Health Data Commons GORC Profile WG

(HDC GORC WG)

[Response to TAB](#)

WG Charter

Rationale

Health data commons have been or are being launched across a number of geographies to enable the reuse of participant-level health data at the national and cross-national levels. Health data commons will enable machine learning and related artificial intelligence (AI)-based approaches to health data analysis and support the national and cross-national detection and response to epidemics. Health data commons can facilitate public health surveillance, observational clinical research, personalised medicine, and the design and conduct of randomised controlled trials (RCTs) by enabling country- and cross-country or global analyses of health data. Whether and how the FAIR (findable, accessible, interoperable, reusable) principles[1] are implemented affects how metadata and participant-level data can be reused across health data commons. FAIR convergence, as when related stakeholders take the same or similar routes to implementing FAIR, can help foster interoperability in the health data space where there are many standards for the capture or exchange of health data and for which there are limited crosswalks that link ontologies. A similar approach can be considered regarding the TRUST (Transparency, Responsibility, User focus, Sustainability and Technology) principles[2] for management and operations of data systems and the CARE (Collective benefit, Authority to control, Responsibility, and Ethics) principles[3] regarding data and resource governance and

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[1] Wilkinson, M. D., Dumontier, M., Aalbersberg, Ij. J., Appleton, G., Axton, M., Baak, A., Blomberg, N., Boiten, J.-W., da Silva Santos, L. B., Bourne, P. E., Bouwman, J., Brookes, A. J., Clark, T., Crosas, M., Dillo, I., Dumon, O., Edmunds, S., Evelo, C. T., Finkers, R., … Mons, B. (2016). The FAIR Guiding Principles for scientific data management and stewardship. *Scientific Data*, *3*(1), Article 1. https://doi.org/10.1038/sdata.2016.18

[2] Lin, D., Crabtree, J., Dillo, I., Downs, R. R., Edmunds, R., Giaretta, D., De Giusti, M., L'Hours, H., Hugo, W., Jenkyns, R., Khodiyar, V., Martone, M. E., Mokrane, M., Navale, V., Petters, J., Sierman, B., Sokolova, D. V., Stockhause, M., & Westbrook, J. (2020). The TRUST Principles for digital repositories. Scientific Data, 7(1), Article 1. https://doi.org/10.1038/s41597-020-0486-7

[3] Carroll, S. R., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., Lovett, R., Materechera, S., Parsons, M., Raseroka, K., Rodriguez-Lonebear, D., Rowe, R., Sara, R., Walker, J. D., Anderson, J., & Hudson, M. (2020). The CARE Principles for Indigenous Data Governance. Data Science Journal, 19(1). https://doi.org/10.5334/dsj-2020-043

privacy. The TRUST and CARE principles are crucial as they ensure ethical governance, user focus, and sustainable management of health data, fostering trust and cooperation among stakeholders. Open collaboration on FAIR, TRUST, and CARE implementation also helps stakeholders reuse available resources and standards rather than developing new ones.

The goal of interoperability across and FAIRness for Health Data Commons aligns with the overarching vision of the Global Open Research Commons (GORC). The Research Data Alliance (RDA) Global Open Research Commons-Interest Group[4] (GORC-IG) has been working since 2019 to support coordination amongst national, pan-national and domain-specific organizations as they build interoperable resources to enable researchers to address societal grand challenges, including but not limited to data reuse, accessibility, discoverability, management, and analysis. The GORC's overarching goal is to provide frictionless access to all research artefacts to everyone, everywhere, at all times, with the appropriate infrastructure, protocols, and support. In the health context, research artefacts, information resources, and artefacts created in practice are within scope. The GORC-IG examined a range of existing Research Commons architectures and developed a typology of the essential elements in a Commons complete with definitions[5]. In support of the GORC-IG, the GORC International Model Working Group[6] (GORC IM WG) has analyzed a range of existing commons to collect and curate a set of attributes that will allow Commons developers to compare features, existing key performance indicators, and metrics. From this analysis, the WG has created a non-prescriptive Commons model that provides a common language to describe all aspects of a commons and a guide to identify priority areas. The GORC international commons model[7] is a first step in developing a comprehensive roadmap for global commons alignment and was developed with significant consideration of the FAIR, TRUST, and CARE principles.

