A Strategy for Engaging the Public with Longitudinal Studies
A draft strategy to the Economic and Social Research Council
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*This strategy forms part of a report currently under review, due to be published later this year.*

Background
To address important questions such as how the wellbeing and life chances of people interact with their social and economic welfare, population researchers gather evidence from a wide variety of data sources. The richest forms of these data are longitudinal surveys, information about individuals linked through time, often based upon samples drawn from official administrative databases. Such surveys rely upon the voluntary cooperation of those selected to participate and their continued willingness to engage with successive enquiries. If members of any particular group of participants, defined say by age, gender or ethnic background, are less willing to participate than others, these important sources of research information lose representativeness. Key to the value of existing or new longitudinal surveys is the motivation behind voluntary participation in such studies. This, in turn, is driven by the existence of a general understanding of the societal good arising from personal involvement in longitudinal surveys.

There is evidence that voluntary participation in surveys generally, not just longitudinal surveys, is in decline\(^1\). This is variously attributed to the rise in cold-calling for legal and illegal purposes, the growth of online and telephone consumer surveys more generally, coupled with increased public concerns about the security of personal information harvested from social media platforms and the uses to which this information is put. But information about the mechanisms underpinning this decline is fragmented. **This project sought to address this gap in knowledge via a three-pronged approach – a literature review, consultation with and oversight from experts and through a series of dialogue workshops held across Great Britain using what is termed a deliberative methodology. The information so gathered forms the basis for a strategy for engaging the public with longitudinal studies, a strategy designed to promote recruitment to and continued participation in longitudinal studies.**

Introduction
This draft section of the report provides evidence of the conditions required to promote public engagement with longitudinal studies. This evidence underpins a strategic approach towards public engagement with survey-based longitudinal research. The approach recommended recognises that each study is different in terms of its research aims, the population it represents and the stage in the lifecycle of participants that it has reached. Thus, the strategy is overarching, in that it sets out the general aims that those responsible for each major longitudinal study are expected to achieve via a plan specific to their particular study.

Aim of the strategy
The aim of the ESRC public engagement strategy for longitudinal studies is to raise awareness of and to engender public support for participation in the major longitudinal

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\(^1\) See for example [https://aspe.hhs.gov/system/files/pdf/255531/Decliningresponserates.pdf](https://aspe.hhs.gov/system/files/pdf/255531/Decliningresponserates.pdf) for the USA and [https://ukdataservice.ac.uk/media/455313/moore.pdf](https://ukdataservice.ac.uk/media/455313/moore.pdf) for the UK.
studies, whether existing or planned, that fall within the purview of the ESRC, thereby enhancing recruitment into and retention within such studies. These aims are to be achieved by:

- building trust between those members of research community designing and maintaining longitudinal surveys and the general public;
- promoting the societal benefits from the research so generated;
- providing wider access to knowledge of and information about the safeguards used to protect privacy;
- and lastly, by providing oversight of these elements.

The principal elements of the strategy
Four main elements underpin the strategy. These relate to trustworthiness, clarity, safeguarding and oversight. Each is outlined in turn.

Trustworthiness
As has been shown clearly in various studies, an essential component for engaging with the public in order to gain their support for the use of personal data in the development and maintenance of longitudinal data resources, is that the processes through which these resources are created and sustained must be trustworthy. These processes include the means through which data controllers may supply or use personal data for purposes other than those for which they were collected. They also cover the processing of such data for research purposes, whether through the collection of additional information or the use of this information for research, as well as those who interpret findings, publish research findings and develop policies on the basis of such research.

Clarity of purpose
A necessary condition to develop trust between the public and all who are involved in the process of creating, developing, maintaining and sustaining longitudinal studies is that there should be a clearly articulated and legitimate purpose for this work. This condition alone is not sufficient.

What has been made clear via public engagement workshops and from other studies is that the purpose of the studies should be clearly articulated in terms of the direct public benefit that will derive from research use of the information it generates.

Safeguarding
While extensive progress has been made by data controllers and data intermediaries such as the UK Data Service in establishing conditions that provide for the processing, retention, storage and archiving of personal data in secure conditions, the public perception of this is problematic. For this reason, any public engagement plan associated with a particular study should find ways to explain such safeguards to the public in a clear and unambiguous manner, including the penalties associated with misuse of personal data.

Oversight
Currently, the governance of longitudinal studies is complex and varies considerably from study to study. While this reflects the nature and scale of each study, engagement with the public to promote new and/or existing studies must consider many elements, such as the

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2 The ‘Five Safes’ framework (safe people, safe projects, safe settings, safe outputs and safe data) is a leading example of a safeguarding framework and is widely adopted within the UK (see https://www.youtube.com/watch?v=MLn9Ts2mwj0 for details).
audiences to be addressed, the messaging channels to be used, and the safeguarding arrangements, legal and ethical approvals. A common concern echoed across public dialogue workshops was the need to share information about oversight arrangement between studies and for a degree of independence to be incorporated into these arrangements.

