

# Building data capabilities for HIV, sexual and reproductive health through inclusive design

Kath Albury



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# About this Project

**ARC Future Fellowship: Digital and data literacies for sexual health policy and practice (FT210100085)**

Funder: Australian Research Council

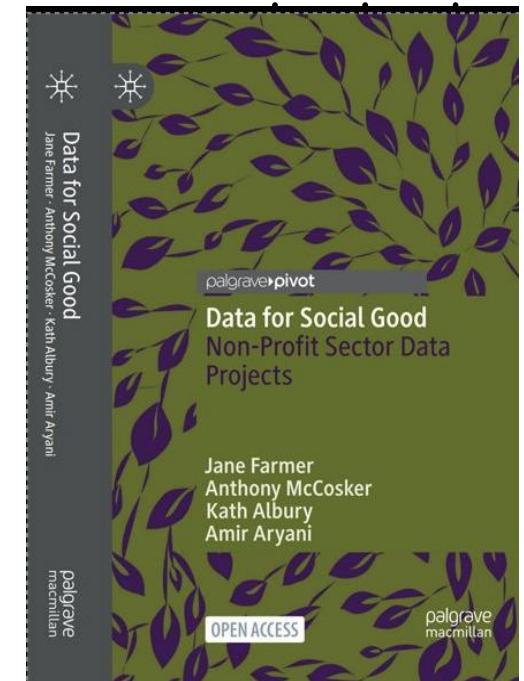
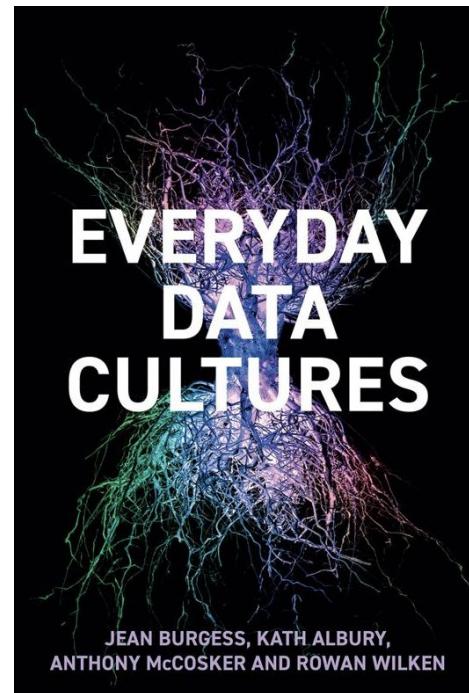
Duration: 2022-2026

## Project Team

**Professor Kath Albury** Future Fellow, Associate Investigator, ARC Centre of Excellence for Automated Decision-Making + Society;

**Dr Samantha Mannix** Postdoctoral Research Fellow, Affiliate Investigator, ARC Centre of Excellence for Automated Decision-Making + Society;