WG Objective

The core objective of this WG is to create a Health Data Commons profile of the GORC IM to advance FAIR convergence and interoperability for health data. Health data commons are the health-data-focused versions of data commons, which bring together and expose metadata from health data infrastructures.

The "profile" of the GORC IM refers to a subset (or extension) of considerations from the GORC IM that are relevant for health data commons, including different types of biomedical data (e.g., clinical data, surveillance data, EHR data, biomedical sample metadata) and concerns related to the reuse of sensitive human-derived data (e.g., GDPR). We will accompany the profile with

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[4] https://www.rd-alliance.org/groups/global-open-research-commons-ig

[5] Jones, S., Leggott, M., Lopez Albacete, J., Pascu, C., Payne, K., Schouppe, M., Treloar, A., & Global Open Research Commons IG. (2023). GORC IG: Typology and Definitions (1.01). Zenodo. https://doi.org/10.15497/RDA00087

[6] https://www.rd-alliance.org/groups/gorc-international-model-wg

[7] Woodford, C., Treloar, A., Leggott, M., Payne, K., Jones, S., Lopez Albacete, J., Madalli, D., Genova, F., Dharmawardena, K., Chibhira, N., Åkerström, W. N., Macneil, R., Nurnberger, A., Pfeiffenberger, H., Tanifuji, M., Zhang, Q., Jones, N., Sesink, L., Wood-Charlson, E., & RDA GORC International Model WG. (2023). The Global Open Research Commons International Model, Version 1 (1.0). Zenodo. https://doi.org/10.15497/RDA00099

examples of actual metadata from health data commons to further explain the metadata in the GORC IM Profile. We aim to bring together different stakeholders engaged or otherwise interested in any stage of planning or implementing Health Data Commons to:

1. identify what items in the GORC international model (IM) are relevant for country-level or transnational health data commons;
2. identify additional metadata needed to understand different levels of interoperability and address sensitive data concerns (e.g., access conditions, data governance, benefit sharing) relevant to health data commons and not addressed in the GORC IM;
3. collect agreed-upon metadata from the Health Data Commons GORC profile to understand how Health Data Commons are being implemented.

The Health Data Commons WG profile will support the implementation map of the GORC model and identify where and how organizations are currently addressing aspects of FAIR, where the gaps are, and the tools to address the gaps in the health data space. The GORC IM becomes more useful as it is adopted by commons in different research domains. Through developing and populating the GORC IM for the health data commons space, this WG will support the continuation, extension, and uptake of the GORC IM approach. Profiles, like the health data commons profile of the GORC IM, are needed to implement the GORC IM.

The health data commons metadata schema from this WG will support semantic and technical interoperability between health data commons and support FAIR health data commons, where health data has maximum citability, reusability, and interpretability while addressing local policy, ethics, and security concerns.

The intent of this WG is not to solve FAIR, TRUST, or CARE for health or to provide best practice for implementing health data commons. Instead, we would like to support community development of FAIR metadata that health data commons and related stakeholders can use to understand what implementation decisions have been made by other health data commons or commons in other domains and to share their health data commons' implementation decisions. Rather than being prescriptive, these metadata can identify gaps in cross-commons interoperability or the coverage of other global issues in the Health Data Commons space (e.g., indigenous health data sovereignty) and opportunities for semantic and technical interoperability with commons in other spaces (e.g., climate data, environmental exposures data, biodiversity data, oceans data).

To enable FAIR convergence, stakeholders in the health data commons space must understand how FAIR has been implemented in similar initiatives, which resources (e.g., ontologies, data governance mechanisms) have been used, and why these choices have been made.

Recognizing that there are additional barriers to and concerns in adopting FAIR, CARE, and TRUST in the health data domain, this working group will create a Health Data Commons profiling of the GORC International Commons Model that can then be used to understand FAIR, CARE and TRUST implementation and compare features across health data spaces and between health and related domains (e.g., oceans, climate, ecology). By generating machine-actionable metadata that describes commons in a consistent, structured way, we will make visible the choices communities of practice make when implementing FAIR, CARE, and TRUST across health data commons.

