourishing.

Information feedback

Information feedback refers to a pivotal component of systems where information resulting from some action in a given part of a system, travels through that system and eventually returns in some form to its point of origin, *potentially* influencing future action. This influence is potential rather than mandatory because system action does not necessarily depend on new information. Information feedback is a separate concept from causal feedback (see circular causality).

Linear and non-linear systems

The terms linear and non-linear systems are borrowed from systems engineering. In systems engineering the input of some systems lead to proportional outputs. If an input is increased by x-amount, the output will increase by x-amount and vice versa. In contrast some systems – typically complex social and environmental systems are non-linear. Inputs into systems often result in disproportional outputs. If an input is increased by an x-amount, the output might be much larger than x or much lower than x or sometimes alternates between larger, same or lower.

⁶ Alan Hayes and Andrew Hacker, “Persistent Disadvantage in Australia: Extent, Complexity and Some Key Implications,” Australia’s Welfare Series (Canberra: Australian Institute of Health and Welfare, 2017), <https://www.aihw.gov.au/getmedia/9592571c-801c-46be-9c9d-75d0faffbb5b/aihw-australias-welfare-2017-chapter1-6.pdf.aspx>.

⁷ “Homepage | Australian Institute of Family Studies,” Australian Institute of Family Studies, 2023, <https://aifs.gov.au/>.

⁸ David Gruen, “Realising the Potential of Data in Government,” Australian Bureau of Statistics, 2022, <https://www.abs.gov.au/about/our-organisation/australian-statistician/speeches/realising-potential-data-government>.

⁹ Australia: Funding the Australian bureau of statistics to better collect data on disadvantage. (2022, Sep 08). MENA Report Retrieved from <https://virtual.anu.edu.au/login/?url=https://www.proquest.com/wire-feeds/australia-funding-australian-bureau-statistics/docview/2711767530/se-2>

¹⁰ Tyler J. VanderWeele, “On the Promotion of Human Flourishing,” Proceedings of the National Academy of Sciences 114, no. 31 (August 2017): 8148–56, <https://doi.org/10.1073/pnas.1702996114>.

Lived experience experts

We use the expression lived experience experts to denote people who have had lived experience navigating support systems as a vulnerable person or a person who has experienced or is experiencing disadvantage.

Rich data

In this report, we have used rich data to describe datasets that are useful or potentially useful for social intervention purposes. Highly complex and sensitive data sets that are always expanding in both breadth and depth are rich in the sense that they contain many and increasing variety of attributes to continue to add breadth and depth.

EXECUTIVE SUMMARY

CSIRO's 2022 'Our Future' report reemphasised that Australia and the world are at a pivotal point in the ongoing complex and interrelated systemic challenges of climate change, public health, automation, labour, education and others¹¹. With the prevalence of machine learning applications, one sustained effort towards managing these complexities has been the deliberate and concerted effort to utilise complex and linked datasets in solutions to these grand challenges which, for Australia, includes entrenched disadvantage. The 2023 Commonwealth Government's 'Data and Digital Strategy' agrees that extreme system dynamics 'have supercharged the adoption of data and digital technologies across Australia' and that data presents a 'wealth of opportunities' for delivering 'services to provide better outcomes for all people'¹². In 2015, the Committee for Economic Development of Australia (CEDA) made a similar case when it called disadvantage "a wicked problem for any society" and wrote in their 'Entrenched Disadvantage' report that "poverty and disadvantage are experienced by many people at some point throughout their lives, but the issue of entrenched disadvantage has not had the focus it deserves."¹³ Close to a decade later, entrenched disadvantage continues to be a key challenge for the Australian Commonwealth Government, which announced in the 2023 Budget, a '\$200 million package to target entrenched community disadvantage.'