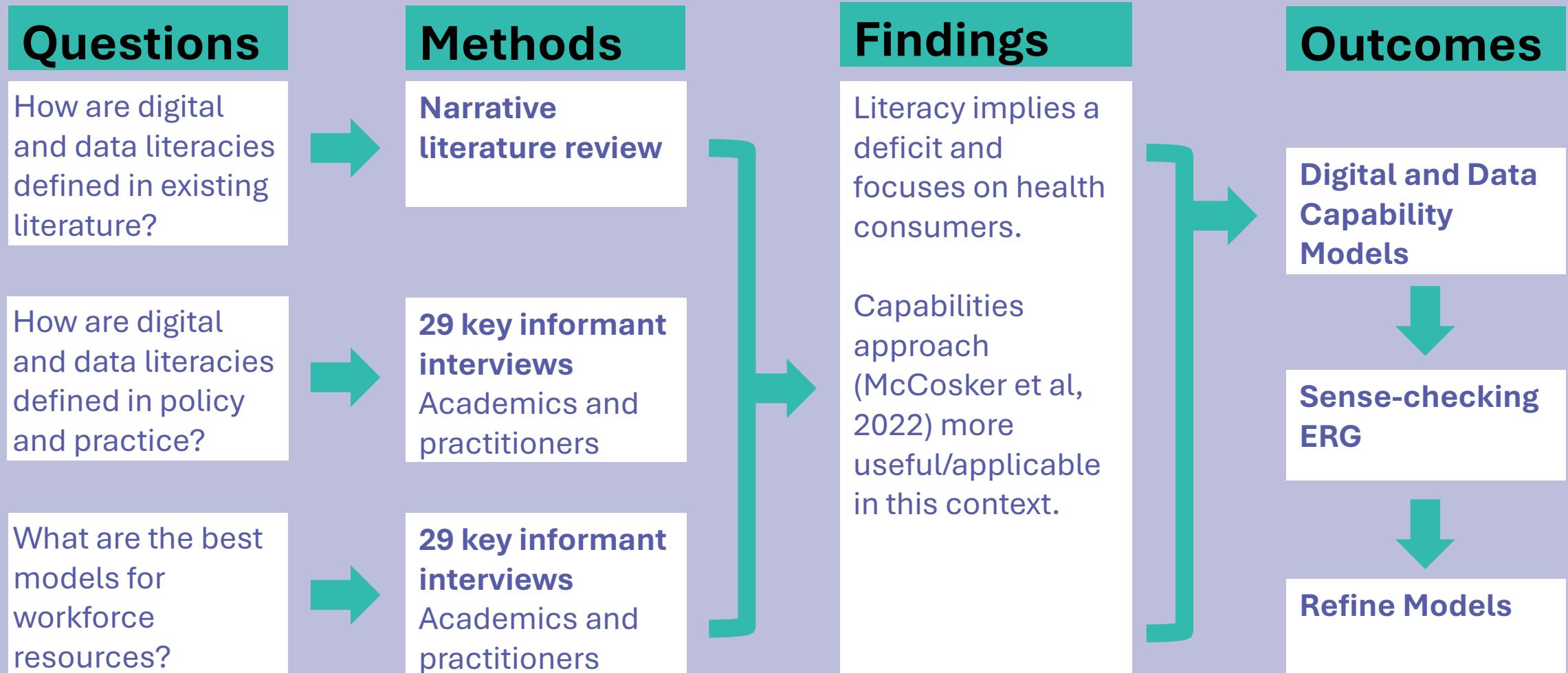
**Ms Caitlin Learmonth** Higher Degree Researcher, ARC Centre of Excellence for Automated Decision-Making + Society.



# Why are data capabilities important for HIV/SRH?

- Data-driven technologies are **central** to healthcare, research and social support systems (ie digital intake forms and surveys, automated decision-making tools, client management software) **and** community experiences of connection, wellbeing & learning (ie dating app profiles/search practices/AI companions/chatbots)
- HIV and SRH data are sensitive and can be stigmatising
- Data are generated, circulated and interpreted by clinical and health promotion practitioners, researchers/epidemiological surveillance systems, policy-makers, commercial actors **and** community/health consumers

# Iterative stages of DDCSRH Model and Website Development: Stage One



# Methods

## Literature Review

Database search		
"digital literacy" "digital health literacy" "eHealth literacy" "data literacy" AND "sexuality" "sexualities" "sexual health" "intimate relationships" "sexual relationships" "sexually transmitted*" "HIV"	Web of Science Medline, PubMed Cinahl Embase PsychInfo Communications and Mass Media	<b>= 30 results</b> (with duplicates and unrelated results removed)  <b>No results using this combination of terms and "data literacy"</b>