The intended outcome of this working group is to increase FAIR implementation and FAIR convergence in the health data commons space, identify gaps in technical and semantic interoperability across commons, and enable cross-commons reuse of participant-level data to facilitate global coordination in addressing shared challenges (e.g., including detection and response to emerging pathogens), and enabling cross-domain data reuse through building semantic and technical interoperability between health data commons and data commons from other domains, including climate, ecology, biodiversity, etc. to understand and address our society's most pressing challenges, including the impact of climate change on human health.

The IM health data commons profile will be built out in normal text. Outside of the scope of the working group, pending funding, we will codify the health data commons GORC IM schema in RDF/JSON-LD to ensure that the health data commons can be represented in a connected knowledge graph. Through the application of the health data commons GORC profile, we will develop a health data commons implementation profile that will then become a roadmap for FAIR convergence, the common adoption of ontologies or provenance and permissions mechanisms to facilitate cross-commons data reuse within the health data and cross-domain space.

Value Proposition

High-quality, interoperable health data and related metadata can change the trajectory of individual health and local and national public health initiatives through improved surveillance, public health, clinical care, and research and development. Interoperability across independent components is achieved by agreeing on a set of rules describing how to operate together to achieve a desired result. Identifying components common across health data infrastructures can support convergence on a set of broadly accepted rules and assessment criteria for research-enabling capabilities. Adopting common definitions of components and Open Science enabling capabilities can increase interoperability across health data infrastructures. Many governments are investing in national initiatives to create a unified structure for health data reuse at the national and cross-national levels. These initiatives face myriad challenges related to the high level of fragmentation by data type, data capture or exchange standard, disease, body system, population, institution, state, and data governance approach, amongst other factors. In contrast to (supra)national open science cloud efforts to facilitate access to other data types (e.g., climate, ocean, deep earth), in the health data space, ethical, legal, social, and institutional (ELSI) barriers to data sharing, reuse, and the low level of adoption of the FAIR principles present additional challenges. Understanding how health data commons address these barriers helps facilitate shared approaches to common problems, which would support cross-Commons reuse of participant-level data through FAIR convergence.

By establishing and using a health data commons profile of the GORC model, health data commons can learn from and help each other solve shared problems. How health data commons implement the FAIR principles and data reuse-related governance, including addressing legal and ethical concerns, has significant consequences for cross-ecosystem semantic and technical interoperability and data access. When considering the adoption of data capture or exchange standards for discovery or descriptive metadata or participant-level data, using the same standards or standards that have established crosswalks can support cross-ecosystem interoperability. Similarly, interoperability, transparency, and machine actionability of ecosystem governance, including how consent for data or sample reuse is operationalized at the participant level, is important for enabling cross-ecosystem and cross-domain analyses, especially for sensitive health data. Understanding how health data ecosystems encourage and facilitate engagement with data users and providers, in addition to how they measure success, can help other health data commons develop strategies to address these shared challenges.

Similarly, understanding how health data commons have implemented the CARE and TRUST principles will be useful for governments, citizens, and other stakeholders. Exposing well structured metadata to describe health data commons will help ensure transparency, ethical governance, and sustainable management of health data, which in turn fosters trust, cooperation, and equitable benefits and could highlight opportunities for cross-national health data space learning and collaboration related to CARE and TRUST. Findings on how health data commons have adopted FAIR, CARE, and TRUST will be used to set priorities for adoption and serve as benchmarks for tools that attempt to measure and stimulate progress towards adoption.

Health does not exist in a vacuum. Efforts to improve the adoption of the FAIR, CARE, and TRUST principles in climate, ecology, agriculture, conflict, education, etc., have important implications for understanding the social determinants of health and the distribution of disease. Climate change is directly related to the emergence of novel pathogens and to epidemics of well-characterized non-communicable and infectious diseases. By understanding how health data ecosystems implement FAIR, CARE, and TRUST, RDA will help highlight areas for cross-domain convergence (e.g., metadata ontologies). Moving towards FAIR, cross-domain metadata will also help enable the One Health approach, where animal and ecosystem health are considered alongside human health, incorporating health data into disaster response and exploring the relationship between climate and health.