In agreement with the 2015 CEDA report, the 2023 budget announcement centred data as the key to a comprehensive solution to entrenched disadvantage and lamented that community change-makers were 'hampered by a lack of relevant, available data' or 'difficulties in accessing suitable data across health, education, employment and security.'¹⁴

The literature shows that it's common for grand data initiatives to centre or focus on the data often without a detailed consideration of how these data projects and products might interact with other systems not considered in the design process. Considering this, we are proposing that decentring data helps make explicit the ways that datasets and their related processes and resources affect and are affected by many other systems. By drawing the boundary more broadly around what is being analysed in data projects, it is possible to see the ways that the design and implementation of data and computation technologies reveal themselves as being contingent on human values, on time and circumstances, on locations, interactions, and the events experienced by the individuals who create, maintain and use it.

Through our project, we are presenting another approach to responsible data practice that counterintuitively decentres data as we explore other productive ways for data professionals to account for the dynamic nature and consequences of systemic influences on data projects that are geared towards disadvantage interventions. Our focus on decentring data means that data, as crucial as it is, cannot be our prime focus. This decentring approach invites data professionals to become aware of interactions between a set of systems where data systems are only one of those systems. It does not devalue the relevance of data but places it within the context of larger conversations about other systems and concepts that also matter.

Recognising the ever-evolving ethical, technical, societal, and environmental systems surrounding these data assets, we firmly believe in the importance of adopting a systems

¹¹ CSIRO, "Our Future World" (CSIRO), accessed October 4, 2023, <https://www.csiro.au/en/research/technology-space/data/our-future-world>.

¹² "Introducing the Data and Digital Government Strategy | DDGS," accessed October 4, 2023, <https://www.dataanddigital.gov.au/>.

¹³ "CEDA - Addressing Entrenched Disadvantage in Australia," Kentico, 2015, <https://www.ceda.com.au/ResearchAndPolicies/Research/Population/Addressing-entrenched-disadvantage-in-Australia>.

¹⁴ "Introducing the Data and Digital Government Strategy | DDGS."

approach and cultivating a high level of reflexive disposition among data professionals. This approach is essential in not only mitigating or minimising harm to vulnerable individuals but in supporting those individuals on their journey towards human flourishing ends.

Our project was founded on the view that data professionals working in very dynamic and complex data environments can help us identify current best practices in collecting, managing, and using data for social good, especially in situations with unclear or competing policies and regulations. The complex data systems we are focusing on in this project are the Multi-Agency Data Integration Project (MADIP)¹⁵ - an effort on the part of federal government to better leverage the administrative data sets collected in the course of providing public services; and Generation Victoria (GenV), a longitudinal, life-course health study of Victorians born in a particular pre-defined 'generation' (birth window), following a cohort from birth to death.

We have been focusing on these two data systems because they are highly complex and are visibly interacting with various other complex systems across a variety of domains. They offer a rich linked-data system within which to explore different kinds of data use and data decision-making that has greater complexity than traditional longitudinal studies. As they both collect data on dynamic, changing subjects, in dynamic, changing contexts, they are inherently high-stakes and therefore also incredibly valuable and useful in a range of settings while also needing safeguards against the potential for misuse or inadvertent harm over time. While examples of data systems like MADIP are many worldwide, GenV is unique and a trail blazer in terms of the extent to which it seeks to provide a holistic data ecosystem for health and life outcomes¹⁶. Lastly, the analysis of data assets like MADIP and GenV are particularly well suited to cybernetic concepts and approaches especially given they have been purposefully designed with higher levels of data sophistication and maturity.

In this research, we are using cybernetics in two ways. Firstly, we are using it as a tool for articulating the variety of systems and their interactions with MADIP and GenV. Secondly, we are conceptualising a cybernetic reflexivity tool to understand and explore opportunities to improve data decision-making in the context of wicked problems such as disadvantage interventions. Our project has been scoped over several phases, with this initial phase dedicated to understanding best practices in decision-making within complex, data-rich environments within uncertain legal and policy settings.

