DEVELOPING INFRASTRUCTURE FOR RESEARCH ACROSS THE BIOMEDICAL AND SOCIAL SCIENCES WORKSHOP

14-15 OCTOBER 2008

SUMMARY REPORT

Background to Workshop

Britain has a unique collection of prospective studies – research resources which facilitate regular monitoring of the health, well being, education and socio-economic situation of individuals and family groups over their lifecycle. Drawn variously from birth registration, child benefit or General Practice records, Civil Service employment data or the Postcode Address File, these studies re-contact people periodically to provide rich information which combine data collected via face-to-face or telephone interviews, from health records, measures of physical and mental health with information describing their social relationships, employment, education and lifestyles. Many studies now routinely collect physical samples from individuals (blood, urine, saliva) for biomedical analysis.

Following the creation of the first national birth cohort study in 1946 (the National Survey of Health and Development [NSHD]), subsequent birth cohort studies commenced in 1958 (National Child Development Study [NCDS]), 1970 (British Cohort Study [BCS]), 1990/91 (Avon Longitudinal Study of Parents and Children [ALSPAC]), and 2000/01 (Millennium Cohort Study [MCS]). Provisional funds have now been 'earmarked' for a new birth cohort covering up to 50,000 children to commence in 2012/2013 and for related activities to achieve improved access to information from all the major birth cohorts and to facilitate cross-cohort research (Birth Cohorts Facility [BCF]).

Major national age cohorts include the Whitehall Study II [WII] which has been tracking over 10,000 civil servants who were aged 34-56 in 1985-88, the English Longitudinal Study of Ageing [ELSA] which is following annual changes in the health and social situation of over 12,000 people aged over 50 in 1998-2000. The UK Biobank is being launched with a target population of 500,000 people aged 40-69 at entry.

In addition to these birth and age cohorts, the Scottish Longitudinal Study [SLS] is a prime example of a resource created exclusively via record linkages and now covers more than 5 per cent of the Scottish population. *Understanding Society*, the new UK Household Longitudinal Study [UKHLS] will be collecting annual information from a representative sample of 100,000 members of the UK population (40,000 household interviews conducted in 2009-10, then annually thereafter).

The aims of the workshop

The agencies which are the funders or co-funders of these studies (MRC, ESRC and Wellcome Trust) wish to promote increased use of these resources, particularly where this facilitates the combination of research across the medical and social sciences. As a first step in this process, the MRC, ESRC and Wellcome Trust agreed to convene a workshop to bring together key investigators to explore ways in which the potential benefits from this complex and diverse range of resources could be maximised.

The workshop had three aims;

- Assist in delineating the major research questions and challenges that social and medical scientists can address collaboratively using these resources.
- Help clarify the enhancements required on specific studies to facilitate such research.
- Assist in determining how to achieve the highest degree of complementarity across the full range of these resources.

Structure of Workshop

The workshop was held over two days on the 14th and 15th October in London. Day one commenced with a series of short presentations from the lead investigators of existing studies addressing the following questions:

- What are the key features of their study which make it suitable for interdisciplinary research (and, if appropriate, to give examples of such research and associated findings)?
- What are the most important enhancements that are required to make their study more valuable for interdisciplinary research?
- Which other studies/resources best complement their study?

They were also asked to provide information on current and planned arrangements for record linkage and for research access to data and biological specimens.

The presentations were followed in the early afternoon with a panel discussion focussing around issues relevant to the aims of the workshop. Participants then broke into discussion groups, tasked with addressing these issues, reporting back in the late afternoon. The following morning was spent in open discussion about the issues covered the preceding day, with the aim of trying to achieve some consensus about the research issues that require interdisciplinary research across the social and biomedical sciences and helping to establish mechanisms that will promote and foster such research across the range of these important research resources.

The workshop programme and presentations can be downloaded from: http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/nds/events/default.aspx

Attendance

Attendance at the workshop was by invitation only. Approximately 40 people attended the event, including principal investigators or their representatives from the major longitudinal studies which already (or have the potential) to provide data for research spanning the biomedical and social sciences.

