Promoting public engagement with longitudinal research

A report to the Economic and Social Research Council

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Acknowledgments

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1. Promoting public engagement with longitudinal research: Executive Summary

1.1   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 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.

1.2   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 concerns across many population groups 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. The project described in this report 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 has formed the basis for the strategy presented here, an ambitious plan for engaging the public with longitudinal studies, aiming to promote their recruitment to and continued participation in longitudinal studies.

1.3   All the information presented in this report was gathered immediately prior to the commencement of restrictions across the UK to prevent the rapid spread of the Covid19 coronavirus. These restrictions have had and will undoubtedly continue to have a profound impact upon the economy and society. This may cause the reader to question the relevance in a post-pandemic environment of the findings presented in this report. However, the pandemic has brought into sharp focus the need to have in place robust measures that address issues such as the ethics of data sharing, the importance of good data governance and, above all else, a requirement for the research community to engage with the public in ways that were previously deemed unnecessary.

1.3   Key findings from the project are:

- Effective communication between the research community and the public is paramount to the promotion of the beneficial nature of longitudinal survey research. Crucially important in this respect is the targeting of communications to the variety of potential beneficiaries of research based upon longitudinal studies, together with clear and accessible styles of messaging and careful selection of the communication channels to be used. These channels should, when appropriate, allow for two-way communication for dialogue, reactions, and engagement more generally.

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[1] See for example https://aspe.hhs.gov/system/files/pdf/255531/Decliningresponserates.pdf for the USA and https://ukdataservice.ac.uk/media/455313/moore.pdf for the UK.

- There exists a growing concern among some communities about the potential misuse of data, including the loss of privacy and commercial exploitation of personal information, fuelled in large part by the growth in online communication, the ubiquitous nature of social media and news reports of data protection violations.

- There is little knowledge outside academic and government circles about the measures that are employed by the research community and data controllers to maintain the security of personal information held by public bodies, protecting against privacy violations.

- An expressed need was noted, both in the reviewed studies and in the dialogue workshops, for partnership working to be formed between those designing and undertaking longitudinal studies and potential or actual study participants. There is a role here for community or third sector groups to represent the views of specific demographic groups and/or to facilitate engagement with them.

- The oversight of security measures required to maintain confidentiality is not regarded as sufficiently independent in some instances. Where these measures are based upon the requirements of university research ethics committees, they were not seen as sufficiently independent from the research community to foster public trust.

1.4   These findings informed the development of a more strategic approach towards engagement with groups within the general population about the benefits deriving from 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. **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 study.** These aims are:

- to build trust between those members of research community designing and maintaining specific longitudinal studies and the public, particularly those most likely to benefits from findings relating to a particular study;
- to promote clearly and effectively the wider societal benefits from the research so generated;
- to improve access to and information about the safeguarding methods used to protect privacy;
- and lastly, to publicise how oversight of their public engagement plan will be achieved.

1.5   **The research team responsible for each longitudinal study, existing or proposed, should establish a public engagement plan, or review its existing plan.** This should be a detailed plan covering the various ways of engaging with diverse groups within the population about the proposed methods for recruitment into a study and the for the continued retention of all participants within it. It should be a plan covering the lifetime of the study, with periodic updates. It should assess the risks and benefits associated with the study, including the risks associated with planned research based upon the information collected via the study. The plan should elaborate how these risks, as well as the potential benefits, will be communicated by appropriate methods to the public.

1.6   **Sufficient resources in terms of both staff time and money should be allocated by funders to achieve a wider and more continued engagement with the public than is currently the situation for many longitudinal studies**. This may be provided by ring fencing the budget for each study for all public engagement activities, with the ring-fenced amount set as a significant proportion of the total budget for the study. It also requires expertise in public engagement to be embodied at a

senior level within each study, providing leadership and assuming overall responsibility for engagement activities.

1.7   For the major longitudinal studies, **sharing of information between studies about their public engagement activities, particularly with respect to their effectiveness, should be organised on at least an annual basis.** This can assist with the identification of successful approaches and with coordination of activities between studies.

