

CLOSER Data Linkage Working Group (DLWG) 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 population studies.

2. Accountability

- Agendas are set by the Chairs on topical, substantive issues relating directly to achieving data linkages with longitudinal records. The outcomes from the meetings are reported back to CLOSER through CLOSER Leadership Group representation at the meetings.
- Members are encouraged to surface topics with the Chairs that can be tabled for discussion at meetings.

3. Membership and attendance

- The joint Chairs of the DLWG are Andy Boyd (University of Bristol), Karen Dennison (University College London) and Danielle Freitas Gomes (University College London).
- The DLWG is an external facing network including longitudinal population studies that form part of the CLOSER consortium, as well as non-CLOSER longitudinal population studies.
- Although there is no limit to the membership capacity of the DLWG, the capacity for each meeting is a maximum of 25 attendees. Between 1-3 people from each of the member organisations are welcome to attend a 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, for example, 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.
- Whilst membership to the DLWG is reviewed on an individual basis, it is expected that group members are working on establishing and/or maintaining linkages for longitudinal population studies as part of their role. The group is not aimed at analysts using linked data, although applied researchers working on establishing innovative linkages would be suitable.
- Membership may be extended to individuals' in other aligned organisations, such as those developing linkage capacity in government departments.

- The CLOSER Administrative and Events Assistant will provide administrative support for meetings.

4. Responsibilities of members

- The below list details the typical types of topics the DLWG meetings may be themed around (please note this list is not exhaustive):
 - 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
 - Linkage to COVID-19 datasets
 - 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, for example, linkage application forms).

5. Meetings and procedures

- The DLWG will meet three times a year. Each meeting will be set at least six-weeks in advance.
- The DLWG meetings will mainly take place online.
- 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. We will store your details in a password-protected database stored on the UCL S Drive which is only accessible to nominated CLOSER staff members who help administer the account. You can unsubscribe at any time by informing the Chair of the group. Find out more about Microsoft's privacy details on [Microsoft's Privacy Statement](#).

Last reviewed: February 2024

Next review date: September 2024