

Preparing for the future

Executive summary

On Thursday 6 December 2018, CLOSER hosted a one-day conference entitled *Preparing for the future: Tackling the key challenges facing the UK's longitudinal population studies*, at the Wellcome Trust in London. The event brought together around 70 delegates from across the longitudinal community, in social and biomedical sciences, including study Principal Investigators, researchers, professional staff, policymakers and funders. In a packed programme, the delegates discussed key issues in new forms of data collection, data harmonisation, data linkage, biosample management, impact, and engagement with policymakers.

The conference report documents the day's discussions, and the actions proposed by delegates to address key challenges, and fill knowledge & skills gaps. This Executive Summary provides an overview of the key points raised.

1 New forms of data collection

- 1.1 To drive innovation in longitudinal population studies, we must share and value learning on our failures as well as our successes, without judgement or risk to funding.
- 1.2 While the novelty of new technology may be attractive, longitudinal population studies need to carefully consider the biases it introduces, longitudinal continuity, and the practical and financial implications they will face. These need to be weighed against the quality, utility and scientific potential of data produced by new technology.
- 1.3 We need more research into what participants are willing to do, and how acceptable they find new data collection methods.
- 1.4 Data infrastructure and researchers' analytical skills will need an upgrade to cope with new forms of data.

2 Data harmonisation

- 2.1 Collaboration between studies is essential to achieving prospective harmonisation, particularly when considering new technology and methods of data collection.

- 2.2 There is a risk of sacrificing data quality in harmonisation, and researchers need to ensure the right balance is struck between precision and scope.
- 2.3 Good quality documentation is vital.
- 2.4 Harmonisation has important scientific benefits, but has been insufficiently resourced and incentivised. The longitudinal community needs advocates from across disciplines to promote the value of this work.
- 2.5 Harmonisation practice could be improved by researching new methods for retrospective harmonisation, developing more techniques for validating harmonisation outputs, and by exploring opportunities offered by calibration and emerging analytic techniques.
- 2.6 Strategies for overcoming the challenges of data harmonisation should be developed through cross-disciplinary collaboration, and an overall coordinating role could prioritise measures to be harmonised and to promote the added utility of harmonised data.

3 Data linkage

- 3.1 Longitudinal population studies need to collectively champion administrative linkage, advocate for their needs, and proactively

make the case for the value of linked data in answering research and policy questions.

- 3.2 The multiplicity of government data holders means longitudinal population studies struggle to navigate different application processes and requirements, including what constitutes good practice for consent.
- 3.3 Longitudinal population studies face specific challenges related to consent, including ensuring its validity over time and managing consent as their participants' transition from childhood to adult life.
- 3.4 Public perceptions of data sharing affect both participant and administrative data holders' attitude and engagement with linkage efforts.
- 3.5 Staffing, resource and documentation issues in data holding organisations create practical problems for the linkage and post-linkage processes.
- 3.6 Collective problem-solving and collaboration between studies, and between studies and data holders, could help overcome technical issues, and challenges like missingness and disclosure risk.

4 Biosamples

- 4.1 Longitudinal population studies need a long-term storage solution for biosamples that is low cost but secure, and is supported by a stable funding stream.
- 4.2 A coordinated approach to the analysis of biosamples – favouring a multiplex or omics platform – could avoid unnecessary waste of a precious, exhaustible resource.
- 4.3 While remote methods of biosample collection are cheaper and reduce respondent burden, more research is needed to understand how the quality and integrity of samples collected remotely compares to conventional methods.

5 Impact & policy engagement

- 5.1 The longitudinal community needs to broaden its working definition of impact, and crucially give more prominence to scientific impact.
- 5.2 The longitudinal community can maximise impact by pushing both the evidence and the data to policymakers.
- 5.3 There are several areas where joint action could push forward progress, including developing more sophisticated methods for capturing impact, developing best practice

guidance on impact metrics, and enforcing DOIs for datasets.

- 5.4 Both the generation and tracking of impact need dedicated staff resources, however reward structures in academic institutions do not always place high value on this work.
- 5.5 Longitudinal population studies need to develop a better understanding of the policy landscape and the policymaking cycle, as well as guidance on how to cope with the mismatch of timescales between policy processes and research.
- 5.6 Studies need an 'access point' to the policy landscape, such as the Government Office for Science, network of What Works Centres, or government chief scientific advisors.
- 5.7 Government Areas of Research Interest are potential starting points for discussions with government departments on aligning longitudinal studies to policy needs.
- 5.8 Policymakers value synthesised evidence across a number of studies, and academic outputs should be accompanied by plain English translations.
- 5.9 Studies and policymakers require specialist, dedicated resource and training to support better engagement.

Full report

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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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