

CLOSER Data Linkage Working Group Terms of Reference

1. Purpose of the group/network

- To provide a forum to share good practice, contacts, concepts and materials on data linkage.
- To identify and lower the barriers to linkages to support coordinated development of linkage processing and cross-cohort investigations.
- To provide a forum to share updates on study linkages, including successes and challenges.
- To improve data linkage to the longitudinal studies.

2. Accountability

- The Working Group falls under the Data Linkage workstream of CLOSER which is led by the CLOSER Data Linkage theme lead. Agendas are set by the Chair on topical, substantive issues relating directly to achieving data linkages with longitudinal records. The outcomes from the meetings are reported back to CLOSER by the Data Linkage theme lead.
- The CLOSER team provide administrative and operational support for meetings.

3. Membership and attendance

- The Chair of the Working Group is Andy Boyd, Data Scientist at the University of Bristol.
- The Deputy Chair of the Working Group is Rebecca Hardy, Director of CLOSER.
- The Working Group is an external facing network including longitudinal studies that form part of the CLOSER consortium, as well as non-CLOSER longitudinal studies.
- Although there is no limit to the membership capacity of the Working Group, the capacity for each meeting is a maximum of 25 attendees and attendance is aimed at those closely working on developing linkage capacity within studies. Between 1-3 people from each of the member organisations are welcome to attend any one meeting. Where more than 25 people have accepted an invitation CLOSER will request for member organisations with multiple attendees to select one representative to attend.
- Prospective members will be sought via CLOSER's existing communication channels with study representatives from the current and future CLOSER Discovery studies, as well as via CLOSER newsletters, blogs, website adverts and social media. On receipt of expressions of interest, the Chair and CLOSER Director will confirm membership based on a) role/area of expertise and b) study or organisation represented. The Chair and CLOSER Director will ensure a diverse range of studies/organisations are represented on the Working Group.
- Membership may be extended to individuals' in aligned organisations, such as those developing linkage capacity in government departments.
- The CLOSER Director will represent the core CLOSER team at each meeting and the CLOSER Project Officer will provide administrative support for meetings.

4. Responsibilities of members

- The below list details the typical types of topics the Working Group meetings may be themed around (please note this list is not exhaustive):
 - The group considers linkage to health, social and geospatial data
 - Navigation of UK-specific administrative datasets
 - Navigation of UK-specific governance and data linkage regulations
 - Study level governance matters, including consent and consent alternatives
 - Linkage to novel forms of data
 - Data integration
 - The use of standards for structuring, processing, code mapping and describing data
 - Secure research platforms
 - Derived variables
- Members are encouraged to share practical examples of materials and approaches which may be of benefit to others in the group (e.g. participant fair processing materials, example linkage application forms).

5. Meetings and procedures

- The Working Group will meet 4 times a year (quarterly). Each meeting will be set at least six-weeks in advance. The Working Group will meet face-to-face in London unless circumstances dictate otherwise in which case meetings will be hosted virtually using Zoom. Where there is a face-to-face meeting, online participation (through Zoom) will be provided for those who are unable to travel.
- Meetings will be approximately 2 hours in duration, including a 30-minute update on study linkages followed by 1.5 hours allocated to topics outlined above.
- Agendas and relevant papers will be circulated electronically to group members 10 working days (two weeks) prior to the meeting date.
- Minutes and actions will be circulated within 10 working days (two weeks) of the meeting date.
- Terms of reference will be reviewed on a yearly basis to ensure they are fit-for-purpose and remain in-line with CLOSER's aims and objectives.
- Membership requires that contact details are held by CLOSER and shared with wider group members, for example, for the purposes of circulating calendar invites and minutes.

Last reviewed: 9 June 2020

Next review date: June 2021