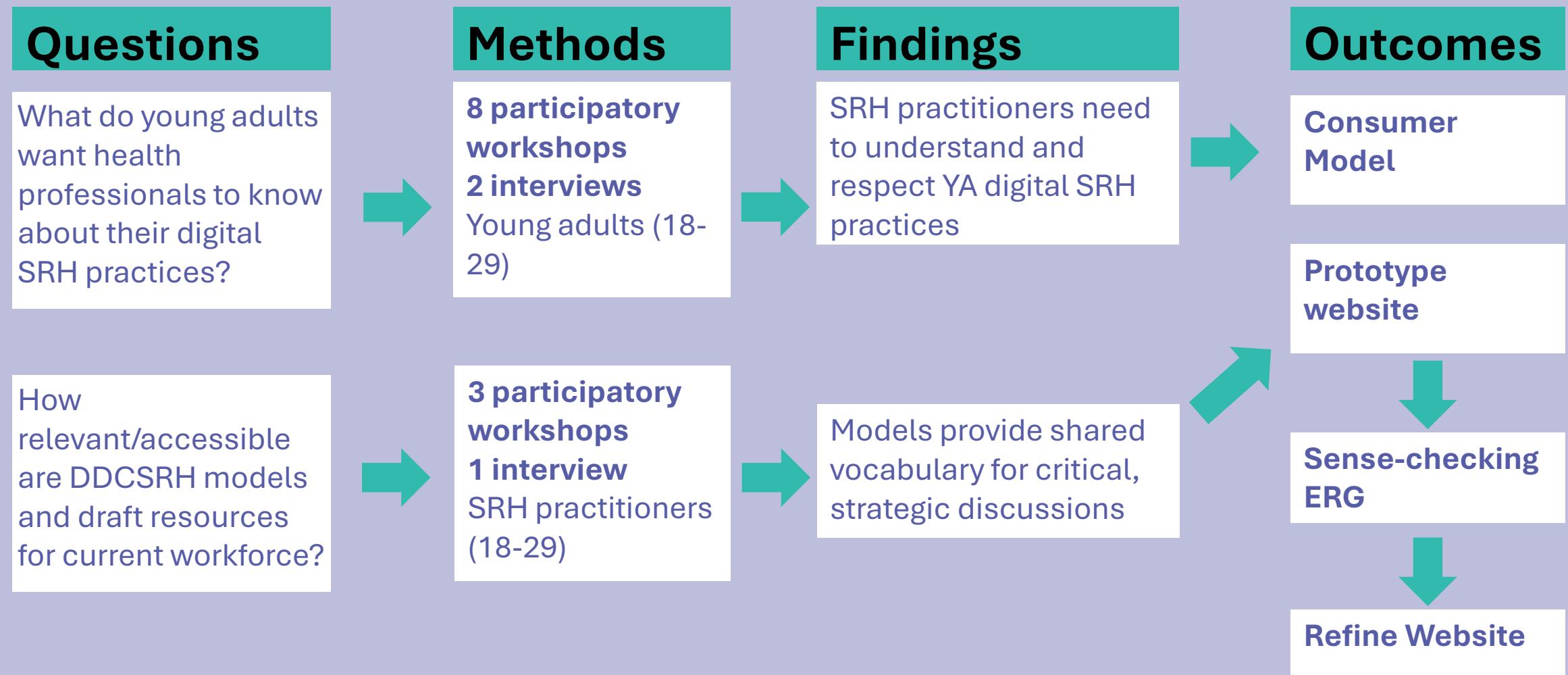
## Key Informant interviews

Researchers	Sites of practitioner experience	
<b>Field</b>	<b>#</b>	
Public Health	9	.
Digital Health	1	.
Sexual Health	6	.
Digital, Data Studies	4	.
Gender, Sexuality Studies	4	.
Youth Studies	1	.
<b>Organisation</b>	<b>#</b>	
Local Health	9	.
Sexual Health	1	.
Women's Health	6	.

