

# Review of consent for record linkages

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## Summary

Given that consent is not our legal basis for processing personal data, but is currently obtained for ethical reasons, we explored whether we could take a different approach to the record linkages consent we currently seek.

- The organisations we spoke to had different approaches to consent for records linkage including the use of explicit informed consent, implicit informed consent or no consent.
- For existing CLS cohort studies, given that explicit informed consent has already been collected, it's important to consider this precedent and resulting expectations of CMs. It would be challenging, though not impossible, to change our consent model.
- For a new cohort study and new cohort members in existing studies it would be feasible to use implicit informed consent from the outset and to consider taking an unconsented approach.
- CLS should develop a strategy around its future consent model within a legal and ethical framework and this should be informed by advice from, and consultation with, key stakeholders.
- CLS should conduct public and participant engagement exercises and liaise closely with relevant data controllers to gain their agreement to any new approach within the relevant legal and ethical frameworks. Any new approach should also be trialed/piloted and assessed before being fully rolled out.

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## Introduction

In this project the Centre for Longitudinal Studies (CLS) undertook a short scoping review related to a number of strategic aspects of our record linkages programme. The review focuses on building a set of recommendations for record linkages in the CLS cohorts. A central part of this project is a review of the consent models currently being used and / or considered within a range of UK studies, especially in light of the new General Data Protection Regulation (GDPR) which enables linkage to be undertaken 'in the public task'. This short report summarises this review which focused specifically on consent for record linkages conducted at the individual level.

## Background

CLS has a programme of data linkage for the four cohort surveys that it runs and which is based on explicit informed consent from cohort members (CMs) to link health, education, economic and crime records into their survey data and to make the linked data available in de-identified form to researchers.

Following guidance from Research Councils, University College London and the Information Commissioner's Office, we have determined that our legal basis for processing (acquiring, linking and sharing) personal data is for a public task under GDPR. In addition, for ethical purposes, we currently continue to seek explicit informed consent from CMs to link specific administrative records to their survey data on an opt-in basis. We seek the consent of CMs for each type of linkage (for example, they can agree to health records but not education records being linked) and they can also withdraw their consent for one or more record linkage types at any time. Being able to withdraw consent is one of the key requirements of 'informed consent'.<sup>1</sup>

Although we gain consent, we are not using consent under GDPR as our legal basis for processing data. Given that consent is not our legal basis, this review explores whether we could take a different approach to the consent we currently seek. Changing our approach could mean fewer or the same number of refusals or withdrawals for records linkage (though this would need to be trialed) alongside efficiency gains in terms of administrative processes and, if it were ethical and acceptable to study members to move to unconsented linkages in certain scenarios, the removal of potential obstacles around the ongoing agreement of consent wording with data controllers.

## What we did

In this project we spoke with other survey organisations to find out more about their policies around consent for data linkages in the context of legal and ethical frameworks, including the form of consent they currently use or are considering

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<sup>1</sup> <https://esrc.ukri.org/funding/guidance-for-applicants/research-ethics/frequently-raised-questions/what-is-freely-given-informed-consent/>

using. We also sought their guidance around the legal and ethical issues of changing our existing consent model. We then used this information to consider how we could review future consents for – (i) current CMs in existing studies (ii) a potential new cohort survey (iii) new CMs (for example children of current cohort members that we might bring into the surveys).

## Outcome

The organisations we spoke to had different approaches to consent for records linkage including the use of explicit informed consent, implicit informed consent or no consent.

### Examples of different approaches to consent

#### Explicit informed consent

The Institute for Social and Economic Research uses and will continue to use this model of consent for Understanding Society, with data being processed for a public task under GDPR and explicit informed consent obtained for ethical purposes. ISER contact all respondents every 2-3 years to inform them of the consents they have agreed to and to give them the opportunity to withdraw from any of them. These regular reminders are seen as a way to foster transparency and trust with their respondents.

#### Implicit informed consent

##### Avon Longitudinal Study of Parents and Children (ALSPAC)

For postal or online surveys, explicit informed consent is not obtained for data linkages but respondents are provided with information about what will be done with their data and they can withdraw their consent at any time for any particular data linkage. In the case of face-to-face interviews it is much more practical to obtain explicit informed consent where there is a greater opportunity for any issues to be explained and discussed. The legal basis for linking to health data (such as NHS and GP records) without explicit consent is S251 of the National Health Service Act 2006 – this provides an exemption where it's not practical to obtain explicit consent. GDPR does not require consent for data linkage.

