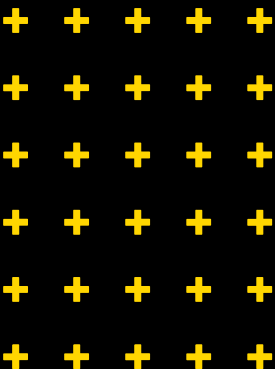


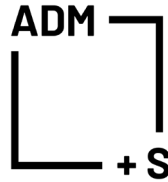


Digital and data capabilities for sexual health policy and practice

Stage One Report - July 2023

Kath Albury
Samantha Mannix





Acknowledgement of Country

In the spirit of reconciliation, we acknowledge the Traditional Custodians of Country throughout Australia and their connections to land, sea and community. We pay our respect to their elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

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This work builds on the Data Capability Framework developed by McCosker et al, 2022b. It has been developed by the project team with input and guidance from 29 local and international researchers and practitioners in the field of sexual health and digital/data studies.

Special thanks to our Project Reference Group:

Professor Joanne Bryant, UNSW, Sydney
Professor Angela Dawson, University of Technology, Sydney
Ms Lily Day, Youth Affairs Council Victoria
Dr Andrew Farrell, Macquarie University
Professor Anthony McCosker, Swinburne University of Technology
Dr Natalie Hendry, University of Melbourne
Ms Shelley Kerr, ASHM
Ms Catalina Labra-Odde, Multicultural Centre for Women's Health
A/Prof Jason Ong, Monash University/Melbourne Sexual Health Centre
Mx Daniel Reeders, National Association of People Living with HIV/AIDS
Mr Ben Riley, ASHM
Dr Son Vivienne, Transgender Victoria
Ms Jess Wilms, NSW Health
Ms Joanna Williams, Swinburne University of Technology



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01. ABOUT THIS PROJECT

The Australian 2018-2022 Sexually Transmitted Infection (STI) Strategy notes that “understanding the social drivers that influence the rates of STI in Australia, such as social media and other technology platforms” is a critical gap in the current response to STIs (Commonwealth of Australia, 2018). It is imperative that sexual health policymakers and workforces are able to rise to the multiple challenges and opportunities posed by digital platforms and technologies – ranging from data-driven eHealth and mHealth initiatives, to peer-led communities on social platforms.

New digital and data practices present significant challenges for the fields of sexual health promotion and sexual healthcare provision. The COVID-19 pandemic has necessitated rapid and urgent uptake of digital technologies for sexuality education and health promotion.

At the same time, the rise of commercial sextech apps and platforms; the proliferation of peer-to-peer conversations about sex, sexuality and gender on social media; and the popularity of sexual health and wellness ‘influencers’ has created significant competition for government and non-government organisations in the space of sexual health information and service provision (Albury 2019).

Professor Kath Albury’s Australian Research Council Future Fellowship (2022-2025) addresses these challenges and brings sexual health policy-makers and professionals into dialogue with young adult (aged 18 - 29) users of digital apps and social platforms, via co-design methods.