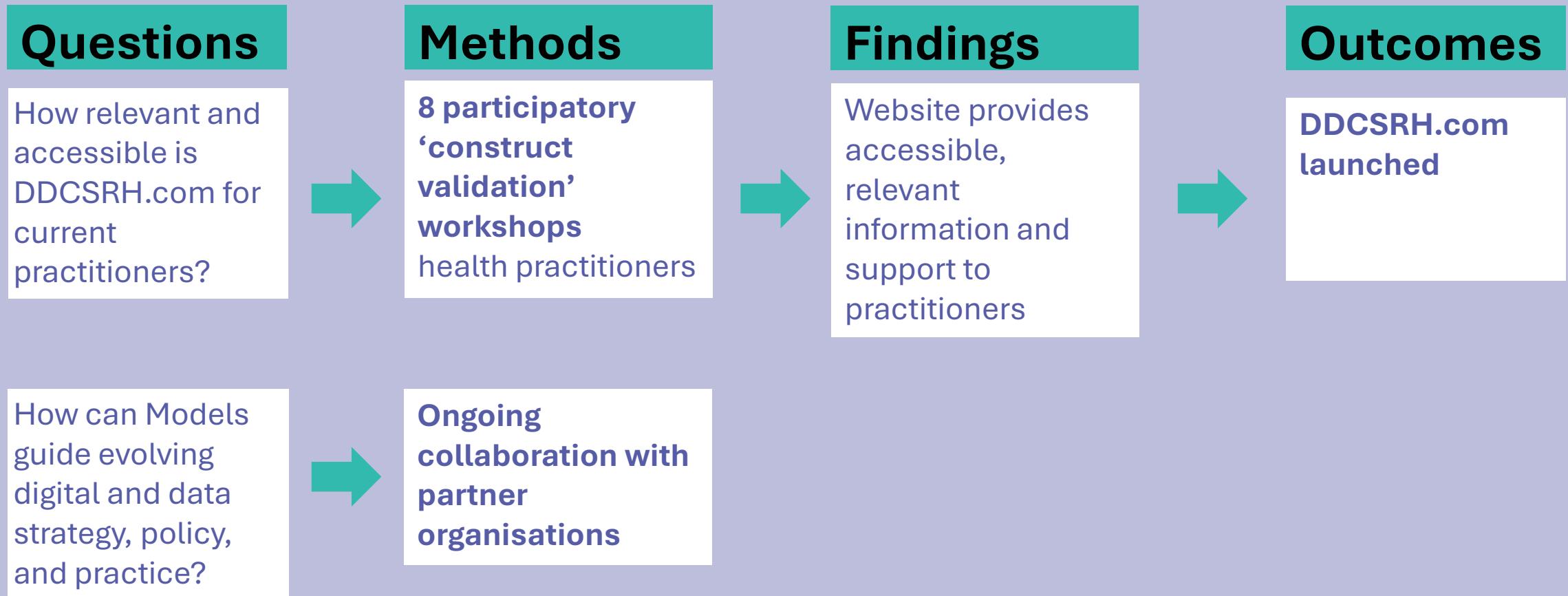
**29** interviews in total

- Albury, K., & Mannix, S. (2025a). Digital determinants of sexual and reproductive health—Workforce perspectives on digital and data literacies. *Health Promotion International*, 40(2), <https://doi.org/10.1093/heapro/daaf013>
- Albury, K. and Mannix, S., (2025b). From Digital Health Literacy to a Digital and Data Capabilities Approach to Sexual Health. *Sexuality Research and Social Policy*. <https://doi.org/10.1007/s13178-025-01110-x>

# Iterative stages of DDCSRH Model and Website Development: Stage Two



# Iterative stages of DDCSRH Model and Website Development: Stage Three/Four



# What are data capabilities?

‘the technical and material conditions, the skills, knowledge and proficiencies, and the strategic and ethical oversight driving the creation and use of data for improving knowledge, problem solving and decision-making’

