The effects of placement and order on consent to data linkage in a web survey

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Accepted for publication in the **Journal of Survey Statistics and Methodology**.

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Acknowledgements

The Understanding Society COVID-19 study was funded by the Economic and Social Research Council (ES/K005146/1) and the Health Foundation (2076161). Fieldwork for the web survey was carried out by Ipsos MORI; fieldwork for the telephone survey by Kantar. Understanding Society is an initiative funded by the Economic and Social Research Council (ES/T002611/1) and various Government Departments, with scientific leadership by the Institute for Social and Economic Research, University of Essex. Fieldwork for the annual survey is carried out by Kantar and NatCen. The research data are distributed by the UK Data Service.

Ethics approval for the COVID-19 web and telephone surveys was granted by the University of Essex Ethics Committee (ETH1920-1271). Ethics approval for the March 2021 web survey granted by the NHS Health Research Authority, London – City & East Research Ethics Committee (reference 21/HRA/0644). This study design and analysis was not preregistered.

The Effects of Placement and Order on Consent to Data Linkage in a Web Survey

Abstract

We report on an experiment in a supplemental web survey as part of a longitudinal study in the United Kingdom where we ask survey respondents to consent to two forms of data linkage to health records and to consent to be mailed a serology kit. We varied the placement (early, early in context or late in the survey) and order (linkage first or serology first) of the consent requests. We also examine reasons for consent or non-consent. We find that order of the requests does not make much difference, but making the requests early in the survey significantly increases consent rates over asking them after a series of content-related questions (by 3.4 percentage points) or later in the survey (by 7.2 percentage points). This is consistent with previous research showing that early requests for consent in a survey have a positive effect. The main reason chosen for not consenting related to the personal nature of the information requested.

Statement of Significance

Finding ways to maximize informed consent when several requests are made of survey respondents is increasingly important as surveys add enhancements such as administrative record linkages and biosample requests. We find that the order of three requests (two administrative data linkages and one serology kit) does not affect consent rates, but making the requests early in the survey significantly increases consent rates over asking them in context (after a series of content-related questions) or later in the survey. These findings will help guide the design of such requests in surveys.

The Effects of Placement and Order on Consent to Data Linkage in a Web Survey

1. Introduction

Surveys are increasingly asking respondents to do more than answer questions. They are being asked for consent to link data from administrative records, social media accounts, or transaction data to their survey responses (e.g., Mneimneh et al. 2021; Sakshaug et al. 2012; Sloan et al. 2020). They are being asked to perform additional tasks, such as provide blood or saliva samples (e.g., Dykema et al. 2017; O'Doherty et al. 2014; Sakshaug, Couper and Ofstedal 2010), wear devices or download apps to track their movements or activity (e.g., Bergmann, Franzese and Schrank 2022; Keusch et al. 2019; Kreuter et al. 2020), and so on. These enhancements to surveys may increase the breadth and depth of data available to researchers. With some exceptions, a key requirement is that survey respondents provide informed consent to the additional requests.

In contrast to studies relying on self-selected volunteers, an explicit goal of probability-based sample surveys is to make valid inferences to the broader population. Non-consent may lead to selection biases, threatening the inferential value of these linked datasets. Finding ways to maximize consent without compromising respondent autonomy is important for maximizing the benefit of such survey enhancements for research.

As the demand for more data rises and new sources of digital data become accessible for linkage, survey respondents are increasingly seeing multiple requests for consent. While there is a growing body of research on differences between consenters and non-consenters, and emerging studies on how best to ask respondents for consent, little is known about multiple requests for

linkage consent in a single survey (exceptions are Walzenbach et al. 2022; Beuthner et al. 2023). Understanding how survey respondents react to these requests and how the placement and order of these requests affects consent is an important step in minimizing consent bias when multiple requests are made.

Much of the methodological research on data linkage requests has focused on single consent questions. Asking for consent after a module of questions related to the content of the data to be linked increases consent compared to asking at the end of the questionnaire (Sala et al. 2014), and asking it at the beginning of the survey rather than the end has a positive effect (Eckman and Haas 2017; Jäckle et al. 2023; Sakshaug et al. 2019). This runs counter to much anecdotal advice, which is to make such requests near the end of the survey, giving time to build rapport and trust. In our view, this might be due to respondent fatigue which might diminish the chances of a positive response by the end of a survey.

