

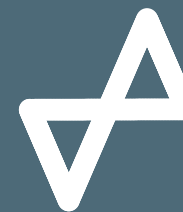
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COVID-19 GM CARE RECORD

**Secondary uses and research governance and
operational access process
SUMMARY**

September 2020



The GM Care Record COVID-19 secondary uses

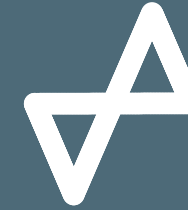
- The legal basis for use of the data is defined in the COPI notice, which gives a legal requirement to share to NHS organisations for the purposes of the COVID-19 response.
- Cloud-based BI and analytics platform, 5.3bn rows of data
- Data Protection Impact Assessments: one for GM university research, one for other secondary uses
- Public communications and engagement plan

What is classed as secondary uses and research?

- understanding COVID-19 and risks to public health, trends
- controlling and preventing the spread of COVID-19
- identifying and understanding information about patients or potential patients with or at risk of COVID-19
- delivering services to patients, clinicians, the health services
- planning in relation to COVID-19
- research in relation to COVID-19

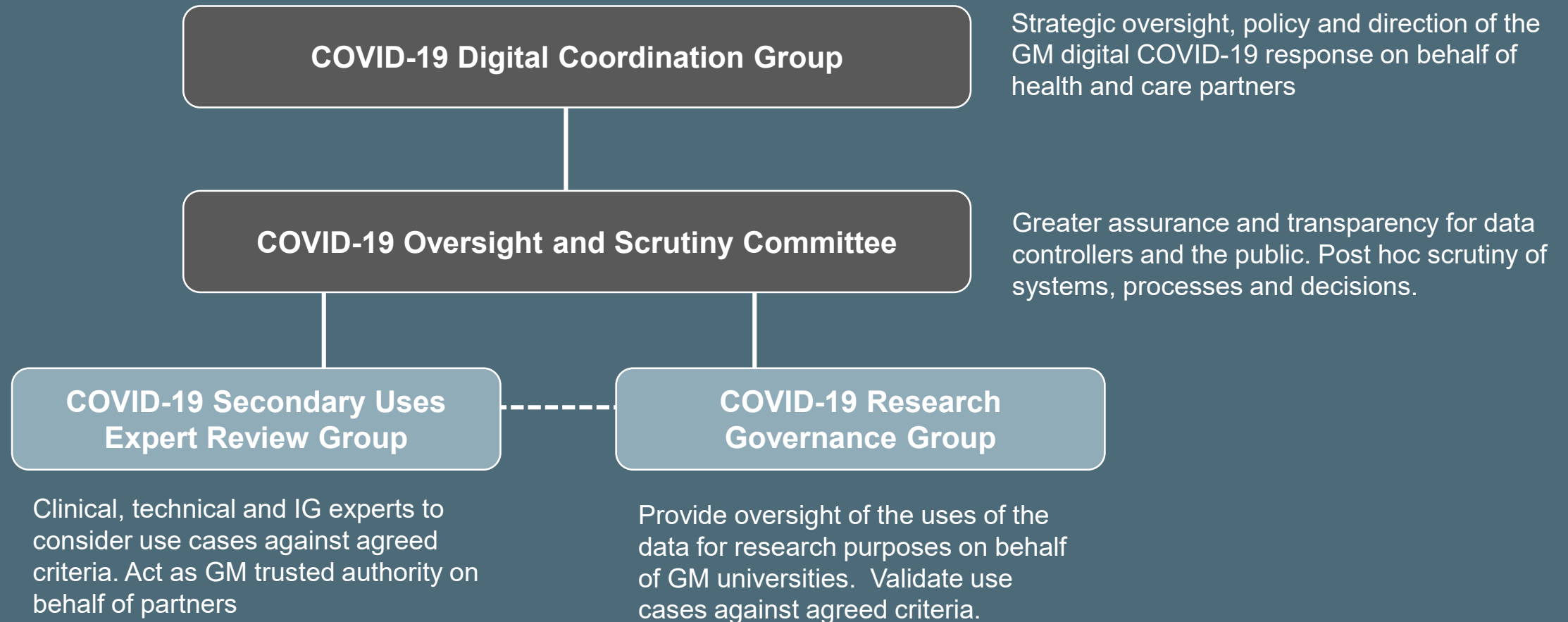
COVID-19 GM CARE RECORD

Secondary uses governance



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GMCR COVID-19 Oversight and Scrutiny Committee

PURPOSE:

The Oversight and Scrutiny Committee has been established to provide enhanced transparency and trust with data controllers and the public, providing assurance that decisions and activities are taken out in accordance with legal and regulatory requirements.