By documenting how health data ecosystems operationalise health data governance, including legal and ethical concerns, this working group will facilitate conversations with stakeholders around opportunities to align approaches to interpreting shared concerns. Understanding what ontologies and tools or approaches are used by existing health data ecosystems will help health data ecosystems that are in the formative stages use existing tools and ontologies, which, in turn, facilitates semantic and technical interoperability across health data ecosystems. The shared implementation of FAIR is especially important for enabling federated learning and the reuse of participant and patient-level data without moving the data, which may fast-track timelines for epidemic detection and response.

In addition to far-reaching impacts on health and health data, the creation of a health commons profile of the GORC international commons model will benefit other discipline-specific commons by laying the foundation (e.g., process, semantic description) for other GORC model profiles that can foster FAIR convergence within those domains and in the cross-domain space. The challenges we will face in creating and implementing the health data commons profile will provide lessons learned that can be shared with groups conducting similar work to describe commons in other domains. The development of more GORC profiles described in RDF/JSON-LD will enable a cross-commons knowledge graph that can guide future investments to increase the global interoperability of commons, bridging discipline-specific and -agnostic commons. These discipline-specific profiles, which build on learnings in the health data commons WG, will provide a roadmap for FAIR convergence in their respective disciplines, highlight unresolved differences and incompatibilities between disciplines that hamper interdisciplinary research, and feed into GORC-IG's roadmap to commons integration.

Lastly, by fostering collaborations across health data commons and between health data commons and commons in other domains, the working group will help enable the open channels of communication and trust needed to facilitate collaborative work during epidemic response and to address societal grand challenges like the SDGs.

Engagement with existing work in the area

The GORC IM is the basis for the health data commons (HDC) implementation work described above. Our work will also be informed by a scoping review that summarises publications related to country-level and transnational health data commons[8] and snowball sampling where WG chairs or members working to develop health data commons will help identify related initiatives. In addition to this, we will incorporate outputs from and work with related RDA groups to inform our outputs, including the Health Data Interest Group[9], Sensitive Data Interest Group[10], Life Science Data Infrastructures IG[11], Raising FAIRness in health data and health research performing organisations (HRPOs) WG[12], Artificial Intelligence and Data Visitation (AIDV) WG[13], and others affiliated with or working on health data and medical practice and research initiatives, with a focus on groups that are addressing interoperability challenges in the health data space. We will also work with and foster participation from related groups external to RDA, including working groups such as EOSC's FAIR metrics and Data Quality Task Force[14], CODATA's GOSC "Sensitive data in population health" Case Study Group[15], members of which are co-chairs of

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[8] Maxwell L. Mapping the international ecosystem of national health data spaces. A scoping review protocol. Open Res Europe 2023, 3:87 (https://doi.org/10.12688/openreseurope.15982.1)

[9] https://www.rd-alliance.org/groups/health-data.html

[10] https://www.rd-alliance.org/groups/sensitive-data-interest-group

[11] https://www.rd-alliance.org/groups/life-science-data-infrastructures-ig

[12] https://www.rd-alliance.org/groups/raising-fairness-health-data-and-health-research-performing-organisations-hrpos-wg

[13] https://www.rd-alliance.org/groups/artificial-intelligence-and-data-visitation-aidv-wg

[14] https://eosc.eu/advisory-groups/fair-metrics-and-data-quality/

[15] https://codata.org/initiatives/decadal-programme2/global-open-science-cloud/case-studies/sensitive-data-in-population-health/

this group, and the UNESCO/CODATA Data Policy in Times of Crisis WG[16] in addition to existing health data research infrastructures or global collaborations that may already be or intend to become health data commons or support such commons, e.g., the NIH[17], ARDC People Research Data Commons[18], UK Health Data Research Innovation Gateway[19], ELIXIR[20], NFDI4Health[21], and GA4GH[22].