McCosker et al, 2022



**Access & Infrastructure**

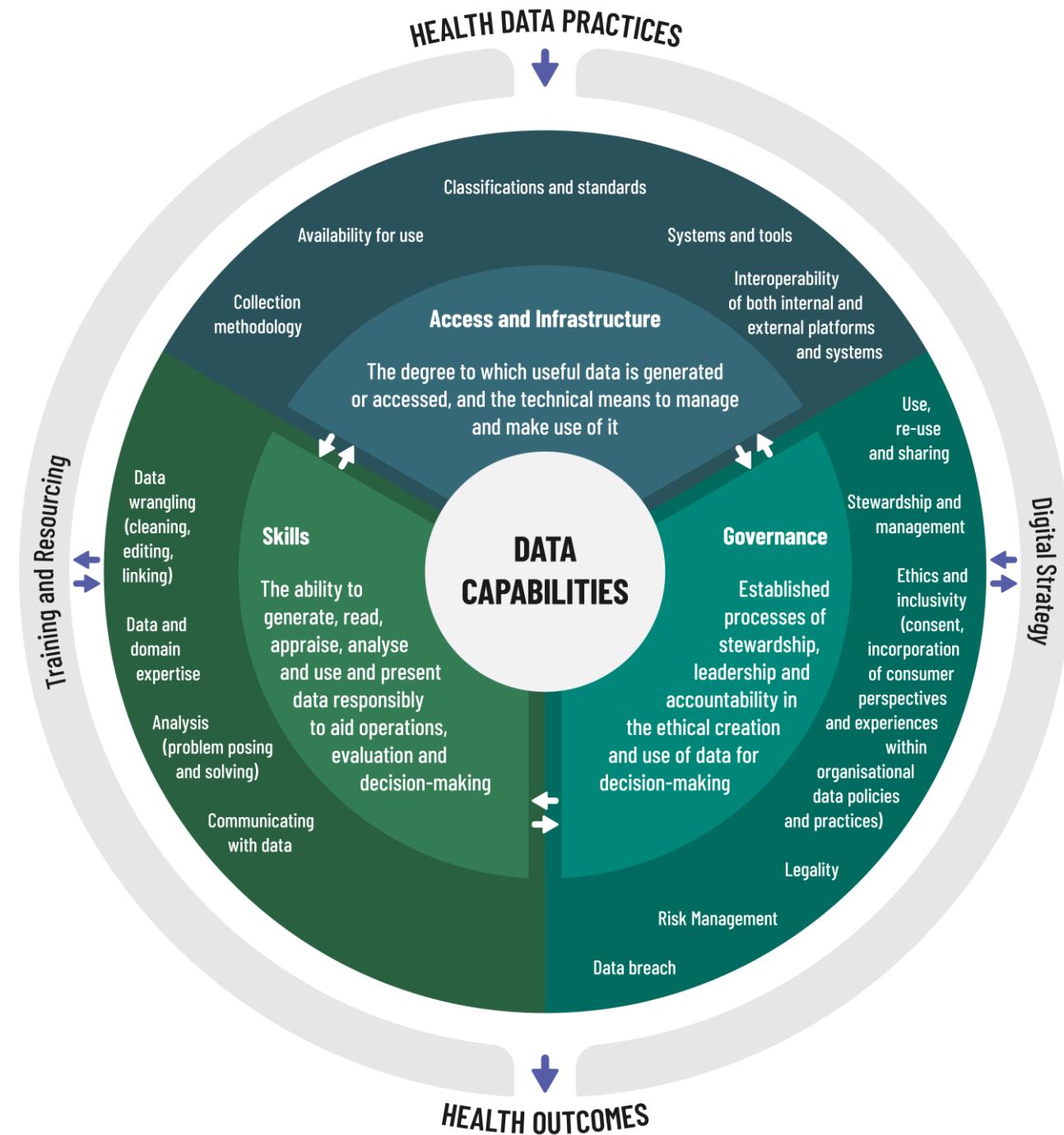


**Skills**



**Governance**

# Data Capability Model



## DATA CAPABILITIES FOR SEXUAL HEALTH POLICY AND PRACTICE

Capability	Definition	Sub-capabilities	Core Questions
<b>Access and Infrastructure</b>	The degree to which useful data is generated or accessed, and the technical means to manage and make use of it	<ul style="list-style-type: none"> <li>• Collection methodology</li> <li>• Availability for use</li> <li>• Classifications and standards</li> <li>• Systems and tools</li> <li>• Interoperability of both internal and external platforms and systems</li> </ul>	<ul style="list-style-type: none"> <li>• What counts as sexual health data, and how is it generated and accessed?</li> <li>• Are datasets siloed and difficult to access?</li> <li>• Can the organisation access and use the data it generates?</li> <li>• Is there an organisation-wide strategy for integrated data software systems?</li> <li>• How well do different platforms (and their methods of data collection and abstraction) work together?</li> <li>• How well do data technologies support organisational purpose?</li> </ul>

## DATA CAPABILITIES FOR SEXUAL HEALTH POLICY AND PRACTICE CONT.

Capability	Definition	Sub-capabilities	Core Questions
<b>Skills</b>	The ability to generate, read, appraise, analyse and use and present data responsibly to aid operations, evaluation and decision-making	• Data wrangling (cleaning, editing, linking)	<ul style="list-style-type: none"> <li>• How do organisations and individuals understand and articulate their own data generation practices?</li> <li>• How do organisations and individuals distinguish the difference between organisational data, and externally generated research evidence?</li> </ul>
		• Data and domain expertise	<ul style="list-style-type: none"> <li>• How are informal or 'everyday' data practices recognised by individuals and organisations?</li> <li>• How are roles and responsibility for the use of data allocated within the organisation?</li> <li>• How is data expertise fostered and to what extent is this inclusive?</li> </ul>
		• Analysis (problem posing and solving)	<ul style="list-style-type: none"> <li>• What is the quality of data and the value of data analysis for decision making?</li> </ul>
		• Communicating with data	<ul style="list-style-type: none"> <li>• How is data analysis communicated internally, with funders, clients and the wider community?</li> </ul>

## DATA CAPABILITIES FOR SEXUAL HEALTH POLICY AND PRACTICE CONT.

Capability	Definition	Sub-capabilities	Core Questions
<b>Governance</b>	Established processes of stewardship, leadership and accountability in the ethical creation and use of data for decision-making	<ul style="list-style-type: none"> <li>• Use, re-use and sharing</li> <li>• Stewardship and management</li> <li>• Ethics and inclusivity (consent, incorporation of consumer perspectives and experiences within organisational data policies and practices)</li> <li>• Legality</li> <li>• Risk Management</li> <li>• Data breach</li> </ul>	<ul style="list-style-type: none"> <li>• Who is accountable for datasets, and who has the authority to control access and use them?</li> <li>• Who takes responsibility for managing privacy and data security?</li> <li>• What are the guiding ethical principles for ethical decisionmaking around issues such as data sovereignty and stigma?</li> <li>• How are ethical issues identified and addressed?</li> <li>• How does the organisation make decisions around what data to store and how to store it?</li> <li>• How does lived experience inform decision-making around the collection, use and storage of data?</li> <li>• How are legal requirements and security monitored and implemented?</li> <li>• What processes are in place to prevent, monitor and respond to a data breach?</li> </ul>