1.8   A further recommendation relates to an important area of public concern – the **oversight of procedures for the maintenance and enforcement of data security requirements.** Currently these are in part the responsibility of research ethics committees within the higher educational establishment where the lead research team is located and partly the responsibility of data controllers to meet the legal requirements for data sharing. While the latter responsibility is well managed, with clear penalties for any breach of procedures, the extent to which institutional ethics committees impose standards for data security and penalties for procedural lapses is perceived as an issue of public concern. **Within the public engagement plan for each longitudinal study there should be a section describing in a clear and accessible manner the data security measures in force for the different types of data to be collected, together with details about who will have access to sensitive information, how it will be shared in a secure manner and how the right to privacy for all who participate in a study will be maintained. It should stipulate how all data security measures will be enforced and provide for independent adjudication of breaches of these measures.** If studies can emphasise similarities between their data safeguarding methods and standards, this will assist with their public acceptability.

2.   Background to this report

2.1   In 2017 the Economic and Social Research Council (ESRC) published its Longitudinal Studies Strategic Review (LSSR). The aim of the review was:

> *'to provide an evidence-based and challenge-led assessment of the future social and interdisciplinary scientific and policy-relevant needs for data to address the types of research questions for which longitudinal data has typically been used (or could be used), and the value of the life-course evidence from our longitudinal studies in comparison with other sources of evidence.'* (Davis-Kean *et al*. 2017; p. 48).

2.2   The review concluded that the combination of longitudinal cohort and panel studies funded by the ESRC provided not just an adequate data landscape to support a broad range of research on the life course but were highly valued by government analysts in terms of their ability to deliver an important evidence base for informing policy. Two important recommendations stemming from the review related to the value of **an administrative data spine** for sampling purposes and for the study of representativeness, and that a new **population-representative birth cohort** sampled from such a data spine should be commissioned within a reasonable time frame (*op. cit*.; p. 7).

2.3   Following the review, the ESRC established the 'UK Population Lab' programme, funded under the UKRI Strategic Priorities Fund (SPF). The programme consisted of a wide range of scoping studies, think pieces and evidence summaries[2] to further inform the review recommendations. It had been noted by the authors of the review that one of the main weaknesses of longitudinal and panel studies was that they became less representative of their original population through time due

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[2] See https://esrc.ukri.org/news-events-and-publications/publications/corporate-publications/innovation-and-development-in-longitudinal-studies-outputs-from-the-uk-population-lab-programme/ for other outputs from the programme.

to attrition. Furthermore, a pilot survey undertaken in 2015 for a planned UK birth cohort had a disappointingly low response rate of 19 per cent (Dezateux and Elias [eds.], 2016). Accordingly, the ESRC commissioned a study to engage with members of the public to ascertain their views on participation in such studies, particularly those with a longitudinal dimension, and to explore what they may perceive as potential barriers to their participation. This report describes the results of this public engagement work, informing a strategy for engaging with the public on longitudinal studies.

3.   Public engagement research for the SPF UK Population Laboratory

3.1   The overall aim of this research project, which commenced in November 2018, was to provide evidence about the extent to which the public is engaged with issues relating to research use of personal data, the concerns that they have about such use, the confidence that they have about the processing of their personal data held by various bodies and the information that they would like to be provided with to alleviate any concerns that they have.

3.2   As an invited proposal, it was important that the design should be flexible, responding to changing events in the use of personal data for research, recent changes in the legislative environment [3] and should reflect any learning gained from similar work conducted in the UK and elsewhere in the world that was relevant to the aims of the project.