In this initial phase, we have been assessing the presence of a culture of cybernetic reflexivity within the rich-data environment as demonstrated by data professionals from various sectors and positions. These sectors are the Commonwealth Government departments (ABS, Department of Education, Department of Services), research institutes and universities. We have been looking for tangible evidence of this reflexivity through the data decision makers' awareness of key system components that are crucial in the realm of complex data systems. We have achieved this, by applying our novel PAFCARSS method to identify signs of cybernetic reflexivity through activities such as boundary selection, recognition of causal loops, and the identification of opportunities for information feedback. These activities provide us with

¹⁵ In May 2023, the Australian Statistician, Dr David Gruen announced that in recognition of what the MADIP data asset represents, the asset's name would transition to PLIDA (Person-Level Integrated Data Asset). There is a phased transition towards PLIDA branding and MADIP will continue to be used in tandem.

¹⁶ Melissa Wake, Sharon Goldfeld, and Andrew Davidson, "Embedding Life Course Interventions in Longitudinal Cohort Studies: Australia's GenV Opportunity," *Pediatrics* 149, no. Suppl 5 (May 2022): e2021053509R, <https://doi.org/10.1542/peds.2021-053509R>; Melissa Wake et al., "Integrating Trials into a Whole-Population Cohort of Children and Parents: Statement of Intent (Trials) for the Generation Victoria (GenV) Cohort," *BMC Medical Research Methodology* 20 (September 24, 2020): 238, <https://doi.org/10.1186/s12874-020-01111-x>; Yanhong Jessica Hu et al., "1059 Innovative Epidemiological Methods in a Whole-of-State Cohort of Children and Parents: Generation Victoria (GenV)," *International Journal of Epidemiology* 50, no. Supplement_1 (September 1, 2021): dyab168.290, <https://doi.org/10.1093/ije/dyab168.290>.

insights into the extent to which data itself was decentred in the context of rich data approaches to interventions addressing disadvantage. Additionally, they reveal opportunities for enhancing system-wide improvements through systems mapping workshops, education and training.

In examining the reflexive attitudes of data professionals, their views broadly fall in to one of three thematic areas. We explore attitudes towards disadvantage, legitimacy and trust and towards their experiences navigating data access and data asset resource allocation. In each thematic area, evidence of system visibility and cybernetic reflexivity have readily been observable. These observations are helping us to develop a series of practical lessons for each thematic area. Our main research findings for each thematic area and their associated practical lessons are detailed in full in Appendix 1 and in the discussion section. In the following sections, we provide our notable research findings and their related practical steps forward.

Data professionals' attitudes towards disadvantage

We found that definitions of disadvantage were often pragmatic, focusing on quantifiable factors and minimal examples of cybernetic reflexivity were observed. Even so, reflexivity was more prevalent during the initial project stage in which data options were being considered but much less evidence for reflexivity in the final stages and post-production.

Data professionals often admitted openly that they lacked in-depth knowledge of the disadvantage literature and there was general agreement that involving lived-experience experts¹⁷ in modelling disadvantage was valuable. We propose that lived-experience experts could play a pivotal role in establishing information feedback mechanisms that could improve data interventions. Moreover, it was clear that disadvantage data projects that involve a community of lived-experience experts throughout the duration of those interventions were likely to create mutually beneficial data-driven or data-informed interventions.

Our interview analysis revealed that asset-framing or strength-based data approaches were not widely practised even though data professionals expressed a strong desire to learn asset-framing and strength-based data approaches to disadvantage.

Practical lessons for addressing attitudes to disadvantage

1. The data community will benefit from creating widely agreed definitions of disadvantage for each domain while making sure to canvass diverse perspectives.
2. If senior data decision-makers align themselves with high-level system purposes, they can increase the uptake of reflexive practice by other data workers.
3. Identifying and aligning relevant datasets to asset-framed objectives will support data professionals to cultivate reflexive data approaches to disadvantage.
4. Charities and support systems could shift toward human flourishing goals when adopting a systems view.
5. Funding should support frontline workers' data skills to enhance the deployment of interventions that have been approved by lived-experience experts.
6. Data professionals expressed strong desire for development programs that give them opportunities to interact with systems involving disadvantaged communities.

Data professionals' attitudes towards legitimacy and trust

We found that data professionals' attitudes toward legitimacy and trust manifested most strongly through data collection methods and during the development of consent tools.