PROJECT AIMS

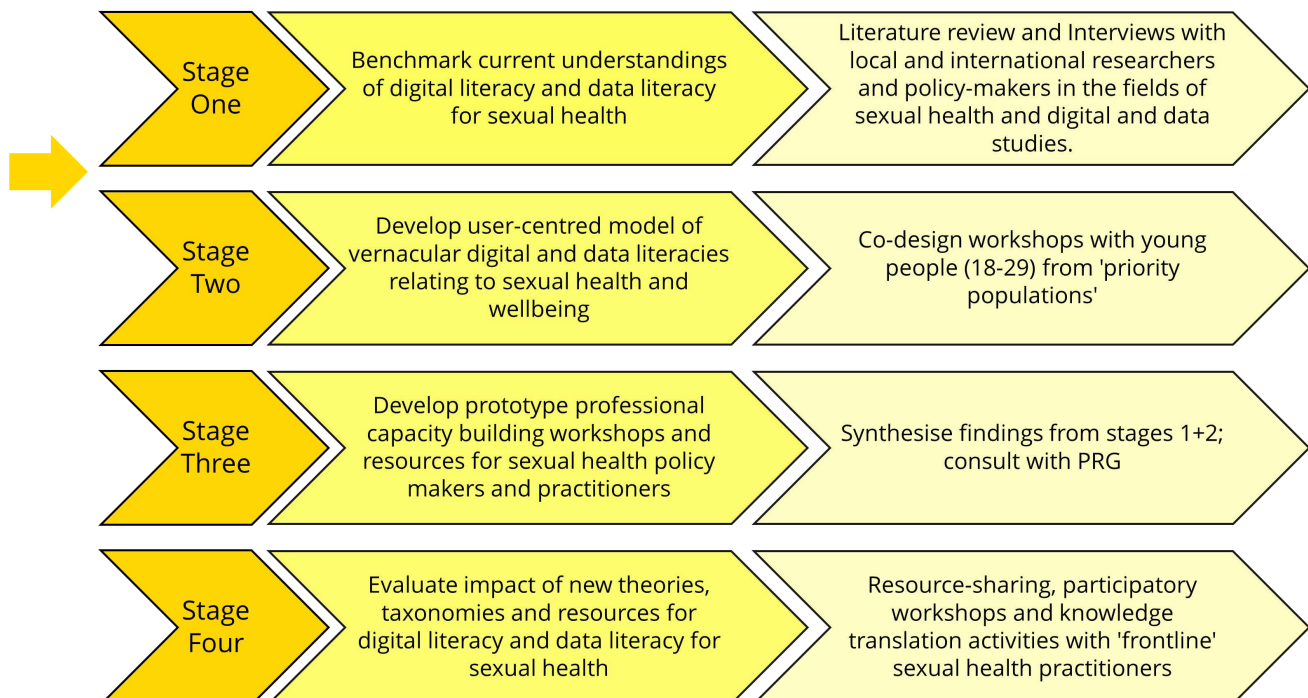
1. Analyse the role of digital technologies and platforms in the everyday sexual and romantic lives of young Australian adults most affected by STIs and HIV.
2. Map and benchmark digital literacies and data literacies among Australian government and non-government sexual health promotion and clinical service-providers (including leaders and policy-makers).
3. Develop new theoretical and applied models of young adult's everyday digital and data practices, to guide sexual health policy-makers and practitioners' digital and data capabilities.

This report presents key findings from Stage One, and outlines planned activities for Stages Two-Four.

While the initial Fellowship proposal focused on digital and data literacies for sexual health policy and practice, this report outlines a shift in project emphasis, from literacies to capabilities. We offer a Model that draws on the Data Capability Framework for the not-for-profit sector developed by Anthony McCosker and colleagues (2022b).

By adding a 'digital capability' dimension - and explicitly incorporating sexual health - we recognise existing work and expertise in sexual health policy and practice, while addressing some of the gaps, concerns, and needs identified in our Stage One literature review and qualitative interview process.

Figure 1: Future Fellowship Overview





02. WHAT ARE 'DIGITAL AND DATA CAPABILITIES FOR SEXUAL HEALTH', AND WHY ARE THEY IMPORTANT?

2.1. BACKGROUND

Our research is taking place in parallel with the development of the Australian Digital Health Capability Framework (the Framework), which was initiated by the Australian Digital Health Agency as part of The National Digital Health Capability Action Plan (CAP)¹.

The CAP focuses on a) assessing current levels of digital capability in the Australian health workforce, and b) planning the upskilling of current and future workforces. Kath Albury participated in a draft Framework consultation in February 2023, facilitated by the Australian Institute of Digital Health.

Our project has similarly shifted focus from digital health literacies to digital and data capabilities, based on the findings of our Stage One research, which included a literature review, and interviews with researchers and practitioners. We also build on a series of recent research collaborations that seek to better understand current digital and data practices (and future needs) in the Australian Not-For-Profit sector (Farmer et al 2023, McCosker et al 2022a, McCosker et al 2022b).

Additionally, our Model is underpinned by recent investigations of the 'everyday data cultures' in which individuals, workforces and communities build new literacies and facilitate intimacy and public participation, through their engagements with data-driven digital devices, apps and platforms (Burgess et al. 2022, Wilken and Kennedy, in press).

Our adoption of the term 'capabilities' also resonates with humanities and social-science scholarship – particularly the work of Amartya Sen and Martha Nussbaum (2003). In this context, a 'capabilities approach' implies an orientation towards social justice. Such an approach encourages us to move beyond instrumental approaches to the classification and measurement of digital health literacy that focus on individual health consumers. Instead, we engage with current theory, policy and practice relating to digital inclusion, data sovereignty and data justice, in order to identify systemic barriers and enablers of sexual health and wellbeing.

¹ <https://www.digitalhealth.gov.au/about-us/strategies-and-plans/national-digital-health-capability-action-plan>



03. DEVELOPING A MODEL FOR DIGITAL AND DATA CAPABILITIES FOR SEXUAL HEALTH

3.1. LITERATURE REVIEW

A literature review was conducted in 2022 to map and synthesise current approaches to digital and data literacies in sexual health. This review utilised a social sciences narrative review methodology to offer both

a summary of findings, and a deeper understanding of extant literature via interpretation and critique (Greenhalgh, Thorne, & Malterud 2018).