3.3   The original proposal stated these aims as follows:

3.3.1   Understanding conditions for public support for accessing and linking data about people from various sources including administrative records and longitudinal research data. This includes:

- *what is understood by the phrase 'population research' and why do researchers need access to personal data to undertake such research?*
- *Under what conditions is such research seen to be in the public interest?*
- *What types of data are more or less sensitive when reused for research purposes?*

3.3.2   Exploring public acceptability for the creation and use of an administrative data spine which would seek to use longitudinal survey data and administrative data together in innovative and transformative ways to deliver significant benefits for research. Public acceptability to be explored in relation to issues such as:

- *privacy and ethics;*
- *consent;*
- *data ownership;*
- *policies and safeguards;*
- *public perceptions and understanding of potential benefits.*

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[3] The Digital Economy Act 2017 provided new legal gateways for access to and linkage between personal data held by government agencies. The European Union General Data Protection Regulation was transposed within UK law as the Data Protection Act 2018.

3.3.3   Providing recommendations on how ESRC can best proceed with the development of its data strategy and the delivery of an administrative data spine in a way that works positively and pro-actively with issues of public concern and builds trust in research using administrative and linked data.

3.4   The project was designed with three stages. The first stage comprised of a review of existing and planned activities and reports that have addressed issues relating to the research use of large volumes of personal data, specifically where such research was in the public interest and conducted via public sector bodies. In the second stage this information, together with plans for the remaining stages, was submitted for review by an Advisory Group[4], consisting of senior academics in the social, economic and health sciences, data controllers, data infrastructure managers and others with an interest in public engagement activities in this area. The third stage took the advice from this group to inform the design and conduct of five dialogue groups, convened in different countries of the UK with members of the public to explore their perceptions of data sharing and data linking for research purposes. 100 participants reflecting a broad spread of demographics took part in the dialogue groups. This piece of work has the benefits and limitations of in-depth qualitive research, compared with larger scale but less in-depth quantitative approaches such as a survey. While the sample size was small and the opinions voiced in the dialogue groups may not be reflected at the population level, many of the participants in the dialogue groups shared the same key concerns. This suggests that the findings of this report represent prevalent public views on data sharing and data linking for research purposes. Each stage, including the key learning it provided, is described in greater detail in the following sections of this report.

3.5   The evidence gathered has been synthesised to develop strategic guidelines for public engagement in line with the recommendations of the LSSR - to promote recruitment to and the retention of participants within longitudinal studies funded by the ESRC, particularly where these draw their samples of potential participants from official administrative data sources.

What is meant by 'public engagement' and 'public benefit'?

3.6   At an early stage in this work it was important to address these seemingly simple questions about the audience for engagement and the notion that research may have wider impacts across the population than those who its primary targets are. For this report, 'public engagement' is defined in its widest sense to encompass engagement with all those whose lives are affected in any way, directly or indirectly, by the findings derived from research. For example, research on a cure for a rare form of childhood cancer is of benefit not just to children who may experience this cancer, but it includes all who place value on the lives of children as well as those who may be disadvantaged via a redirection of scarce medical resources. While this may seem intuitive, when research has a long-term aim and a focus on a specific group, such as studying the later life social and economic implications of family breakdown in childhood, it could be argued that engagement should be narrowed to a more specific group – such as those who had childhood experiences of family breakdown and were affected by this in their adulthood. Likewise, when research is focussed upon specific demographic groups in the population, defined say by ethnicity, age, gender, or social background, public engagement may be defined more narrowly to focus on the groups of interest within the population. This is not the approach adopted within this report. Public engagement for research purposes is defined here in its widest sense to encompass engagement with all who may be affected directly or indirectly and either positively or negatively by potential research findings stemming from longitudinal population research.

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[4] Referred to later in the work programme as the 'Oversight Group' (see section 5).

3.7   An obvious problem with the above definition derives from its inclusivity. Engaging with the public on a wide scale is not feasible except in certain rare situations such as with national referenda. To overcome this problem, engagement often takes place with small but representative groups of the population of interest. In such circumstances it is important that the demographic diversity of the wider population of interest is reflected in the composition of the group.

