Research Data Governance Board (RDGB)

Terms of Reference

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Scope

1. The Research Data Governance Board (RDGB) acts as a central point for application receipt, screening, review, and prioritisation of data requests prior to accessing the Central Statistics Office (CSO) service which will facilitate secure and controlled access to data in the Health Research Data Centre (Health RDC).
2. The RDGB will consider research that is defined as health research according to the Health Research Regulations 2018 (Regulation 3(2)(a)). <http://www.irishstatutebook.ie/eli/2018/si/314/made/en/pdf> .   
   All research should be compatible with statistical use and confidentiality requirements from the Statistics Act, 1993.
3. The RDGB will review all proposals for CSO Health RDC to ensure that:
   1. The proposed study is scientifically valid and justifiable and feasible given the available data.
   2. Adequate steps have been taken for data governance.
   3. The confidentiality of all personal data and medical information is ensured and privacy maintained.
   4. Consent is truly valid (informed) and given without any form of duress.
4. The RDGB will require evidence of approval from both a Research Ethics Committees (REC) and from the Health Research Consent Declaration Committee (HRCDC) when making its final recommendation.
5. The RDGB will provide this recommendation to the Central Statistics Office.
6. The RDGB will assist in the identification of new data sources of potentially high value for research purposes.

Membership

* + - 1. The RDGB should have sufficient members to guarantee the presence of a quorum at each meeting. The minimum and maximum should be 7 and 21 members respectively (inclusive of Chair and Secretariat). This should allow for a sufficiently broad range of experience and expertise.
      2. Members should be appointed for fixed terms, normally 3 years. Terms of appointment may be renewed, but not normally more than three consecutive terms should be served.
      3. Appointment of independent members shall be by an open process. Vacancies should be filled following advertisement via the press, local professional and/or other networks as most appropriate to the vacancy to be filled.
      4. Consideration should be given to public/patient involvement groups/representatives.

Quorum

A meeting/review quorum shall consist of 5 members. It shall include the Chair and/or Vice-Chair, at least one ‘expert’ member with relevant research and/or methodological expertise, one ‘lay’ member.

External reviewers and observers do not count towards quorum requirements.

Conflicts of interest

1. An appointed member must be prepared to have published their name, profession and affiliation. When making appointments conflicts of interest should be avoided if at all possible. Where unavoidable there should be transparency with regard to such interests. Such conflicts of interest may include (but are not limited to) interests in studies, projects and/or sponsors which could be personal, financial or professional.

Meetings

1. The Committee will meet a minimum of six times a year (or more often where required) according to a publicised schedule.
2. Meetings will occur by videoconference to assist in meeting quorum requirements.
3. Closing dates for submissions will be 2 weeks prior to the meeting. These will be published and will be strictly adhered to.
4. If the chair cannot attend a meeting, the vice chair must chair that meeting.
5. Decisions are reached by a consensus OR 2/3rd majority vote +/- queries/conditions.
6. The decision is documented in the meeting minutes and the Committee secretariat will forward the decision of the Committee +/- queries/conditions to the applicant within ten days of the meeting taking place.
7. Where the decision is accompanied by queries or conditions, the applicant will be given 10 working days to respond to the Committee to satisfy same and/or to provide supporting documentation. Should the queries/conditions not be met within this timeframe, the application will be considered rejected and the applicant will be informed of same.
8. Each Member in attendance at a meeting of the Committee shall be entitled to be heard and given opportunity to justify their views and reasoning. No proxies shall be permitted in relation to a member’s participation at Committee meetings.

Secretariat

Central Statistics Office