In Table 1, we describe how we will engage with the work of some of these groups. We include a more complete list of groups within and beyond RDA that we will work with in Table 2.

Table 1. Specific groups we will engage with and the rationale for that engagement

Group/output	Relevant now or to be addressed after WG started	Why relevant	How we build on existing work
GORC IM	Relevant now	Provides a set of characteristics and entities describing components of a commons, generic and not discipline specific.	Review each item and consider how each is relevant to HDCs, make more or less granular as needed.
DRAWG	Relevant now	Provides basic metadata to describe infrastructures for data preservation and reuse.	Reuse the DRAWG metadata recommendations in combination with the GORC IM.
Life Science Data Infrastructure IG	Relevant now	Source of stakeholders who might be interested in supporting GORC IM extension to health data spaces.	Attend meetings to utilise network and engage related group.
EOSC's FAIR metrics and Data Quality Task Force	Relevant now	Best practice on metrics to measure FAIRness of data and infrastructures.	Engage group participants, monitor and use group outputs.

Table 2. Full starting list of groups that this WG will work with

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[16] https://codata.org/events/conferences/fair-convergence-symposium-2022/data-policy-in-times-of-crisis/
[17] https://www.nih.gov/
[18] https://ardc.edu.au/people-research-data-commons/
[19] https://www.healthdatagateway.org/
[20] https://elixir-europe.org/
[21] https://www.nfdi4health.de/en/
[22] https://www.ga4gh.org/

Group type	Known Groups (starting list)	Involvement mechanism
HDCs / Health Data Infrastructures	● People Research Data Commons (ARDC)[23] ● NIH[24] ● Canadian Institute for Health Information (CIHI)[25] ● Canada Health Infoway[26] ● Gemini[27] ● Health Data Research Innovation Gateway[28] ● ELIXIR[29] ● NFDI4Health[30] ● GA4GH[31] ● European Health Data Space[32] and its precursors ● German Swarm Learning Network[33] ● HealthRI[34] ● Spanish Health Data Space (Arogon Health Data Space)[35] ● African Population Health Research Centre[36] ● SALURBAL[37] ● African CDC[38] ● AOSP[39] ● NHDS[40] ● The Virtual Platform developed under the European Joint Programme on Rare Diseases (EJP RD) and continuing as the	Invitation to participate in questionnaire, speaker series, and as WG member(s)

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[23] https://ardc.edu.au/people-research-data-commons/

[24] https://www.nih.gov/

[25] https://www.cihi.ca/en

[26] https://www.infoway-inforoute.ca/en/

[27] https://geminimedicine.ca/

[28] https://www.healthdatagateway.org/

[29] https://elixir-europe.org/about-us

[30] https://www.nfdi4health.de/en/

[31] https://www.ga4gh.org/

[32] https://health.ec.europa.eu/ehealth-digital-health-and-care/european-health-data-space_en

[33] https://www.uniklinik-duesseldorf.de/patienten-besucher/klinikeninstitutezentren/klinik-fuer-gastroenterologie-hepatologie-und-infektiologie/forschung-und-lehre/decade/workprogram

[34] https://www.health-ri.nl/en/about-health-ri

[35] https://datos.gob.es/en/blog/national-health-data-space-strategic-project-country

[36] https://aphrc.org/

[37] https://drexel.edu/lac/salurbal/overview/

[38] https://africacdc.org/

[39] https://aosp.org.za/

[40] https://www.nhds.com/

	European Rare Diseases Research Alliance (ERDERA)[41] ● Estonia Digital Health System[42] ● Other infrastructures for clinical and health research in Europe[43] ● National Bioinformatics Sweden (NBIS)	
RDA IGs / WGs	● GORC IG[44] ● GORC IM WG[45] ● Sensitive Data Interest Group[46] ● Health Data Interest Group[47] ● Raising FAIRness in health data and health research performing organisations (HRPOs) WG[48] ● Data Repository Attributes Working Group (DRAWG)[49] ● Life Science Data Infrastructures IG[50] ● Artificial Intelligence and Data Visitation (AIDV) WG[51] ● RDA-OfR Creating a Multi-omics Metadata Schema Standard Reporting Matrix WG[52] ● Neuroimaging Data WG[53] ● Blockchain Applications in Health WG[54] ● Epidemiology common standard for surveillance data reporting WG[55] ● Virtual Research Environment IG (VRE-IG)[56]	Use draft and endorsed outputs, invite to participate in WG as members