3.8   'Public benefit' is a less tangible concept. It relates to the potential benefits and the possible negative effects of research findings drawn from research using information supplied by members of the public. Research is, by definition, an activity that has an uncertain outcome. While its aims might be clear, the extent to which these aims will be realised is not. Public benefit is the benefit arising from the realisation of these uncertain outcomes, net of any negative impacts or costs that may also arise and are attributable to the research. But these benefits and costs, as well as being uncertain, are often not quantifiable. Nonetheless, the process of seeking to identify them and understand them is perhaps as important as any attempt at measurement.

4.   Review of the literature and related activities

4.1   This review, published in June 2019 (Kispeter, 2019), aimed to explore public attitudes to data and data science practices to inform the following broad research questions:

- Under what conditions does the public support accessing and linking data about people from various sources? What is understood by the phrase 'social and economic research' and about the need to access personal data to undertake such research? Under what conditions is it seen to be in the public interest?

- What is the current thinking among members of the public on their trust of the scientific community to process their personal data for research, and the related concepts of trustworthiness, transparency, and authenticity?

- What do we know about public acceptability for the use of (longitudinal) survey data and administrative data linked together in relation to: privacy and ethics, consent, data ownership, policies and safeguards and the public perceptions, focusing on different groups of the public where possible?

- How does the public make sense of the potential societal benefits of social-economic research and data linkage, and what do the public expect of public engagement activities in the context of data sharing and linkage?[5]

4.2   While the focus of the literature review is on social-economic research, studies on public attitudes towards linking health data were also covered in the review.

4.3   The review identified the following key conditions of public support for research based on personal data:

- there must be a sufficient, well-articulated and legitimate purpose to the research, explained in ways that relate to the benefit of the public in question. This may only be

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[5] Data-sharing involves information moving from one organisation or department to another, whereas data-linkage is defined as: "the bringing together from two or more different sources, data that relate to the same individual, family, place or event" (Cameron *et al.*, 2014, p. 11).

relevant for specific groups of the public, but the important issue is the need to communicate with these groups the potential benefit in clear and unambiguous terms and in ways that relate to their lived experience.

- Issues around privacy and confidentiality and the level of de-identification (often referred to as 'anonymity') need to be addressed and clearly explained to the public. This helps build up trust by the public in the research and by the institutions involved in the use of data and data linkage.

- Data security, in particular safeguarding data against misuse, and effective data governance was identified as an important condition for public support. Slightly less important were respect for the autonomy of the public, consent, how any profits emerging from the research were managed and whether the private sector was involved and finally, what types of data were linked together.

- Trust and trustworthiness emerged as one of the key conditions of public support for data linkage. The relationship between trust, transparency and authenticity was argued to be complex: transparency is necessary to build trust, but trust is required in order for the transparency to be recognised as adequate.

- Debates about control and consent were linked to the public's trust in the ability of research organisations to keep their data safe. Data relating to mental and sexual health, sexuality and religion were regarded by the public as particularly sensitive in thus respect

- There was not found to be an accepted definition of 'public benefit' and the question 'Who is the public?' was asked in the literature. Some studies argued that the definition of the public should be as inclusive as possible.

- Another important finding was that participants in public engagement suggested that increasing scientific knowledge was in and of itself a benefit and that the public could benefit from greater engagement with the scientific community.

- Finally, there was consensus in the literature that the public want more 'two-way' communication about data-based research, particularly about the social and ethical implications and the safeguards that are in place to protect against misuse, abuse, or harms. Studies which used deliberative methods and gave participants information about research practices led to greater support and acceptance or at a minimum, less concern about the use of data for research purposes.

5. Project management – the roles of the Advisory and Oversight Groups

5.1   An important aspect of this project was the need to consult with a wide range of interested parties through the development stage and as the research proceeded. Two groups were particularly important in the respect. An Advisory Group was formed soon after the inception of the project, meeting on three occasions (March, June, and September 2019). Membership of this group is shown at Appendix 1, consisting of the project team, ESRC officers, academics with interests in public engagement and/or longitudinal studies.