Implementing the strategy

It is proposed that the research team responsible for each longitudinal study, existing or proposed, should establish a public engagement plan. This should be a detailed plan covering the engagement of the public with the proposed methods for recruitment into a study and for the continued retention of participants within it. It should cover the lifetime of the study, with periodic updates. It should assess the risks and benefits associated with the study, including the risks to non-participants. Additionally, it should consider how to gain the active involvement of participants in the continuing life of the study.

There are three related components that are required for the successful implementation of a public engagement plan. These are: the resources dedicated to engagement activities; the engagement plan itself and the oversight arrangements.

The resources

The success of efforts to establish a new longitudinal study, or to ensure the continuation of an existing study, depend critically on the support of the public. The findings of this report indicate that public awareness of such studies is low and may be met with scepticism. However, when fully described in terms of their aims and the potential benefits arising from research based on them, support for them is the majority response. This implies that significant resources for engagement should be made available, not just at the design stage but throughout the lifetime of a study. While no specific recommendation is made here regarding the scale of the resources required for the design, development and conduct of continuing engagement activities, a ring-fenced budget should be agreed for the range of activities to be undertaken, and that sufficient expertise in public engagement should be embodied within the research team responsible for the study.

The plan

There is no single blueprint that should dictate the design of a public engagement plan. Each study will have research aims associated with its proposed or existing structure, covering different populations of interest and with varying research objectives and should align its public engagement plan with these aims and objectives.

The public engagement plan should form the framework for all public engagement activities associated with a specific study. It should be prepared well in advance of contact with study participants and should be reviewed on an annual basis. While there are examples of such plans and guides to their development which provide useful information, the following points provide a checklist against which the plan can be evaluated:

- Establishing the target groups for engagement

There are four groups that constitute the targets of public engagement work – potential study members; actual study members; stakeholders (e.g. funders, data controllers, the policy community) and the general public. Each group will require different forms of messaging through varying channels. The plan should give consideration to the methods by which each

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group will be identified, the means of communicating with each group and the timing and frequency of such communications.

• **Methods for gauging public opinion**
  Public engagement is not a ‘one-off’ or infrequent activity, but a continuing process during the lifetime of a study, through which interactions take place with the target groups. A variety of methods should be given consideration, ranging from media articles, focus groups, participant panels and social media channels.

• **Feeding back information**
  As a study develops, an important aspect of public engagement work is to feedback information on progress, whether this is on recruitment, findings from previous public engagement work, research plans and research findings based on the longitudinal study. This information should be tailored for different audiences, including participants in the study, stakeholders, data controllers associated with the study and the research community.

• **Promoting the study**
  Sufficient resources should be retained to link with media outlets that can help to promote a study. Organisations that may assist with promotion include the Science Media Centre, Science Daily and the science editors of the major newspapers and science magazines.

• **Providing assurance**
  The plan should pay particular attention to the need to provide assurance to potential and actual study participants and members of the general public by describing the range of security measures employed to protect the privacy of individuals, clarify the voluntary nature of participation, and detailing the penalties to be applied if any breach of these protocols should occur.

• **Monitoring and evaluation of the impact of public engagement activities**
  An important aspect of all public engagement work will be to measure its impact. This may take the form of performance indicators, follow-up studies, ad hoc surveys etc. depending upon the nature of the engagement activities concerned. These can indicate the cost effectiveness of different approaches to engaging with the public. Sharing information between studies about the effectiveness of different public engagement activities should be encouraged. One possible mechanism to achieve this will be for all longitudinal studies to host an annual event at which they outline their activities, current or planned and describe the work they have been doing to measure the effectiveness of their public engagement.

Through consideration of the guidance shown above, each study should develop its specific engagement plan, a document to be updated on an annual basis as the study progresses and made publicly available on its website following approval (see below).

**Oversight of the public engagement plan**

*Given the importance of public engagement to the success of any major longitudinal study, oversight of the plan is an essential requirement.* Typically, this responsibility will lie within the terms of reference for a study steering group or senior management board. The funders may also have a specific interest in the nature of the engagement plan and associated evaluation work and could form useful partners in the oversight of plans.

The oversight of procedures for the maintenance and enforcement of data security requirements was highlighted in the dialogue workshops as an area of concern. Currently these are the responsibility of the research team, and there are examples of good practice in this respect by most of the major longitudinal studies. However, the issue is not about practice, but about the public perception of who has responsibility for ensuring that the data
security arrangements are sufficient. At present this responsibility lies in part with individual
data ethics committees within the higher educational establishment where the lead research
team is located. Where access to administrative data forms part of a longitudinal study, the
responsibility for data security rests also with the controller of these data. While the latter
responsibility is well managed, with clear penalties for breaches of procedures, the extent to
which institutional ethics committees impose standards for data security and penalties for
procedural lapses was raised as an area of concern in the public dialogue workshops. This
is an important issue that requires further investigation. **Consideration should be given to
the possibility of an independent review of data governance across all major
longitudinal studies and for the promotion of mechanisms to share the benefits of
such a review.**