Summary of Main Points Raised

Through the presentations and discussion a number of key points and issues emerged. These have been grouped under a number of themes which appeared to emerge during the course of the event.

Policy/ Strategic

- The importance of viewing the studies as a collective resource, promoting harmonisation and complimentarity to further cross study research, while recognising the benefits of diversity between the studies.
- Following from the above the need for a more co-ordinated approach to the funding and co-funding of the studies moving away from the current rather piecemeal approach which was thought to stifle long-term planning, collaboration and methodological innovation.
- There is a dichotomy between hypotheses driven funding proposals and the development of resources which allow for the testing of multiple hypotheses, some of which are not yet conceived. It was agreed that it is important to focus on the important scientific areas/ questions a resource can support research on rather than specific hypotheses.
- In relation to the above consideration needs to be given to how proposals for resource provision are peer reviewed and considered by funding bodies.
- Publicly funded data should be exploited for maximum public benefit. Therefore, all participants subscribed to the view of improving data access and sharing for secondary analysis, subject to necessary safeguards to protect respondents.

Operational

- At present several different systems and processes have been developed in relation to data access and data sharing. There is a need to share expertise and best practise, as well as exploiting technological opportunities.
- Improvements are needed to help researchers discover the resources which are available to them to support research at the interface of the biomedical and social sciences. Perhaps a website or portal could be established which aggregates data and publications from all of these studies.
- We share common problems, such as gaining ethnical clearance, we need to share experience and perhaps take a collective approach to addressing these problems.
- Participants noted the exciting developments taking place within the 1946 Cohort Study involving coordinated data collection through the Wellcome

Trust's various clinical facilities. It was noted that it would be important to learn from these developments as these facilities could be used to support future data collection across a number of studies.

- The high quality infrastructure of UK Biobank for storage, processing and retrieval of biological samples was highlighted and the opportunities to share these technologies more widely.

Engagement, Exploitation and Impact

- In a tightening financial climate it was recognised that it was becoming increasingly important to demonstrate the value and the impact of these studies, not least because of the considerable amount of public funds which has been spent on them over the years.
- There was a consensus that, in a climate of public concern about the collection and use of personal data, more needed to be done in relation to public engagement. Collectively, we need to be demonstrating the importance of collecting personal data for research purposes and the great lengths the research community goes to in protecting the anonymity of respondents.
- There is not much point in investing in research infrastructure if this is not match by the provision of resources aimed at their exploitation. Therefore, we need to consider the role of resource providers in supporting analysts in not only accessing the data, but in also its use.
- It was noted that resources benefit from being co-located within a vibrant research environment. This is so that expertise is developed around particular resources, which can be utilised to not only inform its development but also support other analysts.

Capacity Building

- As noted above, as well as building analytical capacity, there is a need to build capacity in resource provision management to ensure we have the people with the skills to run and provide these resources in the future.
- If the potential of these resources, to support research across the biomedical and social sciences, is to be realised there is a need to invest in building interdisciplinary/ multi-disciplinary research capacity. One suggestion made was that the funders could support some postdoctoral researchers/ fellows working across the various studies.
- There was some debate as to where the focus of this capacity building activity should be. Some participants argued that it should be at doctoral level, while others argued it should be at the postdoctoral level. The consensus appeared to be that efforts are needed at all levels of the research career life-course.
- Participants also noted the current strains on the UK field-force capacity, and therefore the need to work with the survey and market research organisations to build up the UK's field-force capacity.

Enhancements

- Participants noted the opportunity to enhance and enrich existing studies by the linking in of routinely collected administrative and transactional data. In particular, the opportunities presented by e-health records.
- Participants also noted the kind of questions which researchers wanted to address required the collection of a wider range of data, such as cognitive data, physical environmental measures, geospatial, infection and immunity.
- Developments in technology presented the opportunity to use different data collection methods, such as web based data collection.
- Technology also presents opportunities to store and make accessible a wider of range of data not previously possible.
- There is a need to collect a wide range of different measures in order to allow for a variety and to test the validity of different types of measurement.
- There needs to be continued support and incentives for methodological development and innovation. To develop and test the validity of new measures and share knowledge about them. This included in depth phenotyping and novel tools and technologies for the measurement of environmental exposures and behaviours.
- A number of collaborations already exist, we need to consider how we can expand and build upon those collaborations. Perhaps the proposed Birth Cohort Facility should have a broader reach – promoting linkages and collaborations between longitudinal studies.