RESPONSIBILITIES:

1. Ensuring that activities and decisions taken by the expert group and research governance group are in line with agreed processes (post-hoc)
2. Acting as point at which challenges to planned use of data are escalated to other governance structures.
3. Acting as a point of liaison between the GM Digital Coordination Group and other key decision-making groups
4. Liaising and supporting engagement and transparency on data use with a range of GM organisations and data controllers
5. Ensuring public transparency and trust of data usage requests, access granted and reviews of activity.
6. Overseeing public and stakeholder communications and engagement activity to support building of trust and transparency

Membership summary:

- Chair – Kiran Patel, GP and Medical Director
- 3 x One Manchester public members
- Provider Federation Board rep
- Primary Care Board rep
- Joint Commissioning Board rep
- Caldicott Guardian lead
- Information governance lead
- Data Protection Officer
- Research/academia lead
- Digital/technical experts
- PPIE academic lead
- System engagement lead
- Communications lead

GMCR COVID-19 Expert Review Group

PURPOSE:

To provide expert advice and guidance on the appropriate use of GM care record data for secondary uses, including business intelligence, analytics and research.

The group will also act as the GM Trusted Authority to enable access to agreed datasets, on behalf of CCGs and data controllers.

RESPONSIBILITIES:

1. Review and approve secondary use cases by providing expert advice and guidance to assure the validity, suitability and feasibility of use cases
2. Ensure that secondary use of the data is in line with the priorities for GM's COVID-19 response and recovery
3. Ensuring that all activities undertaken are aligned to agreements in the COPI notice and GM secondary uses DPIAs
4. To ensure adherence to the defined data access process for secondary uses, while also continually review and develop the process to ensure robustness
5. Work jointly with the Research Governance Group to ensure appropriate systems and processes are in place to support the use of data in COVID-19 research
6. Provide scrutiny and audit of the activity of all secondary usage users and GM Trusted Authorities, with appropriate escalation to the Secondary Uses Oversight & Scrutiny Committee
7. To oversee the deletion of data once the COPI notice expires.

Membership summary:

- Chair TBC – intended to be CCG or primary care led
- GP/CCIO lead
- CIO lead
- CCG business intelligence
- GMCA information governance
- Health information governance
- GMHSCP business intelligence
- Research group lead
- GM Digital innovation lead
- HInM Business Intelligence
- Graphnet BI lead

GMCR COVID-19 Research Governance Group

PURPOSE:

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

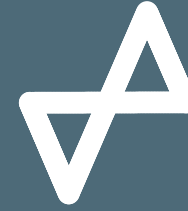
RESPONSIBILITIES:

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 outputs of individual studies prior to publication to help to ensure quality, validity, and reliability

Membership summary:

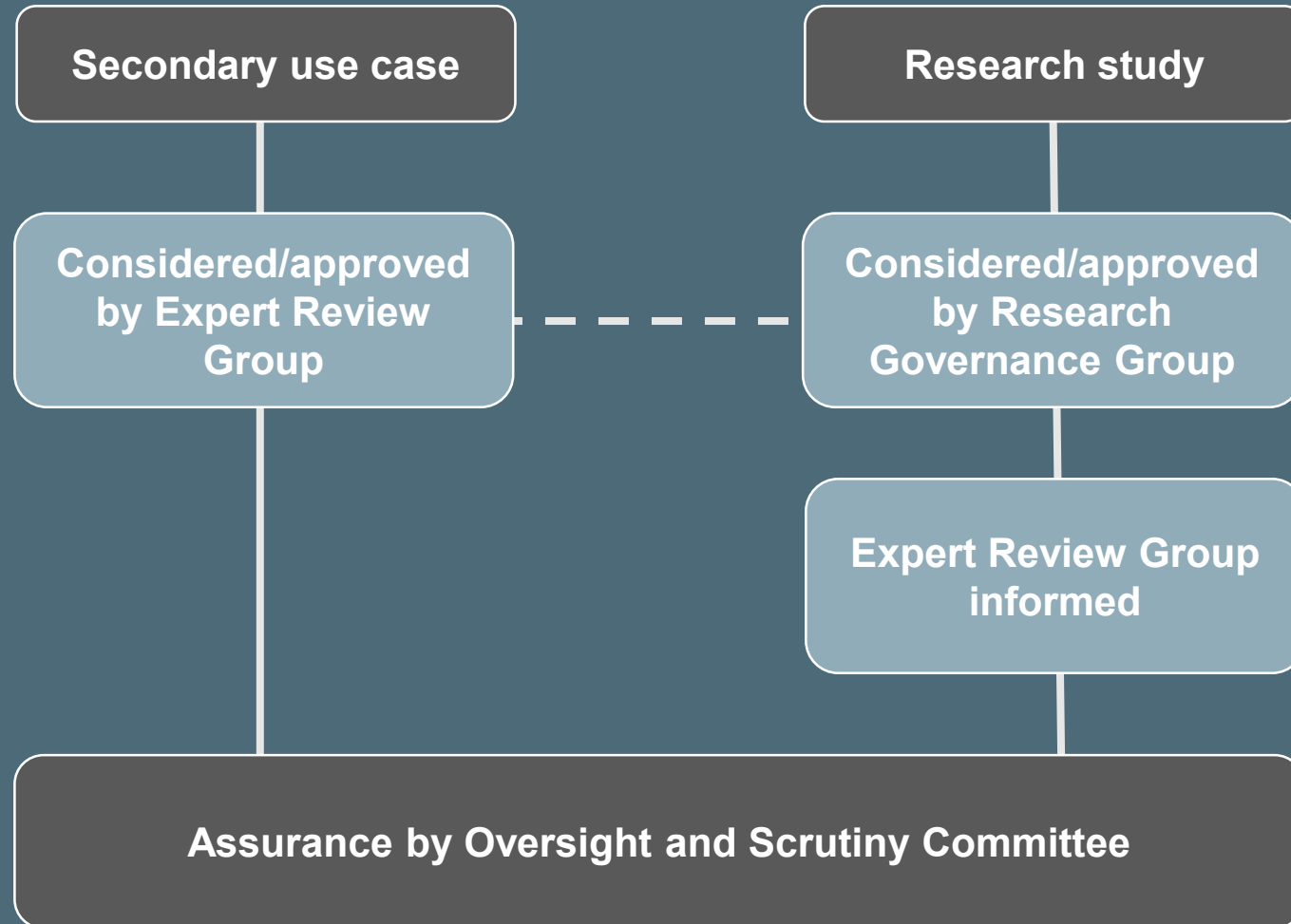
- Niels Peek, Professor of Health Informatics, The University of Manchester
- Mo Saraee, Professor of Data Science, University of Salford
- Yonghong Peng, Professor of AI, Manchester Metropolitan University
- Matt Hennessey, Associate Director/Chief Intelligence and Analytics Officer, Public Health England
- Caroline Sanders, Director of Patient and Public Involvement, Health Innovation Manchester
- Professor Ian Bruce, Director, HInM Research Director, GM Rapid Response Research Group, NIHR Manchester BRC
- Will Dixon, Chair in Digital Epidemiology, The University of Manchester
- Matt Sutton, Chair in Health Economics, The University of Manchester
- Arpana Verma, Clinical Professor of Public health and Epidemiology, The University of Manchester
- Public members
- Primary Care Board rep
- Expert Review Group rep

COVID-19 GM CARE RECORD HIGH LEVEL FLOW DIAGRAM



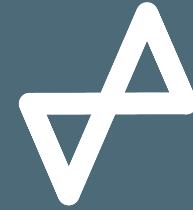
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Terms of reference

| Group | Link |
|----------------------------------|---|
| Oversight and Scrutiny Committee | https://healthinnovationmanchester.com/gmcarerecord/the-gm-care-record-secondary-uses-scrutiny-and-oversight-group/ |
| Expert Review Group | To be created |
| Research Governance Group | To be created |