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	= 30 results (with duplicates and unrelated results removed)
		No results using this combination of terms and "data literacy".

3.2. EXPERT INTERVIEWS

Interviews were conducted in parallel to the literature review process, as a means of sense-checking our findings. This process filled 'gaps' in the public health literature by surfacing everyday aspects of contemporary practice that are not yet represented in peer-reviewed publications. Following ethics approval, we completed twenty-nine interviews with individuals we identified as experts across sexual health and digital media studies².

The final interview took place in March 2023. Interviewees included researchers and practitioners from digital health, public health and sexual health, as well as digital studies,

data studies and gender and sexuality studies. Participants were largely Australian-based, but we also interviewed researchers and practitioners in the UK, Europe, the United States and Canada.

Table 1 below indicates the broad spread of interviewees' overlapping expertise and experience. Many researchers were also practitioners, and we have indicated the health setting in which they worked in the right-hand table, hence the overall numbers in both tables equals more than twenty-nine.

² SUHREC 20226416-10135.

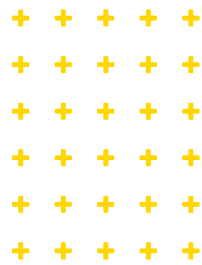


Table 1: Interviewee expertise and experience

RESEARCHERS	
Field	#
Public Health	9
Digital Health	1
Sexual Health	6
Digital, Data Studies	4
Gender, Sexuality Studies	4
Youth Studies	1

SITES OF PRACTITIONER EXPERIENCE	
Organisation	#
Local Health	9
Sexual Health	1
Women’s Health	6

3.3. OVERVIEW OF EVIDENCE UNDERPINNING MODEL DEVELOPMENT

Preliminary insights from the literature review were presented to the Project Reference Group in January 2023.

LITERATURE REVIEW FINDINGS³

- Most research in this area originates from North America and Europe.
- The predominant focus is HIV research, less consideration of broader sexual health.
- Digital technologies are largely framed within the literature as sites for the delivery of health information, and/or delivery of clinical sexual health services.
- The terms 'digital health literacy' and 'digital literacy' appear to be interchangeable within the literature.
- Digital health literacy/digital literacy is assumed to be a relevant skill/attribute for individual consumers/patients.
- Digital literacy associated with sexual health outcomes related to:
 - Behaviour change
 - Treatment adherence
 - Prevention of sexual health issues through the ability to identify accurate health information
- We found no specific considerations of 'data literacy' in relation to sexual health, however, data was discussed in relation to consumer access and understanding of personal health records.
- There is no discussion of sexual health professionals' and/or sexual health organisations' digital and data literacies within the literature examined.

³ Scholarly article outlining these findings in detail currently in development.



EXPERT INTERVIEW FINDINGS:

Interviewees identified the following challenges and needs facing sexual health organisations:

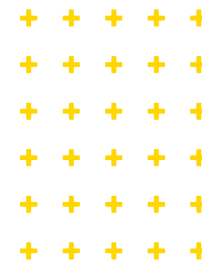
- Difficulty accessing, understanding, and utilising different types of data (epidemiological, research, website). In some instances, organisations did not recognise themselves as generating data beyond the space of clinical practice (ie Medicare data), despite using data-driven enterprise platforms and technologies in health promotion, education and client management activities.
- Siloed expertise and experience (organisational and disciplinary) and a need to develop collective and interdisciplinary approaches to digital and data practices.
- A clear need to build individual skills and knowledge (including workforce development).
- Lack of resources as both a barrier to external collaboration AND a driver of 'reluctant' participation in external projects as the price of accessing analyses of internal data
- Concerns regarding digital and data governance structures and accountability.
- Difficulty sharing data with community members and populations (including concerns relating to Indigenous data sovereignty⁴).
- A need to work with young people and/or co-design processes to better understand (and incorporate) their sexual health digital and data practices within organisational policies and knowledge systems (note: this aligns well with proposed activities in *Stage Two* of our project).

PROJECT REFERENCE GROUP

Based on the above findings, we developed a draft Digital and Data Capabilities Model for Sexual Health, which was shared with our expert Reference Group for review and comment.

Final additions and revisions were made based on feedback, resulting in the Model presented in Figures 2 and 3.

⁴ For discussion of Indigenous data sovereignty in Australian health settings, see Kelaher et al, 2018.