5.2   The Advisory Group had, as its main task, oversight of the commissioning process that would lead to the appointment of the organisations that would conduct the dialogue groups. This included commenting on the tender documents and participation in the evaluation of tenders.

5.3   Following the commissioning of Kantar Public as the organisation that would conduct the dialogue groups, Kantar Public suggested widening the membership of the Advisory Group to include a broader range of stakeholders, not just from the social and economic sciences and statistics, but from the health sciences and from those with interests in data security, ethics and data management. It was also proposed that the lead academics from the major UK longitudinal studies should also be represented.

5.4   This broadening of interests was achieved via a stakeholder workshop, held in London on the 4th July 2019. At this workshop, participants voiced concerns about one of the key recommendations made by the international review team, agreeing that the creation and use of an administrative data spine for survey sampling and for the study of retention in longitudinal surveys was currently not acceptable, given that it would require the creation and maintenance of what would amount to a population register. This would require primary legislation and various civil liberty groups and political groups had shown no willingness to support such a move[6].

5.5   The stakeholder workshop provided the opportunity for participants to agree to join the dialogue workshops for the purpose of answering questions from participants about research methods, data management and the maintenance of data security throughout the research process.

5.6   Following the stakeholder workshop, detailed planning for the dialogue workshops commenced. An Oversight Group was formed with wider membership than the Advisory Group. This group met on three occasions, twice as face-to-face meetings at the London office of Kantar Public (November 2019 and February 2020) and once as a virtual meeting (March 2020). The two later meetings focussed upon topline findings stemming from the dialogue workshops, all of which were completed by 1st February 2020.

5.7   The broadening of interests arising from the wider membership of the Oversight Group was particularly beneficial to the project. Drawing upon experiences from Understanding Patient Data, an initiative funded by the Wellcome Trust, and benefitting from the work undertaken by the Administrative Data Research UK partnership, some important advice was offered by the group at its November meeting. This reflected and extended what had been revealed in the literature review, to include:

- Engagement with the public should be a priority activity and should continue throughout the lifetime of a study. This should be undertaken as a form of partnership between the research community and members of the public, allowing for two-way interactions to facilitate a common understanding of research issues and data requirements.

- There should be clear articulation of the risks involved in data linkage and data sharing for research. This should be presented in language familiar to the public.

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[6] In 2006 the first major attempt in the UK to create a population register took place via the Identity Cards Act (2006). This legislation was struck down by the coalition government passing the Identity Documents Act (2011).

- The governance of the research use of personal data should be structured in a way that gives confidence to those whose data are being used for research[7].

5.8   An important recommendation made at this same meeting was that the dialogue workshops should provide feedback to the ESRC as it took forward plans for a new birth cohort study (now termed the Early Life Cohort Study).

6.   Researching public engagement

6.1   The core of this research was driven by the need to determine the public acceptability of the use of personal data held by government departments and agencies to provide sample frames for survey research, to link such data to survey records and, in the case of longitudinal surveys, to gain a better understanding of the effects of attrition. Deliberative workshops were selected given the complexity of the issues to be addressed, such as the nature and purpose of longitudinal survey research, population representativeness, sample attrition and data security procedures. Participants in such workshops are shown material introducing and explaining these concepts and issues. The process fosters dialogue and consensus building techniques, enabling participants to work together (with expert input) to develop an agreed view or set of recommendations. Deliberative workshops are held in stages, allowing participants time between successive workshop to absorb and reflect on the information provided to them.

The deliberative workshops

6.2   The overall aim of these public dialogues was to explore attitudes to the use of administrative data to underpin plans for a longitudinal research study, specifically a new birth cohort. The research aimed to:

- assess variation in attitudes to the use of administrative data to address issues of representation and retention in longitudinal research and to capture the nuances of drivers of different views;
- explore and identify what concerns the public have about this approach and what is driving these concerns;
- explore what conditions could help to make this approach more acceptable to the public;
- consider specifically the concerns they might have over the use of administrative data on births to create the sampling frame for a new birth cohort.

