

Conference report

Preparing for the future II: international approaches to challenges facing the longitudinal population studies

Executive Summary

February 2020



In January 2020, representatives of 43 longitudinal population studies attended CLOSER's second collaborative conference, *Preparing for the future II: international approaches to challenges facing the longitudinal population studies* in London, UK. The purpose of this conference was to unearth best practice, and identify ways to tackle shared challenges. The programme was informed by the results of a consultation exercise with UK and international longitudinal population studies, which identified data harmonisation, data linkage, new forms of data collection, data discoverability, and reducing attrition and participant engagement as the most important issues facing the longitudinal community.

The conference report documents the day's discussions, including key challenges and opportunities, as well as knowledge and skills gaps, put forward by delegates. This Executive Summary provides an overview of the key points raised.

1. Data harmonisation

- 1.1 Successful data harmonisation on a large scale is a time-consuming endeavour that is only feasible through collaboration and coordination, alongside greater awareness of the importance of data documentation.
- 1.2 Greater consideration of the use of prospective harmonisation attempts should allow for a less complex and resource-intensive process moving forwards.
- 1.3 Key challenges facing data harmonisation efforts include a lack of standardisation, both in terms of study design, and the use of instruments, validated scales or measures.
- 1.4 Technological advances are a cause for optimism with data stored and shared in secure virtual environments.
- 1.5 Data harmonisation efforts at an international level exponentially increase the challenges involved and require greater consideration of linguistic, cultural and other issues around comparability of data.

2. Data linkage

- 2.1 There is an urgent need to develop a shared narrative and language around the benefits of data linkage, in order to convince data holders, participants and the public of the importance of carrying out this work.
- 2.2 Transparency and accessibility of communications materials about the data linkage process can help assuage fears and dispel misunderstandings of what data linkage involves and its risks.
- 2.3 New opportunities for linkage are constantly emerging – however similar challenges persist around data quality, research utility, consent, and participant and public acceptability.
- 2.4 Linkage potentially offers opportunities to improve information held on population subgroups, such as minorities and vulnerable people, which can be difficult to retain in traditional research studies. However, more information is needed on the coverage and suitability of data on such groups held within linkable datasets.
- 2.5 Upskilling users to take advantage of the opportunities afforded by linked data would ensure the investment of time and money in creating these resources have strong returns.

3. New forms of data collection

- 3.1 Delegates highlighted the need for an effective mechanism to share information on successes, failures, risks and benefits. This should include engaging with not just the longitudinal community but new disciplines, commercial companies, market research experts, funders and study participants.
- 3.2 With many new forms of data collection, response rates can be low, particularly among certain groups. More feasibility studies are needed to understand what works well, including with specific demographics, and to realise the opportunities new methods can offer.

- 3.3 The development of new technology demands skills that are not traditionally acquired in longitudinal study teams. Studies should work together and share resources to help reduce the heavy financial and resource burden.
- 3.4 The use of new forms of data collection should be driven by science, and by utilising the best tool to answer a specific question. It should not be driven by technology and innovation for innovations sake.

4. Data discoverability

- 4.1 All initiatives aimed at improving discoverability and interoperability must have clear objectives that are based on a strong understanding of the target users' requirements and research needs.
- 4.2 There is demand for discovery platforms that provide highly detailed metadata, as well as for platforms that provide a higher level of information, and allow users to quickly find out if a certain study or data exist.
- 4.3 Interoperability in discovery platforms can facilitate interdisciplinary research and reproducibility by facilitating research that combines data across domains, and ensure infrastructure adheres to FAIR data principles.
- 4.4 Sustainable and interoperable infrastructure must be prioritised in funders' investment strategies, and the contribution of such work to novel research, open science and reproducibility recognised.
- 4.5 There is a need for a discoverability leadership body with technical skills and knowledge, the ability to advise on standards, and a strong management team capable of coordinating across multiple stakeholder groups.

5. Reducing attrition, and participant engagement

- 5.1 While monetary incentives are not universally appropriate or affordable, most studies make use of some form of 'reward' for participation.
- 5.2 Participants' family members remain critical influences on participation throughout the life course, and studies should treat them as allies in participant engagement strategies.

- 5.3 Cultural and country context deeply affects tracing and participant engagement efforts, both in terms of the barriers presented, and the appropriateness and practical viability of different solutions.
- 5.4 Survey design can be a key engagement tool – making participation flexible and fun can raise response rates.
- 5.5 When engaging participants, most studies are keen to move towards a model of tailored communication for different sub-groups, but not all can afford it.

To improve participant engagement, the longitudinal community needs adequate financial resources and a strong literature base on what works.

Full report

CLOSER (ed.) (2020) *Preparing for the future II: international approaches to challenges facing the longitudinal population studies*. London: CLOSER.

About CLOSER

The UK is home to the world's largest and longest-running longitudinal studies. CLOSER aims to maximise their use, value and impact both at home and abroad. Bringing together eight leading studies, the British Library and the UK Data Service, CLOSER works to stimulate interdisciplinary research, develop shared resources, provide training, and share expertise. In this way CLOSER is helping to build the body of knowledge on how life in the UK is changing – both across generations and in comparison to the rest of the world. CLOSER was funded by the Economic and Social Research Council (ESRC) and the Medical Research Council (MRC) from 2012-17, and by the ESRC from 2017 to present. Visit www.closer.ac.uk.

The views expressed in this work are those of the conference delegates and do not necessarily reflect the views of CLOSER, UCL, ESRC, MRC or the Wellcome Trust.

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