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[41] https://www.ejprarediseases.org/erdera/

[42] https://e-estonia.com/solutions/e-health/e-health-records/

[43] https://www.healthinformationportal.eu/health-information-europe/research-infrastructures

[44] https://www.rd-alliance.org/groups/global-open-research-commons-ig/

[45] https://www.rd-alliance.org/groups/gorc-international-model-wg/

[46] https://www.rd-alliance.org/groups/sensitive-data-interest-group

[47] https://www.rd-alliance.org/groups/health-data.html

[48] https://www.rd-alliance.org/groups/raising-fairness-health-data-and-health-research-performing-organisations-hrpos-wg

[49] https://www.rd-alliance.org/groups/data-repository-attributes-wg/

[50] https://www.rd-alliance.org/groups/life-science-data-infrastructures-ig

[51] https://www.rd-alliance.org/groups/artificial-intelligence-and-data-visitation-aidv-wg

[52] https://www.rd-alliance.org/groups/rda-ofr-creating-multi-omics-metadata-schema-standard-reporting-matrix-wg

[53] https://www.rd-alliance.org/groups/neuroimaging-data-wg

[54] https://www.rd-alliance.org/groups/blockchain-applications-health-wg

[55] https://www.rd-alliance.org/groups/epidemiology-common-standard-surveillance-data-reporting-wg

[56] https://www.rd-alliance.org/groups/vre-ig.html

	- Metadata Standards Catalog WG[57] - FAIRsharing Registry: Connecting data policies, standards and databases RDA WG[58] - Metadata IG[59] - FAIR Data Maturity Model WG[60]	
WGs external to RDA	- FAIR metrics and Data Quality - EOSC Association[61] - Sensitive data in population health - CODATA[62] - UNESCO/CODATA initiative on ‘Data Policy for Times of Crisis Facilitated by Open Science: A Global Project on Developing Guidance, a Checklist, and a Factsheet as Contributions to the UNESCO Open Science Toolkit (DPCT-WG)’[63] - SIG-DigitalHealthData: Special Interest Group on Digital Health Data[64] - EOSC Health Data Task Force[65] - GEANT working group[66]	Use draft and endorsed outputs, invite to participate in WG as members

UN Sustainable Development Goals (SDGs)

The outputs of this group will contribute indirectly to all of the UN SDGs by further enabling interoperability between health commons and supporting opportunities to connect health data commons to commons in other domains (e.g., economic development indices, including education and gender equity; climate health; ocean health). More direct contributions can be identified for:

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[57] https://www.rd-alliance.org/groups/metadata-standards-catalog-working-group.html

[58] https://www.rd-alliance.org/group/fairsharing-registry-connecting-data-policies-standards-databases.html

[59] https://www.rd-alliance.org/groups/metadata-ig.html

[60] https://www.rd-alliance.org/groups/fair-data-maturity-model-wg/

[61] https://eosc.eu/advisory-groups/fair-metrics-and-data-quality/

[62] https://codata.org/initiatives/decadal-programme2/global-open-science-cloud/case-studies/sensitive-data-in-population-health/

[63] https://codata.org/events/conferences/fair-convergence-symposium-2022/data-policy-in-times-of-crisis/

[64] https://community.geant.org/sig-ehealth/

[65] https://eosc.eu/wp-content/uploads/2024/03/Health-Data-TF-ToR.pdf

[66] https://community.geant.org/sig-ehealth/

- "Partnerships for the Goals", where the model profile is intended to increase understanding and interactions between health commons as well as other stakeholders in the health research community to facilitate connections between health and related domains and facilitate global collaborations in health research;
- "Good Health and well-being" directly, as this is the target area of concern for increased interoperability between research teams internationally, efficient globally-oriented research, and access to research artefacts; and
- “Peace, Justice and Strong Institutions,” where the presentation of clear metadata and related tooling for existing health data commons can support the development of related digital public infrastructure in health and other sectors;
- "Quality Education" through the model's innate call for the sustainability of knowledge, engagement with the related research community, and the development, maintenance, and growth of human capacity in the research community through training and education.

