



SYNTHETIC DATA
COMMUNITY OF
PRACTICE
TERMS OF REFERENCE

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1. Background

A roundtable, comprised of sixteen representatives from across the digital health sector (including government, industry and Australian and UK universities), was convened by the Digital Health Cooperative Research Centre (DHCRC) on 15 and 16 March 2023 in Canberra. The purpose of the roundtable was to harness collective energy from a 'coalition of the willing' to 1) establish and set an agenda for the initiation of a synthetic data community of practice and 2) identify priority areas and opportunities for collaboration and advocacy to support advances in digital technology, informatics and data science.

The idea to establish a synthetic data community of practice arose through three independent synthetic data research proposals submitted to the DHCRC, each with origins in different Australian states (Queensland, Western Australia and Victoria). This led to discussions on the value of developing a coordinated program of work and a national collaborative approach to facilitate evidence and knowledge exchange.

The Synthetic Data (SD) Community of Practice (CoP) is being established to create a collaborative platform for professionals, experts, and stakeholders in the field of digital health and data science. This initiative aims to foster knowledge sharing, skill development, and the exchange of innovative ideas to advance digital health solutions and practices regarding synthetic data.

Founding organisational members of the Synthetic Data CoP are:

- DHCRC
- La Trobe University
- The University of Queensland
- The University of Sydney
- Western Australia Department of Health

Founding organisational members have jointly contributed to the development of the Synthetic Data CoP concept and initiate phase Terms of Reference, Roadmap and Plan.

2. Mission Statement

"To unlock the value of health information through the use of synthetic data to advance research, education, innovation and service delivery within the health and care sector."

3. Objectives

Develop a synthetic data coordinated program of work and national collaborative approach to facilitate evidence and knowledge exchange for:

i. Advocacy, education and training

Provide a platform for the promotion of synthetic data use and synthetic data capability development and knowledge through joint research publications, conference and symposium presentations, lectures, workshops, datathons, webinars, training sessions and education short course / micro-credential content development.

ii. Governance processes and standards

Lead the development of national governance processes, frameworks and standards for synthetic data, including data ethics and accountability, privacy protection and data quality assessment.

iii. Technical solutions

Identify and map synthetic data applications and products/assets being used and document and measure the outcomes and impacts from these synthetic data technical solutions to support further synthetic data technical innovation and quality improvement.

iv. Knowledge sharing

Facilitate the exchange of best practices, lessons learned, and emerging trends in the use of synthetic data within the health and care sectors for mutual benefit, to maximise synthetic data opportunities and benefits and provide guidance and support on synthetic data challenges.

v. Use cases

Collaborate on joint synthetic data use cases to solve health related challenges and unlock new synthetic data opportunities for mutual benefit.

4. Membership

i. Membership type, Numbers, Terms and Voting Rights

Membership Type	Membership	Number	Terms	Voting rights
Organisation member representative +/- organisation member standing attendee(s)	Australian government (Federal / State), industry organisations and universities may each nominate one organisation member representative and up to two additional organisation member standing attendee(s) based on their relevant organisational roles and responsibilities relating to synthetic data.	Minimum 4 member organisations Maximum 10 member organisations Minimum 1 organisation member representative and maximum 2 additional organisation member standing attendees who are role-based representatives.	5-year term per organisation and able to re-apply.	1 vote per organisation member representative and proxy attendance and proxy voting allowed. No voting rights for organisation member standing attendees, however proxy attendance allowed (e.g., a delegate for role-based representative)
Technical Expert Member	Technical experts appointed for their individual synthetic data knowledge and expertise	No Minimum Maximum 2	2-year term per individual and able to re-apply with a maximum of 2 terms.	1 vote per person. No proxy attendance or voting allowed.
Health Consumer member	Health Consumers with lived experience of digital healthcare, nominated by the Consumers Health Forum	No Minimum Maximum 2	2-year term per individual and able to re-apply with a maximum of 2 terms.	1 vote per person. No proxy attendance or voting allowed.