In the context of multiple consent requests, Beuthner et al. (2023), hypothesized a possible fatigue effect, with respondents consenting to the first one, but then reaching a critical point where they are not willing to share more information. They tested consent to seven different data types (e.g. administrative data, sensor data, social media data, biomeasures) in an opt-in panel. For each type, asking it as the first consent request resulted in higher consent rates than asking it after other consents. Similarly, Walzenbach et al. (2022) explored order effects for five different administrative linkage types. However, they did not find evidence of fatigue (declining rates of consent across the five requests). While they did not find clear patterns in consent rates across the five domains, they conclude that “the order in which these are asked has potential consequences for the consent rates obtained to each of the domains.” These limited studies

suggest that the order of multiple requests matters, but more research is needed to see how consistent these effects are across domains and surveys, and to understand the reasons behind these mixed findings.

Given the limited research on how best to ask multiple consent requests, we designed an experiment to test the effect of placement and order on the rate of consent to multiple requests. We address three research questions:

RQ1. Does the placement of the consent questions affect consent rates?

Consistent with prior research, we expect to find higher rates of consent when the request is made early in the survey rather than later. We also expect that making the request in the context of relevant questions will result in higher consent rates than asking at the end of the survey.

RQ2. Does the order of consent questions affect consent rates? Is there an interaction between order and placement of consent questions?

Here we have no strong expectations, given the mixed evidence in the literature. But no prior study has explored placement and order together for multiple consent requests, so this is a novel contribution to the literature.

RQ3. Why does the placement of consent questions affect consent rates?

This analysis is largely exploratory. Given prior research suggesting that early placement of the requests is beneficial, we seek to understand possible reasons for this somewhat surprising finding.

We describe the study and experimental design in the next section.

2. Methods

The experiment was embedded in the March 2021 COVID-19 study, conducted as part of *Understanding Society*: the UK Household Longitudinal Study. *Understanding Society* is a representative panel study of adults age 16+ in the United Kingdom. The COVID surveys, begun in April 2020, were designed as short (20 minute) frequent web surveys (with a parallel telephone survey in some waves) to measure the impact of the pandemic on panel members. All eligible members of the main *Understanding Society* panel were invited to the COVID surveys, unless they had expressly opted out.

The March 2021 survey, conducted from 1st March to 9th April, was web-only. It included two requests to participants for their permission to link data held about them by the National Health Service (NHS) to their survey responses. We also included an invitation to have a serology kit sent to participants so they could take a blood sample and return it to test for COVID-19 antibodies. We thus consider responses to three (yes/no) consent questions: (1) to link to NHS data, (2) to link to information about cancer and death registrations held by the General Registrar (also part of the NHS), and (3) to allow us to send a serology test kit through the post.

We took the opportunity to implement an experiment around the placement and the order of the three consent questions in the survey. To investigate the effect of placement on consent rates, we randomly allocated participants to be asked these questions (1) early in the survey (after the household relationships module, but before any substantive questions), (2) early-in-context (after the coronavirus vaccination module), or (iii) late in the survey. To examine the effect of order of

the questions, participants were randomly allocated to receive the (1) health linkage questions (NHS and Registrar data) first, or (2) the serology kit question first. Crossing these two factors results in a 3x2 design. The order of the NHS health and register requests was not varied.

A total of 19,280 adults were invited to the March COVID-19 study and 12,680 completed it (65.8% of issued; RR5, see AAPOR, 2023). Invitees were randomly allocated to the experimental conditions in equal proportions prior to fieldwork. There was no difference in participation rates across the groups (Appendix B1). Appendix Table B2 documents the selection of the analysis sample. The outcome for each consent question is coded as 1 if the respondent consented and 0 if they did not consent or did not answer the question (the item non-response rates are <0.2% for all three consent questions).

Following the consent questions respondents were asked a module of follow up questions. For each of the three consent questions, they were asked a closed question about why they had consented/not consented (depending on their answer). They were then asked four true/false questions to test their understanding of the linkage process for health data.