##### Family Resources Survey (FRS)

The FRS is carried out by the Office for National Statistics (ONS) on behalf of the Department for Work and Pensions (DWP). For many years the FRS included a question seeking explicit informed consent to link the survey data to records held by the DWP. However, legal advice both under the previous and current Data Protection Acts suggested that provided you give respondents sufficient advance information about what you intend to do with their data and explain that the data will only be used for statistical research purposes that this is still classed as 'informed consent' and it is not necessary to explicitly ask for consent. As a government

department they can link without explicit consent because it is necessary to carry out their function as a public body under GDPR. A trial in 2017 where half of the respondents were asked for explicit consent and the other half weren't showed no impact on response rates and didn't result in any complaints or withdrawals and so the approach was successfully rolled out to all respondents. If a respondent were to withdraw this would mean they would no longer be a part of the survey at all – it's not possible to withdraw consent for just the data linkage.

## Unconsented

### A number of ONS surveys and the Census

ONS do not currently seek consent for a number of data linkages for their own surveys to administrative data. At the point of collection they tell people that the data will be used for statistical research purposes. They rely on public task - the exercise of official authority vested in the controller - as their legal basis under GDPR, the Statistics and Registration Service Act and the Digital Economy Act. They are unique amongst government in that they are only using the data for statistical purposes so there is no additional impact on data subjects. Government departments use data for other purposes so matching data raises more concerns for data subjects and so consent may be sought. This consent model is currently being reviewed. Also, more emphasis might be placed on consent where ONS are asked to link administrative data to other survey sources, such as those from CLS and where there is a requirement for onward sharing of the data at the individual level.

### Northern Ireland Longitudinal Study of Ageing (NICOLA)

NICOLA is conducted by Queen's University Belfast (QUB). They mentioned that consent to record linkages is generally much lower in Northern Ireland than the rest of the UK (anecdotally just over 50% compared to around 70%). QUB decided not to ask consent to link a number of administrative records when they set up NICOLA based on the following -

- Legality – they sought advice from the Information Commissioner's Office in Northern Ireland who advised consent wasn't necessary despite it being the default position that most lawyers take.
- Ethical requirements - their application to the National Research Ethics Office was supported by this guidance from the ICO.
- Data controller approval was negotiated and gained in advance.
- Acceptance by CMs was a critical consideration – they invited a random sample of CMs to be on a dedicated panel and sought their views, which were overwhelmingly supportive and CMs in general *expected* data linkages to happen as part of the study. QUB assumed CMs would be most concerned about anonymity but once they understood about the benefits of data linkage they were more concerned that their data would be put to the best use possible.
- Some other key considerations are that you can demonstrate public benefit, that the results of the research are made public, that the data linkage remains

within the purpose or remit of the original study, that the data are accessed securely and there is no harm to the individuals

## Advice to CLS on reviewing consent

Overall, the consensus seemed to be that *some* form of consent is necessary if not for legal purposes but for ethical ones. A key consideration is what respondents would reasonably expect around data linkages with the information that they have been given and the requirement to be fair and transparent. Any review of consent must be taken in the context of what consents have already / previously been obtained under existing studies and therefore what assumptions existing respondents might make.

## Current cohort members in existing studies

Given that explicit informed consent has already been collected, it's important to consider this precedent and resulting expectations of CMS. For example it seems reasonable to suggest that CLS must honour any existing consent refusals or withdrawals unless overwritten by an active opt-in by study members.

An intensive participant consultation exercise would need to be undertaken before any change to this model could possibly be undertaken. If a move away from explicit consent were agreed, there would be a strong obligation remaining to actively inform CMs of our intentions, giving them the option to refuse, and to update privacy notices (this would equate to 'implicit informed consent'). As part of the participant consultation we would also need to consider the potential for this change in approach to alienate and cause mistrust in respondents and the possibility it could increase survey drop-outs, not just consent withdrawals. Maintaining participant trust must be a primary focus of any consultation work.

## A potential new cohort study

For a brand new cohort survey it would be feasible to use implicit informed consent from the outset. This means that we would inform cohort members of our plans and they would have the option to withdraw. Any increased risks of identification would be mitigated by secure access arrangements, as with current cohorts. The advance information given to cohort members would need to be carefully planned with consideration given to the level of detail required. For example, this information could either be (a) very specific about the intended linkages, thereby limiting additional linkages or requiring additional communication with CMs when new linkages are planned or (b) more general, explaining that CLS will conduct a number of different administrative data linkages with a link to a web page that could be updated if new linkages were planned. It would also be necessary to consider the approach we should take regarding granularity of consent withdrawals with the following options –

- Withdrawal of consent to linkage would mean withdrawal from the study
- Withdrawal of consent to linkage would apply to all data linkages.
- Allow CMs to withdraw consent for each type of linkage (as per ALSPAC)

It might also be possible to consider whether we could take a similar approach to the NICOLA study and not seek consent for certain data linkages but this would require a much greater degree of planning and consultation, legal and ethical advice and buy in from data controllers. The latter might be unlikely for particular government departments who are more risk averse or where their preferred legal gateway for sharing requires informed consent.