6.3   Five workshops were held across Great Britain[8] between the 18th January and the 27th February 2020. Each workshop was conducted in two stages and employed what is termed 'Deliberative methods' – an approach that allows for a period of deliberation by participants over information provided to them before reengaging with them after such deliberation. The first stage, lasting a full day, introduced participants to longitudinal research, including examples of research presented by the lead investigators from five of the UK's major longitudinal studies. The second stage, some four to six weeks after the first stage, brought participants back for an evening to reflect on the information to which they had been given and to encourage in depth discussion. One

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[7] For a useful articulation of this idea, see https://understandingpatientdata.org.uk/news/new-approach-decisions-about-data

[8] The workshop locations were Cardiff, London, Birmingham, Newcastle, and Edinburgh.

hundred people participated in these five workshops, with potential participants screened beforehand to ensure that a diversity of views was represented[9].

6.4   A detailed report on the design and conduct of the workshops, together with the key learning these provided, has been prepared by Kantar Public (Coulter *et al.* 2020). Rather than reiterate the findings from this report, these are assessed in terms of their implications for the elaboration of a strategic approach towards engaging with the public on the development and maintenance of major longitudinal studies within the UK.

6.5   The first, and most relevant finding, is the need to increase the awareness of the nature of longitudinal studies and the role they play in shaping important policy issues in the domains of health and wellbeing. These are seen by the public as legitimate reasons to gain access to and make use of personal data held by government departments and agencies for the purposes of sample design, representativeness, and retention. Raising awareness requires a thoughtful and targeted approach to different groups. Those who are potential participants in a particular study are the most obvious targets, but consideration should also be given to the wider public to promote specific studies. Interestingly, one of the core materials sent out to participants in the workshops was a link to series of films shown on ITV and produced by Michael Apted ('7 up', '14 up', '21 up', *etc.* to '63 up'), programmes which followed the lives of a group of 7-year-old children from 1964 onwards. While these documentaries were not designed for research purposes, the interest they generated among a wide audience and for workshop participants is indicative of the fascination that people have with trying to understand the life courses of individuals. Materials like this, plus posters, presentations and short animated films, stimulated workshop participants' interests in research based on longitudinal survey data.

6.6   Tempering this interest was a deep concern shown by participants about the need to preserve the security of any information provided by those who were part of a longitudinal study. This concern was allied to reports of data theft, hacking, impersonation, identity theft, 'phishing' attacks and related scams, some of these having been experienced firsthand by workshop participants or related to them by friends, and from press reports. However, when informed about the various ways in which the research community sought to protect individuals who had supplied them with personal information, these concerns were moderated. A common theme was the fact that they knew little about the steps that are taken by data controllers and the research community to store, maintain and process personal information in a secure manner.

6.7   Two other issues that were raised in nearly all the workshops have relevance for a more strategic approach to public engagement – transparency and oversight. Those involved in the funding and the development100 of longitudinal studies need to be quite clear about the reasons for generating these rich data resources. It is not sufficient to state that the data so generated may be useful for some future research, without clarifying what that research purpose is, how the research will be conducted, what data are required, and the expected benefits in terms of health, education, and social development of individual, families and communities. Oversight was seen primarily as the means of controlling the nature of longitudinal studies by ensuring that those conducting such studies could be held to account, and that a clear system of penalties would be imposed for any transgression of ethical and legal boundaries

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[9] In terms of demographic characteristics, 25% were from Black, Asian and Minority Ethnics groups, 48% were graded as 'C2/D/E' using the Market Research Society's social grade scale, 19 % had no qualifications at GCSE or above ` or Scottish equivalents, 18% were under 34 years, 29% were claiming some type of state benefit and 40% self-reported some form of underlying health conditions.