04. A MODEL FOR DIGITAL AND DATA CAPABILITIES FOR SEXUAL HEALTH

Figure 2: Data Capabilities for Sexual Health Policy and Practice

DATA CAPABILITIES FOR SEXUAL HEALTH POLICY AND PRACTICE			
Capability	Definition	Sub-capabilities	Questions
Access & Infrastructure	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"> Collection methodology Availability for use Classifications & standards Systems and tools Interoperability of both internal and external platforms and systems 	<ul style="list-style-type: none"> What counts as sexual health data, and how is it generated and accessed? Are datasets siloed and difficult to access? Can the organisation access and use the data it generates? How well do different platforms (and their methods of data collection and abstraction) work together? How well do data technologies support organisational purpose? Is there an organisation-wide strategy for integrated data software systems?
Skills	The ability to generate, read, appraise, analyse and use and present data responsibly to aid operations, evaluation and decision-making	<ul style="list-style-type: none"> Data wrangling (cleaning, editing, linking) Data & domain expertise Analysis (problem posing & solving) Communicating with data 	<ul style="list-style-type: none"> How do organisations and individuals understand and articulate their own data generation practices? How do organisations and individuals distinguish the difference between organisational data, and externally generated research evidence? How are informal or 'everyday' data practices recognised by individuals and organisations? How are roles and responsibility for the use of data allocated within the organisation? How is data expertise fostered and to what extent is this inclusive? What is the quality of data and the value of data analysis for decision making? How is data analysis communicated internally, with funders, clients and the wider community?



Figure 2: Data Capabilities for Sexual Health Policy and Practice (Cont.)

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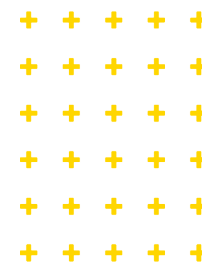


Figure 3: Digital Capabilities for Sexual Health Policy and Practice

DIGITAL CAPABILITIES FOR SEXUAL HEALTH POLICY AND PRACTICE			
Capability	Definition	Sub-capabilities	Core Questions
Access & Infrastructure	Digital platforms and technologies used and the technological means to manage and make use of them	<ul style="list-style-type: none"> Vernacular platforms and technologies Enterprise platforms and technologies Systems and tools (internal and external) 	<ul style="list-style-type: none"> What counts as a digital sexual health platform or technology and how is it used and accessed? How well do digital technologies and platforms support organisational purpose? How well do digital technologies and platforms support and enable consumer self-efficacy and access?
Skills	The ability to generate, read, appraise, analyse and use and present digital content responsibly to aid operations, clinical practice, campaigns and resources, evaluation and decision-making	<ul style="list-style-type: none"> Technological skills and general platform knowledge Search engine optimisation and algorithmic literacies Platform analytics Platform vernacular and vocabularies (text and image) Content creation and distribution Participation in everyday digital cultures (ie responding to comments under campaign content) 	<ul style="list-style-type: none"> How is digital expertise and knowledge fostered and to what extent is it shared across the organisation? How are the roles and responsibility for (maintaining/understanding/initiating) organisational digital identity and digital communication allocated and communicated within the organisation? How is lived experience of digital technologies and cultures incorporated into organisational policy and practice relating to digital identity (including content creation)?
Governance	Established processes of stewardship, leadership and accountability in the ethical creation and conduct of digital initiatives.	<ul style="list-style-type: none"> Digital identity Content moderation Data stewardship, management and moderation Ethics & inclusivity (consent, lived experience) Legality Risk Management (including data breach planning) 	<ul style="list-style-type: none"> Is there an organisation-wide policy to support digital identity, communication and/or technologies? Who takes responsibility for managing organisational digital identity, privacy and safety (including safety of staff who manage and moderate social media forums)? How are ethical principles and issues identified and addressed? How are legal requirements and security monitored and implemented? How does the organisation decide which digital platforms and technologies to engage with? Are there processes in place to safeguard community/consumer safety in digital content co-design and co-creation?



05. NEXT STEPS

The next stage of research will test our understandings of the Model, and build new understandings of vernacular (or everyday) digital and data capabilities with priority populations of young people aged 18-29 (including but not limited to LGBTQ+ young people and Aboriginal and Torres Strait Islander people).

Specifically, we will explore how Stage One findings do (or do not) align with young people's understandings of their everyday digital and data practices and capabilities relating to sexual health.

Stage Two will include co-design activities informing the development of:

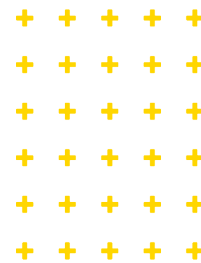
- A Digital and Data Capabilities Model for sexual health consumers
- Digital and data capabilities information and training resources for the sexual health workforce.