International

- Participants noted the unique position and competitive advantage of the UK in having such a rich portfolio of research resources. These resources make an important contribution to the international standing of UK science, making it a destination of choice for many leading international scholars.
- There are a number of developments taking place internationally which will present exciting opportunities for international collaboration. We need to ensure that we are collectively engaged in them.
- Funders can play an important role in helping researchers and resource providers navigate the maize and bureaucracy associated with international opportunities.
- Linking studies internationally can enhance statistical power and provide opportunities to undertake natural experiments.

Research Issues that require Interdisciplinary Research

There was a broad consensus that the following issues represented important research questions/challenges that social and medical scientists should work together to address collaboratively:

- Obesity
- Mental Health
- Immunity and infections
- Chronic diseases
- Ageing
- Intergenerational health

Workshop Recommendation

The main recommendation from the Workshop was that the three funding organisations need to work together to develop a more strategic approach to the future funding, development, enhancement and exploitation of major longitudinal resources at the interface of the social and biomedical sciences. There was also strong support for the development of a cohorts portal.

This could be done possibility through the creation of a Forum, building on the workshop. The role of the Forum would be to provide strategic advice to funders on the development of the research infrastructure to support research across the social and biomedical sciences and stimulate the exchange of information and the sharing of best practice, infrastructure and novel technologies across cohorts. The Forum would build upon/ replace existing bodies such as the National Longitudinal Strategy Committee.

ESRC, MRC and Wellcome Trust Response

The three organisations recognise the need for them to work collectively in order to maintain and enhance the research resources required to support high quality research across the biomedical and social sciences. It is only through such research will we will be able to address some of the most pressing research and policy questions such as the health, economic and social consequences of an ageing population; the role of socio-economic status and social networks on rates of obesity; the impact of early childhood experience and education on later rates of mental health and cognitive function; the risk of and effect of early environmental exposures on later health outcomes; cardiovascular health and how to maintain a health lifestyle to name a view.

As well as investing in the research resources the three organisations also share a common goal in ensuring the fullest exploitation and impact of those resources in order to maximise the public's investment in them.

To carry forward the main outcomes of the workshop the three organisations have agreed the following next steps, more detailed information on each will be provided in due course.

- The development of a Longitudinal Studies Strategy to provide a coherent framework through which to develop and maintain the UK's unique collection of longitudinal studies to ensure their maximum value and impact addressing the key issues identified in the workshop. It is proposed that a Longitudinal Studies

Forum be established to advise the funders on the development and implementation of the Strategy.

- The development of a web portal to enhance the visibility of the UK's major longitudinal studies as collective resource, conveying their research potential and impact to a wider audience (particularly the policy and practice community and academics who have not previously used data from the studies or who are not aware of the full range of data available). The intention is that this will be complimentary to the studies own websites and other sources of information on them. It is proposed that the portal will be in the form of an online brochure, explaining various aspects of the studies' development, purpose, methodology and coverage. Links will signpost visitors to where they can find more information on individual study sites. The site will also include a section on the impact of the studies on policy and society and a consultant will be appointed to work with the studies to draw out key impacts from their studies with the aim of launching the website in the spring.

- The development of a cross cohort research initiative on Obesity. Paul Burton will chair a small working party of experts in nutrition and obesity, which will come up with some initial ideas to feed into a workshop scheduled for March 6th.

Finally, we would like to thank all the contributors to workshop and all the participants for a lively and constructive discussion.

Mr Michael Bright
Head of Research Resources
Economic and Social Research Council

Dr Angela Cooper
Theme Leader for Methodology and Population Health Sciences
Medical Research Council

Dr Pat Goodwin
Head of Pathogens, Immunology and Population Health
Wellcome Trust