

GM Care Record (GMCR) Research Governance Group Terms of reference

Version 1.9 8th November 2021

1.0 Purpose

To provide oversight of the uses of the GM Care Record data for COVID-19 research purposes.

2.0 Governance structure

For details on the governance structure of the GM Care Record for Secondary Uses and Research, see <https://healthinnovationmanchester.com/thegmcarerecord/the-gm-care-record-for-secondary-uses-research>.

3.0 Roles and Responsibilities

This group is responsible for the following:

1. Consider and approve research proposals, ensuring that the use of data is in line with the priorities for GM's COVID-19 response and recovery.
2. Ensure transparency and scrutiny of data usage requests, access granted and reviews of research activity.
3. Ensure that all COVID-19 research activities are aligned to agreements in the COPI notice and GM Data Privacy Impact Assessment for research.
4. Provide regular updates to the expert review group and oversight and scrutiny committee on the approved research use cases, providing clarity where needed.
5. Work with the expert review group to provide trust and confidence to data controllers and system stakeholders.
6. Act as a point of liaison and coordination between GM universities, research bodies and data processors.
7. Act as point at which challenges to planned use of data are escalated to other governance structures.
8. Encourage a research portfolio of quality outputs and publications to be delivered, with focus on impact and novelty.
9. Scrutinise the resultant outputs of individual studies prior to publication to help to ensure quality, validity, and reliability.

4.0 Membership

Sector	Name and role	Organisation	Membership review date
Chair	Sarah Devaney, Senior Lecturer in Healthcare Law and Regulation.	University of Manchester	August 2022
Deputy Chair / Health Informatics	Niels Peek, Professor of Health Informatics	University of Manchester	August 2022
Data Science	Mo Saraee, Professor of Data Science	University of Salford	August 2022
Artificial Intelligence	Yonghong Peng, Professor of AI	Manchester Metropolitan University	August 2022
Public Health	Greg Barbosa, Associate Director, Local Knowledge and Intelligence Service NW, Office for Health Improvement and Disparities	Public Health England	August 2022
GMHSCP	Matt Hennessey, Chief Intelligence and Analytics Officer	Greater Manchester Health & Social Care Partnership	August 2022
Patient and Public Involvement	Caroline Sanders, Professor of Medical Sociology	University of Manchester	August 2022
NIHR Manchester BRC	Professor Ian Bruce, Director, NIHR Manchester BRC Alternate: Tim Felton	University of Manchester / Manchester NHS FT	August 2022
Primary Care	Benjamin Brown	University of Manchester	August 2022
Primary Care	Jung-Yin Tsang, GP, NIHR In-Practice Fellow	University of Manchester	August 2022
Epidemiology	Meghna Jani, Pharmacoepidemiology Researcher; Consultant Rheumatologist	University of Manchester / NCA	August 2022
Health Services Research	Evan Kontopantelis, Professor of Data Science & Health Services Research	University of Manchester	August 2022
Health Economics	Matt Sutton, Chair in Health Economics	University of Manchester	August 2022
Public Health	Arpana Verma, Clinical Professor of Public health and Epidemiology	University of Manchester	August 2022
Public Contributor	Angela Ruddock		August 2022
Public Contributor	Joyce Fox		August 2022

Membership will be reviewed every 12 months. When a member steps down from the Group there will be a 3-month handover period with their successor.

Clinical expert members of the ERG will be invited to attend the RGG meetings on a regular basis.

Other subject matter experts and representatives can be co-opted for specific items where required. For example: Specialist Information Governance/GDPR expertise from the Centre for Health Informatics, The University of Manchester.

Members of the group will be expected to represent their wider sector and to feed in views and concerns from their sector colleagues should they arise to ensure they are considered during group discussions.

5.0 Research Operations Group

At least one representative of the Research Operations Group (ROG) will join each meeting to provide comprehensive and structured updates on GMCR research activities. When a research proposal is being presented to the RGG for assessment, the ROG will make the RGG aware of concerns, if any, regarding methodological quality. The ROG will not communicate those concerns directly to the PI, and leave that responsibility to the RGG. When a research proposal overlaps in terms of scientific objectives and/or study population with another (ongoing or completed) GMCR study, the ROG will make both the PI and the RGG aware of that. Replication is viewed as positive and not necessarily something to avoid.

6.0 Meeting frequency

The GM Care Record (IDCR) Research Governance Group will meet every third week through the COVID-19 crisis, and in line with the COPI notice, this will be reviewed on 31st March 2022.

Declarations of interest should be declared and logged at the start of each meeting. Minutes of each meeting will be circulated to members within 5 working days of the meeting. The minutes will be formally approved at the following meeting.

7.0 Reviews

Review of processes, roles, responsibilities, and membership will be undertaken ad-hoc as required. In addition, in August 2022, the group will assess the study results review process and consider whether to move from a pre-publication review of all results, to a post-hoc or sample review.

8.0 Quoracy

The RGG is considered quorate to make decisions when at least 5 members (including the chair) are present at a meeting. When fewer than 5 members are present, or when the present members feel that the expertise required to make a decision is not represented at the meeting, the RGG can make a *provisional decision*. Provisional decisions are either tabled for confirmation at the next meeting, or confirmed after the meeting via email (either circulated to the entire group or to a selected membership), at the Chair's discretion.