

# Health data Commons Questionnaire and scoping review -current status and call for contributors

## 24th Plenary Meeting Collaborative Notes

**Group(s) name(s) organising the session:** Health Data Commons GORC Profile WG

**Session link:**

[https://www.rd-alliance.org/groups/health-data-commons-gorc-profile-wg/plenary-participation/?application\\_id=174626](https://www.rd-alliance.org/groups/health-data-commons-gorc-profile-wg/plenary-participation/?application_id=174626)

**Session scheduled date/time/breakout session:** 07.04.2025, Breakout 2, 22:30 UTC

### Session summary (for Group co-chairs)

We will use the content in the table below to highlight your work to the RDA community as a report organised by the Technical Advisory Board.

Please complete ALL fields below by **Friday 25th April, close of business** to be included in the report & social media activities.

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| <b>Summarise your session in three sentences:</b>  |
| <i>This session provides an overview of the Health Data Commons GORC (HDC-GORC) Working Group's background, highlighting its connection to the broader GORC WG, as well as outlining its objectives, timeline and outputs. The open discussion segments focused on refining the HDC questionnaire and reviewing the proposed list of speakers for the series</i>   |
| <b>Key outcomes/actions/takeaways</b>  |
| <ol style="list-style-type: none"> <li>1. <i>Introducing the activities of the HDC-GORC Working Group and its collaboration with the broader GORC WG</i></li> <li>2. <i>Presenting the 15 domains covered in the HDC-GORC questionnaire</i></li> <li>3. <i>Engaging the audience in expanding the speaker series list</i></li> <li>4. <i>Showing the protocol search protocol and criteria used for the scoping review</i></li> <li>5. <i>Highlighting the importance of an inclusive definition of the Health Data Commons</i></li> <li>6. <i>Emphasizing the need to finalise the scoping review and include non-english papers</i></li> </ol> |
| <b>Synergies and/or possible collaborations identified with RDA groups and other groups:</b>   |
| GORC; GORC IM;   |

Get involved in [RDA Community](#)

This meeting will take place according to the [RDA Code of Conduct](#)

### Attendee Check-in

*Please complete this table to indicate your attendance (add rows as needed):*

| Full Name                   | Affiliation             | Location | Email                      |
|-----------------------------|-------------------------|----------|----------------------------|
| Lars Eklund                 | Uppsala University/NBIS | Sweden   | lars.eklund@it.uu.se       |
| Robert Grossman             |                         |          |                            |
| Nina Grau                   | CODATA                  | France   | nina@codata.org            |
| Alyssa Foote                | World Data System       | Canada   | afoote@oceannetworks.ca    |
| Martha Ximena Galvis Plazas | RedCLARA                | Colombia | martha.galvis@redclara.net |

### **Collaborative Session Notes** *(To be used by participants and chairs during the session)*

Hello to the participants

#### **1-Intro**

Presentation of the Health Data Common GORC profile

GORC presentation

Link to the GORC intro movie:

<https://drive.google.com/file/d/1XLTeAYLj60-zfvZGNIE6cdSXE6UI-L72/view>

Commons vs Health Data Commons description

GORC profile is for a specific class or instance with a great level of granularity

Set of deliverables :

Scoping review of country level health data commons

HDC questionnaire to disseminate

Implementation GORC metadata

Speaker series with different types of HDC that are existing today

Work on a definition of HDC as the current definition is not enough inclusive

#### **2-Questionnaire**

Goal is to “Collect information from current and emerging data commons that can create data common profile for the GORC”

Survey has 56 questions

Need to split the survey into 3 sections and select which categories fit into which section :  
how should it be split?

Martha involved in any RDA WG? > No, newbie

Area: Telemedicine

Next step : for the next WG regular meeting - go head on the literature review and finished the questionnaire