Membership Type	Membership	Number	Terms	Voting rights
DHCRC member representative member +/- DHCRC member standing attendee(s)	DHCRC nominated staff with relevant organisational roles and responsibilities relating to synthetic data.	Minimum 1 DHCRC representative and maximum 3 additional DHCRC standing attendees who are role-based representatives (i.e., 4 maximum DHCRC members).	5-year term and able to re-apply.	1 vote for the DHCRC member representative and proxy attendance and proxy voting allowed. No voting rights for DHCRC member standing attendees, however, proxy attendance allowed (e.g., delegate for role-based representative).
Co-Chairs	Nominated by Members or self-nominated.	2 Co-Chairs	1 year and able to re-apply with a maximum of 2 terms.	Per membership type above

ii. Eligibility

Membership of the Synthetic Data CoP is open to organisations and technical experts (professionals, researchers, policy makers and other stakeholders) Australian government (Federal / State), industry and universities, as well as health consumer representatives, who demonstrate a strong commitment to actively contribute to the Mission and Objectives of the Synthetic Data CoP.

iii. Recruitment – Members

Membership of the Synthetic Data CoP is determined by completion of a membership nomination form and successful review by existing Synthetic Data CoP members, which may include a selection panel, short-listing process and/or a meeting with the selection panel or their nominee.

Representation from all States/Territories and high quality, broad background membership will be sought to provide Australia wide, diverse experiences and skillset inputs into the Synthetic Data CoP.

Successful organisational membership applicants will be appointed for a 5-year period and will be able to reapply. Successful technical experts and health consumers will be appointed for a 2-year period and will be able to reapply with a maximum of 2 terms.

iv. Recruitment – Co-Chairs

Co-Chairs (two) are determined by active recruitment/invitation and completion of a Co-Chair nomination form and successful review by existing Synthetic data CoP members, which may include a selection panel, short-listing process and / or a meeting with the selection panel. Successful co-chairs will be appointed for a 1-year period and will be able to reapply for a maximum of 2 terms.

v. Orientation

The Co-Chairs will provide an orientation session to all new members. This will include the Synthetic Data CoP Terms of Reference, Roles and Responsibilities, Roadmap & Plan, Key Deliverables and any other relevant training/support.

vi. Remuneration

Member Organisation representatives and Technical Experts will participate in Synthetic Data CoP meetings and activities as part of their primary employment arrangements and will not be additionally remunerated for their Synthetic Data CoP engagement. In-kind contributions from representatives can be recognised by the DHCRC as per the Commonwealth formula.

Health Consumer members of the Synthetic Data CoP will be remunerated for their time in line with Consumers Health Forum policy, which will be funded by the DHCRC as principal sponsor for the Concept, Initiate and Discovery phases.

5. Quorum and Decision Making

Decision making is by consensus with diverse views valued and acknowledged. If a decision is required and where consensus cannot be reached, the Co-Chairs may elect to put the matter to a vote, with majority rules.

For decision making or voting to be valid, there must be a Quorum, which for the Synthetic Data CoP is a minimum of 50% of organisational member representatives (or their proxies) and where organisational member representatives are not less than individual technical expert and consumer members. This ratio also applies to any out-of-session decision making. Refer to the membership table above for voting rights.

Observers, guest speakers and other CoP participants or guests do not hold decision making or voting rights.

6. Governance and Funding

The Synthetic Data CoP is initially under the auspice of the DHCRC and taking a collaborative approach.

Organisation member representatives and standing attendees are individually accountable for their contributions and opinions and collectively responsible to their member organisations for their contributions provided to the CoP in line with their member organisation governance/steering processes.

Funding for the Synthetic Data Concept Phase, Initiate Phase 0 and Discovery Phase 1 funding is being provided by:

- **Direct contributions** by the DHCRC out of the DHCRC Education and Capacity Building budget over approximately 2 years (October 2023 to October 2025) as developed and agreed by the DHCRC.
- **In kind contributions** by CoP member organisations, which will be calculated and reported by the DHCRC per the Commonwealth in-kind contributions formula.

A transition to a sustainable, independent entity is planned prior to the expiration of the DHCRC Commonwealth funding (December 2026 TBC). The Terms of Reference will be updated as relevant.