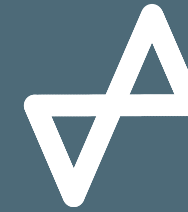
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COVID-19 GM CARE RECORD OPERATIONAL ACCESS PROCESS

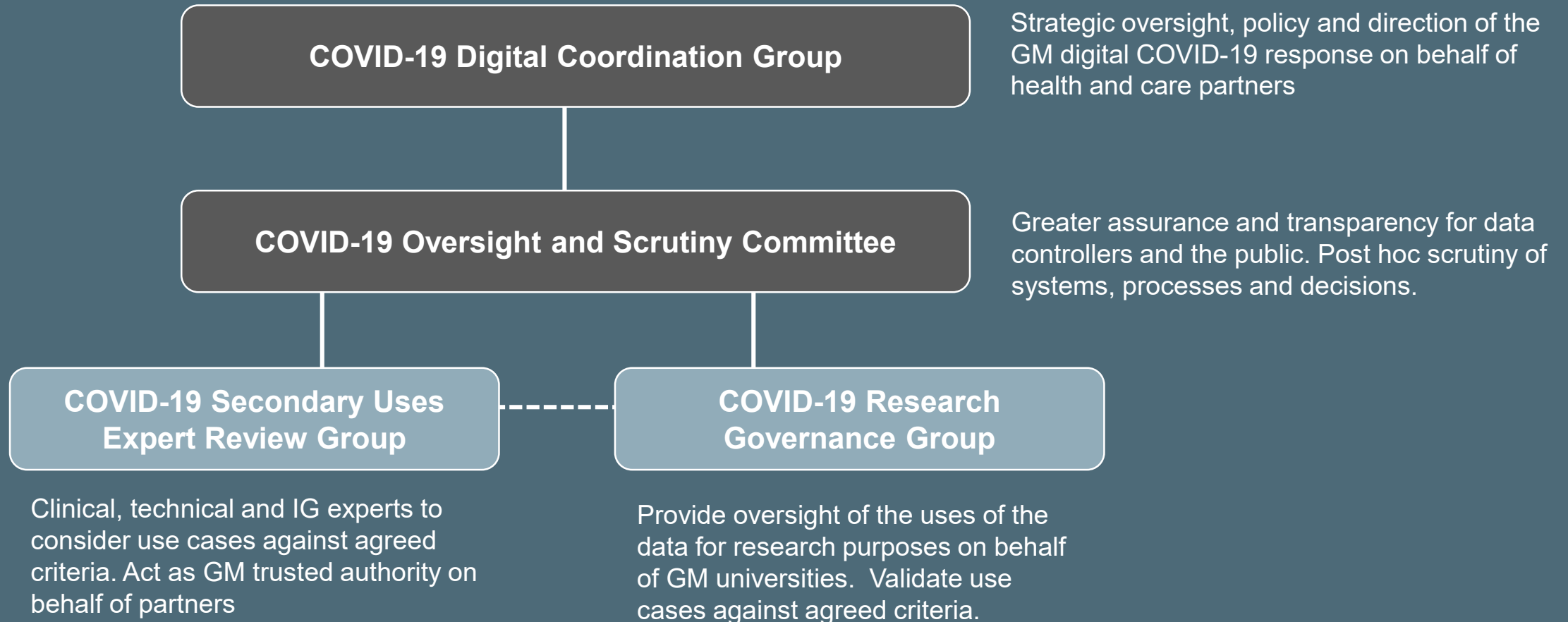
COVID-19 GM CARE RECORD

Secondary uses operational access process