Work Plan

Meeting schedule:

Once the case statement is accepted and the WG is endorsed by RDA TAB and Council, virtual monthly meetings will be held to provide updates on WG tasks, with monthly agendas drawn up by co-chairs. The administrative aspects of the meetings will be organised by the RDA TIGER Facilitator, who will ensure that the meeting invites, Zoom platform links, and agenda documents are circulated in sufficient time for the meeting.

Timeline

1. (0-2 months) Identify country-level health data commons through a systematic search (completed[67]) and snowball sampling (i.e., referrals from health commons stakeholders)
2. (0-2 months) Develop and refine a pitch deck on RDA, GORC model, and goals of WG[68] for use with HDCs
3. (0-2 months) Develop a questionnaire for HDCs
    a. Modelled off the GORC IM WG speaker series questionnaire[69]
    b. How HDCs have been or will be implemented at the attribute level
    c. Targeting GORC IM Attributes and identifying additional attributes (e.g., to describe the different data types and domains that should be described across health data ecosystems)

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[67] https://open-research-europe.ec.europa.eu/articles/3-87/v1

[68] https://docs.google.com/presentation/d/12ICRSXbx7ihYLNh6cTv_fX7ISysVWKmY/edit?usp=sharing&ouid=111262025335859896018&rtpof=true&sd=true

[69] https://docs.google.com/document/d/1vaLT0Me_o_FXOmh2I2uVotZr-WAdwVgCHMojO0YsIPk/edit?usp=drive_link

    d. Identify health-specific domains not included in the GORC attribute list (if any)
4. (0-6 months) Reach out to HDCs individually to discuss the initiative, ask for their participation, and review the list of HDCs
    a. In an initial meeting with each HDC, introduce RDA, the GORC model (lightly), and the goals of this WG (using the pitch deck). If the HDC is interested, we'll ask them to complete (async) the questionnaire, extracting information based on the GORC model but open it up for additional depth and breadth. They will also be invited to be a part of an ongoing speaker series where they can present their HDC and touch on + go beyond the questionnaire, and WG members can ask questions and clarifications.
    b. Anticipate more questionnaires than speaker series participants, but all material will be used. Once a first version of the model is created, invite all HDCs to community of practice-style meetings (see item 8).
5. (0 - 12 months) Conduct a comprehensive, if not systematic, literature review of HDC-relevant content.
6. (3 - 13 months) Speaker Series (~10 speakers)
    a. Engage HDC stakeholders in profile development
7. (3 - 13 months) Qualitative summary of published information on HDCs with special attention to material published by or related to HDCs in the speaker series
8. (5 - 14 months) Develop an HDCs profile of the GORC model in text (with implementations of the items in the GORC IM profile) using data collected from the questionnaires, speaker series, and HDCs GORC IM WG meetings
    a. Fine-tune the HDCs IM, including determining required versus desirable attributes.
    b. Update and refine iteratively every month with new material from the speaker series, rolling literature analysis, and WG consultations
    c. Considerations:
        i. FAIRsharing can host HDCs metadata (e.g., interoperability and standards items)
    d. OUTPUT: D1. V0.1 - V0.9 of the GORC HDC profile
        i. V0.1 GORC profile - what's in the model that's relevant to HDCs
        ii. V.02 Competing profiles of HDCs from systematic review are assessed and compared to GORC profile
        iii. V.03 Gaps in GORC profile addressed - metadata missing or that needs to be reworded from GORC profile
        iv. V.04-V.09 iterations of GORC HDC Profile following additional stakeholder interactions and refinement of the above
9. (14 - 16 months) Convene HDCs stakeholders to review the proposed model and implementations, revise as needed
    a. Convene HDCs leadership to discuss opportunities and challenges for HDCs interoperability
    b. (Ideal) Convene health data commons leadership and related domains from GORC (e.g., Oceans, Deep Earth, Climate, Chemical exposures, etc.) to initiate

    conversation around cross-domain data reuse and cross-domain commons interoperability.
    c. OUTPUT: D2. Metadata profiles that reflect how HDCs express metadata included in the GORC HDC profile.
        i. Combine D1 with implementation examples from participating HDCs
        ii. HDCs will be identified through the systematic literature review, the speaker series, and snowball sampling
        iii. We will include atag for implementations that are health-specific (maybe more granular for specific subdomains) and general (so that other commons can also use the profile, even if they're not health commons)