The Synthetic Data CoP will develop a Sustainability plan and a Commercialisation and Innovation plan as key early deliverables, which will consider a proof of concept and clear value proposition.

7. Meetings and Activities

The Synthetic Data CoP will engage in a variety of activities in line with its objectives including, but not limited to:

i. Online meetings (approximately monthly)

Regular meetings will be held to share information, report on project progress, evaluate outcomes, record risks, issues, actions, decisions, lessons learned, plan projects etc.

Meetings will be held online monthly for the first 6 months (November 2023 to April 2024) and then two monthly commencing June 2024. Meetings will be for approximately one hour.

The meeting schedule will be agreed 12 months in advance. However, meetings can be extended, or additional meetings scheduled, if agreed.

ii. Webinars and Workshops

Regular sessions on relevant synthetic data or related digital health topics.

iii. Collaborative Projects

Initiating and supporting collaborative projects among members.

iv. Discussion / Chat Forums

Online forums for members to discuss challenges, share insights, and seek advice.

v. In-person workshops (approximately 6 monthly)

Approximately, every 6 months members will meet in person over a 2-day workshop to showcase innovations and provide a platform for in-depth discussions, guest speakers and networking. The workshop schedule will be agreed upon 12 months in advance: Brisbane, 7th and 8th May 2024 (TBC), Melbourne, October 2024 (TBC).

8. Meeting Protocols

- Meetings are to be action and solution orientated.
- Co-Chairs may jointly chair meetings or take turns chairing meetings.
- Condensed meeting minutes are taken by the Secretariat. Draft meeting minutes are issued within 3 business days of the meeting and ratified at the next meeting.
- If a member cannot attend a meeting, it is their responsibility to advise the Secretariat and if applicable (refer to Membership table), nominate a suitable proxy to attend in their absence, who is appropriately briefed.
- Agendas for the next meeting will be initially planned at the end of the prior meeting and finalised a week before the meeting by the Co-Chairs with the Secretariat. The final agenda, along with any pre-reading material, will be distributed to all members, a minimum of two business days prior to any meeting.
- Members are required to review the agenda, minutes, and associated documentation prior to each meeting, and follow through on action items prior to the next meeting.
- If agreed, Co-Chairs or Members, may from time-to-time invite guest speakers or other guests to observe CoP meetings or provide additional expert advice on a specific topic.
- To enable timely action between meetings, out-of-session papers and decision making is supported. This will be co-ordinated by the Secretariat with the Co-Chairs. If an out-of-session paper is circulated for comment or approval, a non-response, within the stated timeframe, will be taken as no comment/endorsement of the recommended action, in line with the Quorum rules (refer above). Any out-of-session decisions will be recorded in the minutes of the next meeting.

9. Roles and Responsibilities

i. Members

- Promote the mission and objectives of the Synthetic Data CoP within their organisations and through their networks.
- Contribute effectively to Synthetic Data CoP meetings and activities,
- Respectively reply to emails and other requests within the requested time frames. A non-response, within the stated timeframe, will be taken as no comment/endorsement of the recommended action.
- Adhere to generally accepted meeting and committee codes of conduct
- Maintain appropriate confidentiality
- Declare any conflicts or potential conflicts of interest

ii. Co-Chairs

- Jointly chair meetings or take turns chairing meetings.
- In consultation with the Secretariat finalise meeting dates, times, agendas and any out-of-session business.
- Provide leadership and ensure that meetings are held in accordance with generally accepted meeting and committee codes of conduct and activities and actions align with the Synthetic Data CoP Terms of Reference.

iii. Secretariat

Secretariat support will initially be provided by the DHCRC. Ultimately, it is envisaged that an independent Secretariat may be supported by membership or sponsorship.

Responsibilities include:

- Arrange meetings and send appointments.
- Prepare agenda and supporting papers, review and finalise with committee Co-Chairs and distribute to Members at least 2 business days prior to each meeting.
- Take condensed minutes of meeting.
- Maintain digital records of the group including actions, decisions, risk register, issues list, lessons learnt etc.
- Co-ordinate any out-of-session papers with the Co-Chairs and distribute/collate responses.