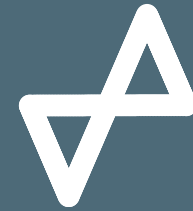
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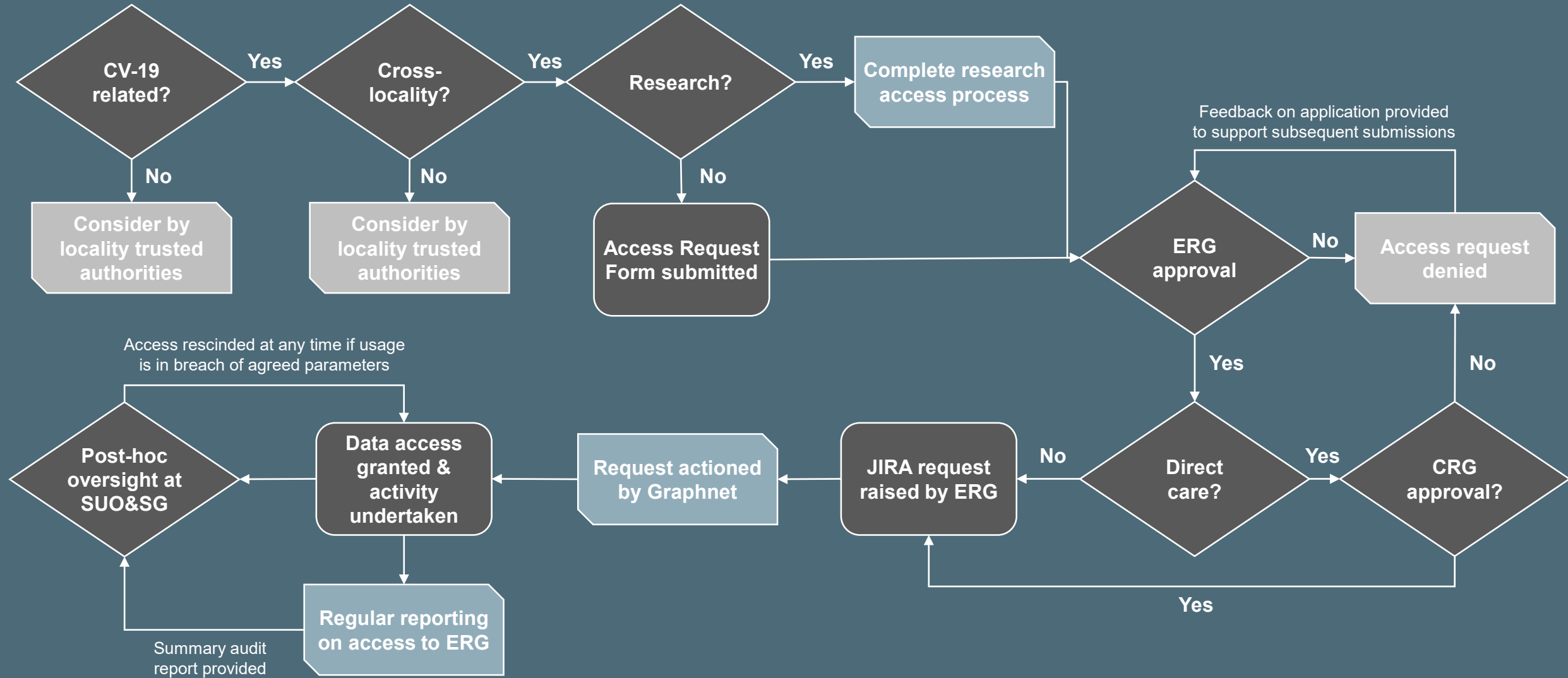
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Secondary uses operational access process