6.8   Via the focus within the workshops on a potential new birth cohort study, some valuable insight was gained into the more specific aspects of public concerns about the use of personal administrative records for sampling, recruitment of study members and for their retention within a birth cohort. Concerns related to the relationship between the data controller and the invitation to participate in the study. Advance notice of participation should originate from the data controller (typically the government department or agency holding personal information about potential study respondents) emphasizing the voluntary nature of participation, the personal information that had been accessed to generate the invitation and the purpose, aims and potential benefits stemming from their participation. All such detail must be made in simple, clear and accurate terms.

6.9   In addition to these views on information surrounding the invitation to participate, another important recommendation was the need to maintain close contact with participants throughout the lifetime of the study. Various ways of achieving this were discussed, including newsletters, research briefings, participant panels and events to celebrate milestones in the life of a study. Allied to this was the possibility of allowing participants to take 'planned breaks' from the study. While this runs counter to the general view that non-participation should be reduced as much as possible, the notion of some flexibility in participation in successive waves of data collection may assist with recruitment back into a study if this is a planned break from participation.

7.   A Strategy for Engaging the Public with Longitudinal Studies

Introduction

7.1   The preceding sections of this report provide 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

7.2   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 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

7.3   Building upon the information revealed in the literature review and bolstered by the learning gained from the dialogue workshops held across the UK, four main elements underpin the strategy. These relate to trustworthiness, clarity, safeguarding and oversight. Each is outlined in turn.

Trustworthiness

7.4   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

7.5   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 purpose (or purposes) should be**

well articulated in terms of the potential public benefit that will derive from research use of the information it generates. It should make clear the reasons for having a study which focusses upon a specific group (*e.g.*, new-born babies, the ageing population, migrant workers, *etc.*) stating plainly the research issues of relevance to the group which will be studied. It should also make clear the fact that longitudinal research may not necessarily prove effective in providing answers to these issues.

Safeguarding

7.6   While extensive progress has been made by data controllers and data intermediaries such as the UK Data Service in establishing environments that provide for the processing, retention, storage and archiving of personal data in secure conditions, the public perception of the processes and procedures that have gone into data safeguarding is minimal. For this reason, **any public engagement plan associated with a particular study should find ways to explain such safeguards[10] to the public in a clear and unambiguous manner, including the penalties associated with misuse of personal data**. There are useful examples to be drawn on for this purpose, including work conducted by the SAIL Databank and the Secure Data Services operated by the ONS and the UK Data Archive, finding ways to make these examples relevant to the public interest in a particular study.

Oversight

7.7   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 audiences to be addressed, the messaging channels to be used, and the safeguarding arrangements, legal and ethical approvals. A common concern echoed across the 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

7.8   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.

7.9   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.

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[10] 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=Mln9T52mwj0 for details).

The resources

7.10   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 preceding sections 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 **sufficient resources in terms of both staff time and money should be allocated by funders to achieve a wider and more continued engagement with the public than is currently the situation for many longitudinal studies**. 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 at a senior level within the research team responsible for the study.

The plan

7.11   There is no single blueprint that dictates 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.

7.12   **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[11] 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 five groups that constitute the targets of public engagement work – potential study members; actual study members; stakeholders (*e.g.,* funders, data controllers, the policy community), demographic groups who, while not participating in the study are more likely to be affected by its policy recommendations, and the general public. Each group will require different forms of messaging through varying channels. For example, engaging with stakeholders may take the form of one-way communications (email, newsletters, blogs, media articles, etc.). For potential and actual study members, two-way channels of communication may be more appropriate (focus groups, recruitment channels, reply paid mail, membership areas on websites. etc.). The plan should consider the methods by which each 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

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[11] See for example, the plan outlined by ADR UK (https://www.adruk.org/our-mission/working-with-the-public/) and the guide prepared by What Works Scotland (Faulkner and Bynner 2020) (https://policyscotland.gla.ac.uk/wp-content/uploads/2020/04/WWSPublicEngagementHandbook.pdf).

variety of methods should be given consideration, ranging from media articles, focus groups, participant panels and social media channels. More frequent monitoring of attitudes and opinions within target groups will enable the leadership team for the study to take appropriate actions to address any concerns that may arise through the lifetime of the study.