### New cohort members (for example children or other family members of current cohort members that we might bring into the surveys)

We could take a similar approach to this as for a potential new cohort survey. It would be important to explain to new CMs that we are taking a different approach with them and why and to be able to justify that the approach is a fair one and also how their data would be kept confidential and accessed securely in exactly the same way as for other CMs. CLS would also need to ensure that any privacy notices are very clear so that there is no confusion around which approach applies to which CMs. This approach might then also pave the way for applying the new approach to new linkages for the older CMs as it could be used to demonstrate its success and take up.

### A note on linkage to the records of non-study members

CLS has also set a precedent for obtaining consent for records linkage from e.g. partners of adult cohort members. It would therefore be particularly challenging to move away from this model for existing cohort studies. For new cohort members or a new cohort study it might be possible to handle this differently. For example, this could be handled in a similar way to how data obtained by proxy are dealt with by ONS. In this case ONS puts the onus on the respondent who is instructed to ensure that everyone in the household sees any relevant privacy information, with the possibility for the other household members to ask that any data about them be deleted. If CLS wanted to link records for children of cohort members (where this has never been done before or no previous consent has been sought), CLS could consider doing this on the basis of implicit informed consent of the parents with the proviso that once the children had reached the age where they could consent for themselves they would be given the opportunity to withdraw this consent.

### Other issues to consider

Although we are not using consent as our legal basis, data controllers may need to use the consent obtained by CLS as *their* legal basis under separate legislation. For example, CLS are currently negotiating with HMRC to link some of its records into the CLS cohort data. Under the Commissioners for Revenue and Customs Act one of the circumstances under which HMRC can disclose information is where the person or organisation that the information relates to has given their consent. Furthermore, HMRC might expect our consent to meet the standards of the GDPR consent which requires a positive opt-in. Therefore, the consent might not be deemed valid by the data controller if we move to a model of implicit informed consent for new CMs or any new cohort study. It is also possible to apply a public interest disclosure, but consent, with its own set of challenges, is likely to be the



most straightforward route. Our current discussions with HMRC may reveal further evidence to inform this issue.

## Recommendations

CLS should develop a strategy around its future consent model within a legal and ethical framework and this should be informed by advice from, and consultation with, key stakeholders. In particular, CLS should conduct public and participant engagement exercises and liaise closely with relevant data controllers to gain their agreement to any new approach within the relevant legal and ethical frameworks. Any new approach should also be trialed/piloted and assessed before being fully rolled out. It is critical that any new approach is conducted in such a way that CMs understand how their data are being used and would not be shocked or surprised to find that their data are being used in a certain way. Whilst there are precedents from other organisations for unconsented data linkages (which CLS could consider for a brand new cohort study) those organisations may have unique circumstances that don't apply to the specific context of CLS with its own precedent set for obtaining explicit informed consent. These recommendations further strategy development and consultation are made subject to capacity and funding constraints

## Annex – who we spoke to

Thanks to the following people for taking the time to speak to us. Any errors in interpretation are the author's own.

### ALSPAC – Bristol University

- Andy Boyd – ALSPAC Data Linkage & Information Security Manager & Lead for ESRC-HDRUK Admin Spine Scoping Study

### FRS - DWP

- Donncha Burke - Family Resources Survey Development, Surveys Branch, Department for Work and Pensions

### NICOLA - QUB

- Dermot O'Reilly - Clinical Senior Lecturer, QUB
- Frances Burns – Project Officer NICOLA Study

### Understanding Society – Institute for Social and Economic Research, University of Essex

- Jon Burton – Associate Director, Surveys
- Ray Ware - Information Technology and Security Manager
- Tarek Al Baghal – Research Fellow

### ONS

- Iain Bell - Deputy National Statistician and Director General for Population and Public Policy
- Rose Elliot - Head of Strategic Data Curation, Admin Data Research

- Ben Humberstone - Deputy Director for Health Analysis and Life Events
- Jim Newman - Head of Longitudinal Study Development, Centre for Ageing and Demography, Public Policy Analysis
- Jason Riches – Legal and International Services
- Karen Tingay - A Principal Statistical Methodologist (formerly at SAIL)

#### SAIL

- David Ford - Professor of Health Informatics, Co-Director of SAIL
- Ronan Lyons - Professor of Public Health, Co-Director of SAIL