10. Reporting and Communication

- The Synthetic Data CoP will utilise an online platform (MS Teams) as a “single source of truth” for digital records, chats, resource sharing etc. Members are required to proactively contribute to keeping digital records current.
- A Contacts register will be maintained for Member use.
- A Stakeholder register, stakeholder map and communication and engagement plan will be developed and reviewed annually or more frequently as required by the Synthetic Data CoP members.

11. Evaluation

- A Metrics and Reporting plan will be developed and reviewed annually or more frequently as required by the Synthetic Data CoP members. Key principles include identifying a lead from the Synthetic Data CoP for each initiative, value at the level of what is being generated and key measures of success.
- The Synthetic Data CoP will undertake an annual self-assessment and feedback mechanism of performance against its Terms of Reference, Mission, Objectives, agreed Metrics and key measures of success to continuously improve activities and engagement.
- The DHCRC may also commission an external review of the Synthetic Data CoP at its discretion.
- Reporting for purposes of transparency and accountability will be through an annual report to the DHCRC and a summary statement provided to organisational members.

12. Conflicts of interest

- A Conflict-of-Interest Register will be maintained by the Secretariat.
- If, during the period of a member’s appointment to the Synthetic Data CoP, a conflict of interest arises, whether actual, potential or perceived, the Member must notify the Co-Chairs immediately. At the discretion of the Co-Chairs, members may be excused from discussions on that issue.
- Declaration of conflicts of interest must be listed as a standing item in meeting Agendas and recorded in the meeting minutes.

13. Resolving issues or conflict

If an issue or conflict arises, a member of the Synthetic Data CoP may raise the issue with Co-Chairs. If it is about the Co-Chair(s), the member should speak to the DHCRC CEO.

14. Confidentiality

Members of the Synthetic Data CoP will maintain confidentiality of all information discussed in meetings that is not in the public domain and seek clarification and approval from the Co-Chairs if unsure. Documents and access to the digital file sharing source (MS Teams) is for members only, unless explicitly stated or there is a general exemption and approval by the Co-Chairs.

15. Amendment and Approval

The Terms of Reference are to be reviewed by the membership and re-endorsed on an annual basis per Membership decision making/voting rules (refer above).

Version History is in the table below:

Version	Date of Approval	Extent of Revision
0.1 Draft	N/A	Initial Draft for Review 15/11/23
0.2 Draft	N/A	Initial Feedback to 30/11/23
0.3 Draft	N/A	Draft 5/12/23 incorporating 1/12 meeting feedback.
V1.0	12/12/23	Version 1.0 incorporating all Draft feedback.

APPENDIX A – Membership List

Membership Type	Organisation (Role)	Name	Joining Date
Organisation Member - Representative	DHCRC (Education & Workforce Director)	Dr Melanie Haines	Dec-23
Organisation Member – Standing Attendee	DHCRC (Research Director)	Dr Clare Morgan	Dec-23
Organisation Member – Standing Attendee	DHCRC (Program Manager)	Meagan Snewin	Dec-23
Organisation Member - Representative	La Trobe University (Chair of Digital Health)	Professor James Boyd	Dec-23
Organisation Member - Representative	University of Queensland (Director of Clinical Informatics)	Jodie Austin	Dec-23
Organisation Member – Standing Attendee	University of Queensland (Data Manager)	Reji Philip	Dec-23
Organisation Member – Standing Attendee	University of Queensland (Research Fellow)	Elton Lobo	Dec-23
Organisation Member - Representative	University of Sydney (Beamtree Associate Professor of Clinical Informatics & Data Science)	Dr Ben Hachey	Dec-23
Organisation Member – Standing Attendee	University of Sydney (Post-Doctoral Fellow)	Dr Amir Marashi	Dec-23
Organisation Member – Representative	WA Department of Health (Director, Data and Information Systems)	Nasir David	Dec-23
Organisation Member – Standing Attendee	WA Department of Health (Lead Data Scientist)	Dr Sylvia Young	Dec-23
Organisation Member – Standing Attendee	WA Department of Health (Manager, Data Linkage Services)	Baldave Singh	Dec-23