- 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 then 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 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.

- Sharing plans and experience

  For the major longitudinal studies, sharing of information between studies about their public engagement activities, particularly with respect to their effectiveness, should be organised on at least an annual basis. This can assist with the identification of successful approaches and with possible efficiency gains from the coordination of activities between studies.

- 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

7.13 **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.

7.14 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. **Within the public engagement plan for each longitudinal study there should be a section describing in a clear and accessible manner the data security measures in force for the different types of data to be collected, together with details about who will have access to sensitive information, how it will be shared in a secure manner and how the right to privacy for all who participate in a study will be maintained. It should stipulate how all data security measures will be enforced and provide for independent adjudication of breaches of these measures.** If studies can emphasise similarities between their data safeguarding methods and standards, this will assist with their public acceptability.

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Appendix 1: Advisory Group membership

Andy Boyd – University of Bristol
Peter Elias – University of Warwick
Emma Gordon – UKRI ESRC
Jane Hutton – University of Warwick
Erika Kispeter – University of Warwick
Clare Lyonette –   University of Warwick
Miranda Mourby – University of Oxford
Madeleine Murtagh – University of Newcastle
Rebecca Perring – UKRI ESRC
Carol Porteous – University of Edinburgh
Maria Sigala – UKRI ESRC
Bridget Taylor – UKRI ESRC
Clare Wilkinson – University of the West of England

Through its terms of reference, the Advisory Group was tasked as follows:

- **Providing advice** on the scope of the dialogue, including but not limited to design of the dialogue groups.

- **Supporting practical dialogue activities** where possible (helping recruit experts, being present for one of the dialogue group events, commenting on drafts of the discussion guide / questions, alerting the team to relevant related activities both within and outside the UK).

- **Receiving and commenting** on reports arising from the dialogue groups.

- **Representing and** where appropriate **ensuring engagement** by a wider group of stakeholders in the dialogue. This includes feeding in opinions and concerns from stakeholders and facilitating good / constructive stakeholder relations and involvement.

- Providing **independent oversight** of the process.

- Regularly **reviewing the existing and emerging risks** as the dialogue process moves forward and recommend mitigating actions where appropriate.

- **Facilitating embedding** of results in policy and institutions; providing a route for dissemination of outputs, thereby reassuring public participants that the results will be used.

- **Providing input** to the project team for an internal evaluation of the dialogue process.

- **Receiving and commenting** on the strategy for public engagement prepared by the project team.

Appendix 2: Oversight Group membership

Natalie Banner - Wellcome Trust
Andy Boyd - University of Bristol
Simon Burall - Involve
Amy Busby - Kantar Public
Gary Coleman - NHS Digital
Alice Coulter - Kantar Public
Karen Danesi - National Cyber Security Centre
Elaine Douglas - University of Stirling
Anastasia Duncan - Kantar Public
James Easy - UKRI ESRC
Peter Elias - University of Warwick
Rosie Giles - Kantar Public
Sarah Henry - Office for National Statistics
Paul Jackson - UKRI ESRC
Kerina Jones - University of Swansea
Erika Kispeter - University of Warwick
Clare Lyonette - University of Warwick
Madeleine Murtagh - University of Newcastle
Matthew Neale - UKRI ESRC
Ellinor Ottosson - Kantar Public
Rebecca Perring - UKRI ESRC
Bridget Taylor - UKRI ESRC
Lauren Wiginton - Kantar Public
Robert Wilson - UKRI ESRC

The Oversight Group had the following terms of reference:

- To participate in a maximum of three meetings (virtual or face-to-face) with Kantar Public and the IER team.

- Prior to these meetings, to receive information from Kantar Public and the IER team relating to plans for the dialogue workshops.

- To appraise these plans and to suggest potential improvements in the design and content of the workshops.

In case of questions or if you would like further information, please contact

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