These will be prototyped in Stage Three, and rolled out in Stage Four.

The Model presented in this report will be revised iteratively, to ensure alignment with the forthcoming Australian Digital Health Capability Framework.

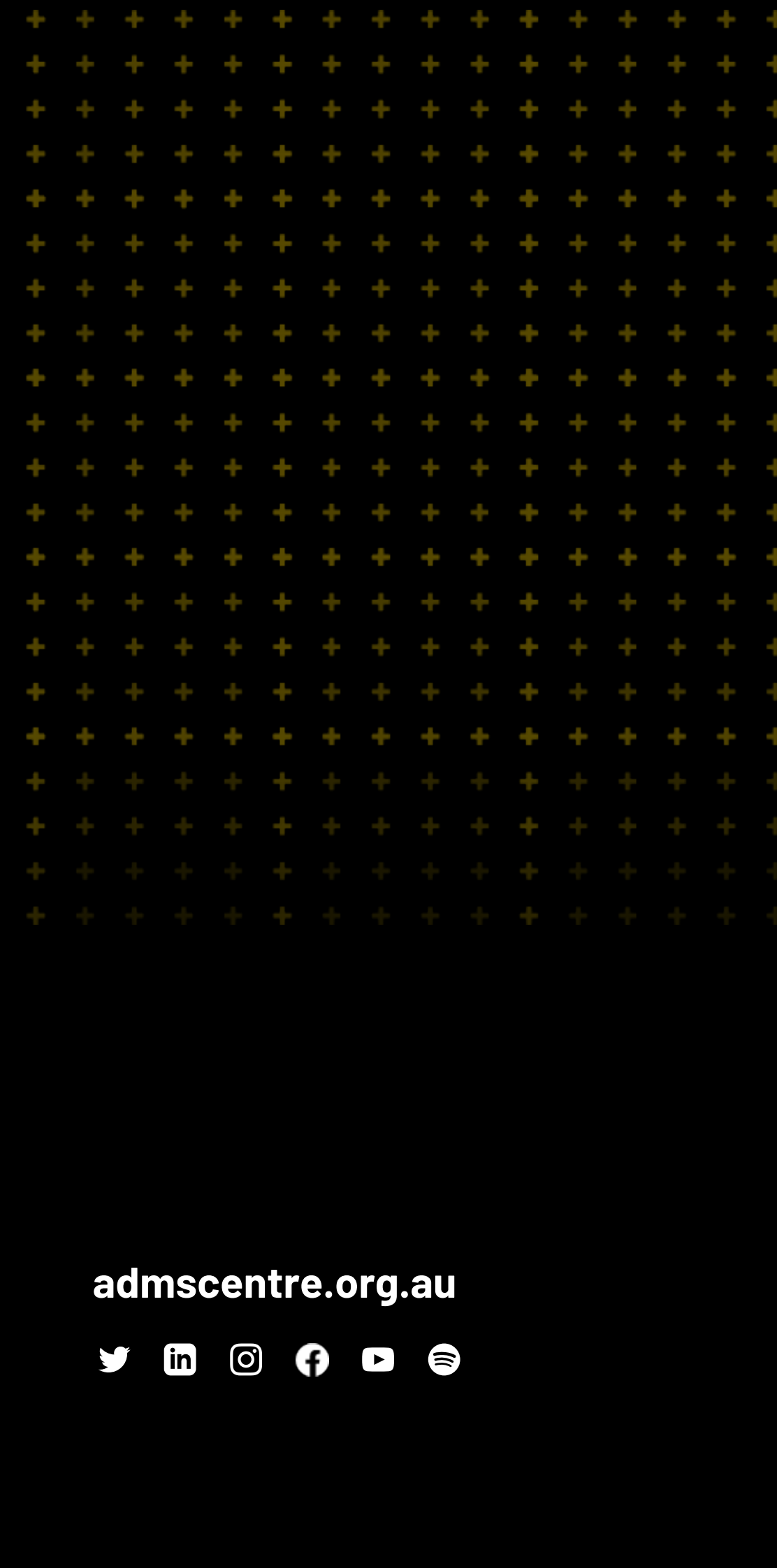
We welcome input and collaboration with researchers, policy-makers, educators, practitioners and health consumer advocates.

Questions, comments and feedback can be directed to Professor Kath Albury:
kalbury@swin.edu.au

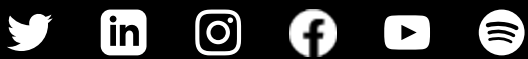


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