10. (15 - 17 months) Identify future funding for semantification of health data commons GORC IM profile and related knowledge graph tooling
        i. Consider ontology through ARDC → demo version: https://demo.vocabs.ardc.edu.au/viewById/1041 Knowledge graph of those items for health commons
        ii. FUTURE OUTPUT (outside of WG scope):
            1. Semantic model of Health Data Commons GORC IM Profile
            2. interactive, shareable network graph of HDC model V1.0 to enable interoperability with IM from other types of data commons.

Adoption Plan

The goal of this WG is to extend and otherwise modify the GORC IM to address the specific challenges of health data commons. The intention is for the health data GORC IM to be implemented by groups responsible for developing health data commons.

The WGs deliverable D1. HDCs Implementation of the GORC IM is intended to be submitted as a recommendation. D2. Metadata from HDCs is intended to be submitted as an implementation profile to display key metadata from HDCs. Beyond collecting high-level metadata to display HDCs implementation decisions visible, we will work with a diversity of stakeholders from health and other domains to implement the Health Data GORC IM metadata in the specific areas of AMR and cancer health data to collect sufficient metadata to understand what investments would be needed to enable federated reuse of AMR or cancer data across commons.

D1, the Health Data Commons GORC IM profile, will be based on the GORC IM and will be developed through the HDC WG monthly meetings, speaker series, and speaker questionnaire. D2, metadata that corresponds to the Health Data Commons GORC IM profile, will be addressed through the speaker series, speaker questionnaire, and convening of HDC leadership to contribute to and review the HDC GORC IM.

Once the HDC GORC IM is endorsed, we will promote adoption through the network of stakeholders engaged in the WG, groups leading HDCs initiatives, and groups working in the cross-domain space, including RDA, CODATA, and UNESCO. We will work with RDA TIGER to provide dissemination materials to facilitate communication around the HDCs GORC IM and will consider pathways to secure funding to support semantification, the development of a knowledge graph with Health Data Commons, GORC IM profile metadata, model adoption, and updating (e.g. online form to register and update machine-actionable metadata to describe HDCs implementation decisions and benchmark the evolution of different levels of interoperability in the health data commons and cross-domain spaces).

Initial Membership

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Rob Hooft	HealthRI	
Ruben Kok	HealthRI	

Relevant Resources

See the Zotero library[70] for the current list of all relevant resources that will be included in the landscape review, as well as their status in the review. Below is the list of resources as of this case statement submission.

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List of Abbreviations

AI - Artificial Intelligence
ARDC - Australia Research Data Commons
CARE - Collective benefit, Authority to control, Responsibility, Ethics
CODATA - International Science Council's Committee on Data
ELSI - Ethical, Legal, Social, Institutional
EOSC - European Open Science Cloud
FAIR - Findable, Accessibility, Interoperable, Reusable
GA4GH - Global Alliance for Genomics and Health
GORC - Global Open Research Commons
GOSC - Global Open Science Cloud
HDC - Health Data Commons
IG - Interest Group
IM - International Model, most often referring to the GORC International Model V1.0

JSON-LD - JavaScript Object Notation for Linked Data
NFDI - Nationale Forschungsdateninfrastruktur
NIH - National Institute of Health
RCT - Randomized Controlled Trials
RDA - Research Data Alliance
RDF - Resource Description Framework
SDGs - Sustainable Development Goals
TRUST - Transparency, Responsibility, User focus, Sustainability, Technology
UK - United Kingdom
UNESCO - United Nations Educational, Scientific and Cultural Organization
WG - Working Group