¹⁷ See our 'key-terms' section for greater detail on 'lived experience experts'.

The format of consent forms for rich data projects were strongly dependent on whether data collection was to be largely automated or through physical interaction.

Consent instruments that embraced systems approaches tended to consider long-term viability of those instruments.

Our research analysis revealed lower than expected instances for revising consent forms. In a dynamic environment with changing privacy regulations and changing data subjects, interviewees agreed that greater opportunities for revising consent forms is a good idea.

Risk orientation and risk communication heavily influenced decision-making and trust within all rich data systems. We found that the need to satisfy and strengthen safeguarding measures were front of mind.

Effective data sharing was hampered by differing risk orientations based on mismatches between foundations and missions of each data donor or asset manager but this was often not explicitly acknowledged within data sharing discussions.

Practical lessons for addressing legitimacy and trust

1. Dynamic consent management was recommended to ensure long-term viability.
2. Active consent management could result in the establishment of ongoing participant support services; such as consent counselling as young research participants mature to consent age.
3. Our analysis revealed that it was critical that data decision makers consider data asset management approaches that are adaptive to shifting norms around data ownership in both private and public spheres.
4. Transparency and collaboration could improve legitimacy and trust.
5. Cybernetics can suggest some reflexive strategies in support of triage processes surrounding the disclosure of medical results while planning bespoke responses to the needs of vulnerable data subjects.
6. Our meta-analysis suggests data donors and asset managers could engage in collaborative data systems mapping exercises to increase transparency between themselves.
7. Workshops that illuminate causal pathways and risk communication channels can open opportunities for risk averse decision-makers to consider economic and service repercussions if their organisations do not share critical public data.

In summary, our reflexivity through systems visibility approach reveals that data risk manifests as the responsibility not only to safeguard but also as a responsibility to make data useful for social good. This finding suggests opportunities for the deployment of cybernetic tools that can supplement data professionals' data pipelines with opportunities for mapping these future facing systems dynamics.

Attitudes towards data system resourcing and access rights

We found that the identification of diverse data user groups and their objectives by asset managers improved access to datasets held by those data assets.

Sustained long-term funding for rich-data projects was a shared concern with some data professionals suggesting that the situation could be improved if funders were continuously made aware or reminded about the interconnected funding needs of all components of complex data assets.

Practical lessons for addressing data system resourcing and access

1. Consolidating data asset information and involving user groups in the process can enhance understanding of the complexities of data assets for new data-asset users.
2. Collaboration among data assets could lead to standardized formats and faster access processes.
3. Training and awareness-raising around complex AI assisted data techniques are essential for data asset managers' ability to manage effectively and efficiently, the access to data assets.

Conclusion

We have relied on our novel cybernetic framework to assess data professionals' reflexive decision-making within data environments aiming to build interventions for vulnerable communities. The findings suggest opportunities for conducting training and awareness workshops to show case how cybernetic reflexivity can promote better definitions of disadvantage, adoption of asset-framed approaches, enhancement of legitimacy and trust, and the optimisation of data system resourcing and access rights.

Our findings show that there is willingness among those working with data for disadvantage to embrace reflexive improvements aimed at fostering safe, responsible, and sustainable practices. The broad lessons outlined in this report can serve as guiding principles for the design of comprehensive tools spanning the variety of disadvantage data domains. These tools can aid in enhancing both systems awareness and the practical implementation and expansion of reflexive practices in the data-driven and data-informed initiatives. Our ultimate goal continues to be to equip data professionals with the necessary tools to reduce immediate and future harm to data subjects and steer data projects toward outcomes that promote human flourishing.

While our findings revealed limited evidence for decentred approaches to data projects and nascent reflexivity among data professionals associated with data assets and disadvantage-focused projects, we did uncover evidence of their strong desire to cultivate this reflexivity. This desire emerged especially within environments characterised by political, legislative, and regulatory opacity. Our research shows there is support for programs designed to support data professionals to cultivate reflexive approaches to navigating the intricate dynamics of highly complex systems, where various systems and agents interact within technological environments.

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