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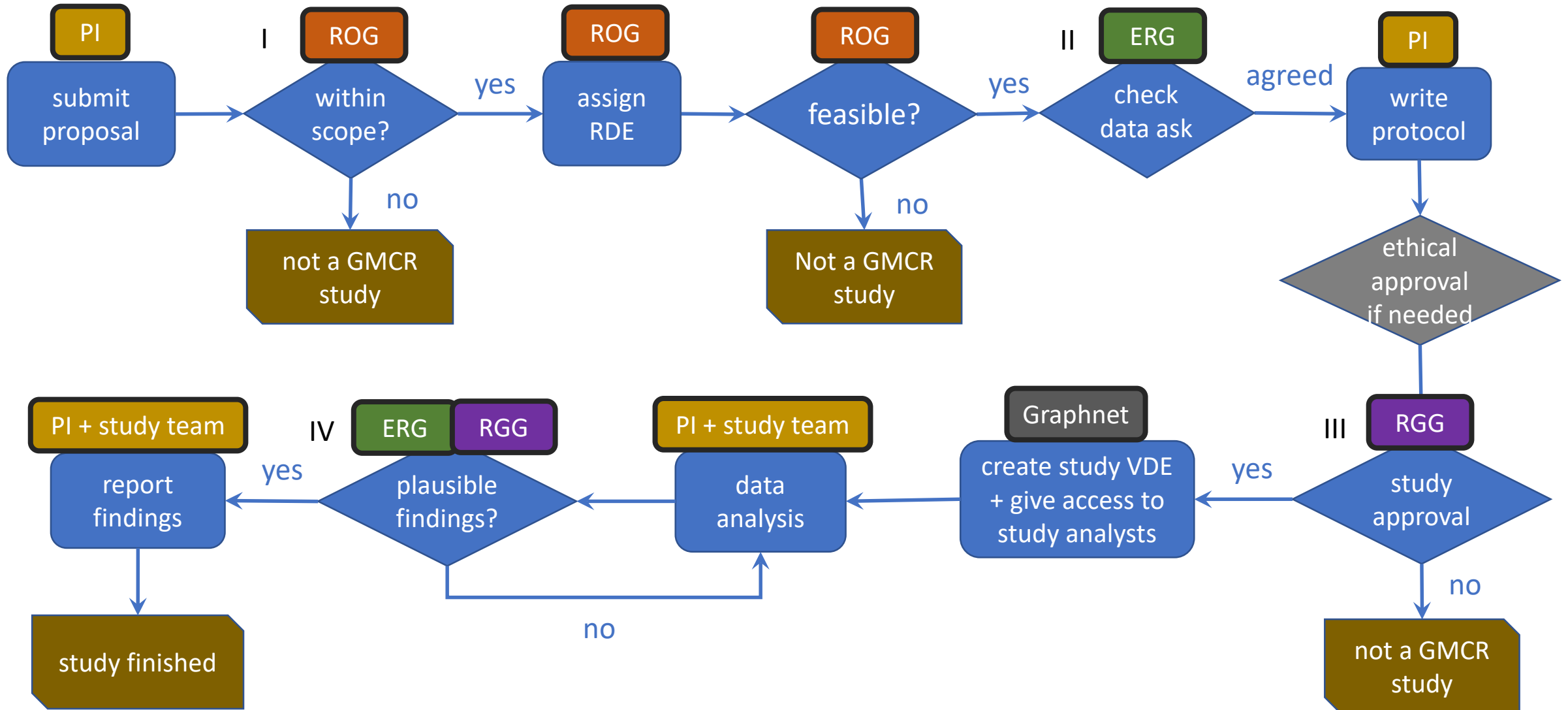


COVID-19 GM CARE RECORD

Research access process

PI: Principal Investigator
 RDE: Research Data Engineer
 VDE: Virtual Desktop Environment

ROG: Research Operations Group
 ERG: Expert Review Group
 RGG: Research Governance Group



Decision making roles and responsibilities between groups for research purposes & other secondary uses

| Decision / task | Research Operations Group | Research Governance Group | Expert Review Group | Oversight & Scrutiny Committee |
|---|---------------------------------------|--|--|---|
| 1. Access to full de-identified data mart for research data engineers | Role: Propose When: In RGG Meeting | Role: Signoff When: In RGG meeting | Role: Signoff & Enact When: After ERG meeting | Role: Scrutinise/Review When: In meeting |
| 2. Study protocol approval | Role: Propose How: In RGG Meeting | Role: Signoff When: In RGG meeting | Role: None | Role: Scrutinise/Review When: In meeting |
| 3. Access to study-specific e-cohort for study analysts | Role: Propose How: In RGG Meeting | Role: Signoff When: In RGG meeting | Role: Signoff & Enact When: After ERG meeting | Role: Scrutinise/Review When: In meeting |
| 4. Define principles for prioritisation of research data engineering resource | Role: Implement | Role: Define and agree When: In RGG meeting | Role: Review When: In ERG meeting | Role: None |
| 5. Prioritisation of research data engineering work | Role: Propose and Implement | Role: Review When: Via email | Role: None | Role: None |
| 6. Define parameters and principles for RGG signoff of 1 & 2 | Role: None | Role: Implement | Role: Define and agree When: In ERG meeting | Role: |
| 7. Define principles for all secondary usage access to the GMCR | Role: None | Role: None | Role: Define and propose When: In ERG meeting | Role: Signoff When: In meeting |
| 8. Access to secondary usage requestors classified as non-research related | Role: None | Role: None | Role: Scrutinise & recommend When: In ERG meeting | Role: Signoff When: In meeting |