More information about the COVID-19 study, including the sample design, is available in the User Guide (ISER, 2021). The full March 2021 (Wave 8) questionnaire is available at: https://www.understandingsociety.ac.uk/documentation/covid-19/questionnaires. The three consent questions are reproduced in Figures 1, 2, and 3 below. These questions and other items used in our analyses are reproduced in Appendix A.

Figure 1 Health data linkage consent

To complement the information Understanding Society collects, we would like to find out more about your health and treatment from data held by the NHS (in the four countries of the UK). This would allow researchers to investigate how your health and wider circumstances interact. If you agree:

- We would like to link to information the NHS has about your health including:
    - data from hospital care records (including dates of admission and consultations, treatments received, and referrals made)
    - primary care records (including doctor and nurse consultations, diagnoses received, treatments given, and referrals made)
    - data on prescriptions
    - information on COVID-19 infection notification and test results
- We will send NHS data holders your personal identifiers (including name, address, sex and date of birth) so that they can identify the records they have about you.
- The NHS data holders will anonymise your records: they will contain an anonymous identification number but not your personal identifiers (name, address, sex, date of birth or NHS number).
- The anonymised NHS records will be added to the answers you have given in this study.
- We will make the combined anonymous data available for academic and policy research purposes only.
- Access to the data will be restricted and controlled, to make sure that researchers use the information responsibly and safely.
- This will not affect the way that you deal with the NHS in any way.

Please read this leaflet and look at this diagram for further information.
Do you give permission for us to pass your personal identifiers (including name, address, postcode, sex and date of birth) to NHS data holders for this purpose?

1. Yes
2. No

Figure 2 Registry data linkage consent

We would also like to link to information about cancer registrations and the death registration records held by the General Registrars and Public Health bodies in each of the four countries of the UK.

Do you give permission for us to pass your personal identifiers (including name, address, postcode, sex and date of birth) to the NHS data holders for this purpose?

1. Yes
2. No

Figure 3 Serology consent

We would like to understand how many of our participants across the country have developed antibodies against the virus that causes COVID-19.

This is part of a national initiative where other research studies in the UK are also asking their participants to complete the same antibody test. Analysing the information from Understanding Society alongside these other studies will allow a greater understanding of the impact of COVID-19 on people's health and other aspects of life. You can take part even if you have recently been vaccinated.

- If you agree, we would like to send you a small kit which will allow you to take an antibody test.
- The test will involve pricking your finger with a small needle and collecting the blood in a small tube.
- You will then need to send the blood sample back in the pre-paid return envelope that will be included in the pack.
- The laboratory will test your blood for COVID-19 antibodies and, if you want it, you will receive a letter with your result within two weeks of posting your sample back to us.
- If you change your mind after you receive the kit, that is fine – you don't need to do anything.
- All the materials and full instructions will be included in the package.
- Your name and address will be used by Ipsos MORI to send you the kit, but no identifiable information will be sent to the laboratory.
- The results of your test will be added to your survey responses, and the data from the project will be available in **anonymised** format to other researchers, through the UK Data Service or other data repositories. **Anonymised** data and sample results may be shared with other bona fide scientists, including those from the Department of Health and Social Care (DHSC) and Public Health England (PHE).
- If you have certain health or medical conditions you will not be able to take part.

For more information, please click <here>.
To see a video of what is in the kit and what is involved, please click <here>.

May we send you the antibody testing kit through the post?

1. Yes
2. No
3. I have one of the health or medical conditions that means I cannot take part

All analyses are unweighted and do not account for the complex sample design. Our focus is on differences between the experimental conditions, rather than inference to the broader population (see PRICSSA checklist in Appendix D).

3. Results

Overall, 79.6% of respondents consented to receive the serology kits, while 71.2% consented to link to NHS data and 69.6% to register data. Around three-fifths (60.6%) consented to all three requests, while 11.7% declined all three, and the balance (27.6%) consented to some combination of the three. There is a strong overlap of NHS and Register linkage consent (phi^2=0.749), but a weaker overlap between either of those and serology (phi^2=0.130 and 0.117 respectively), suggesting that people think of data linkage and serology requests as different types.

RQ1: Does the placement of the consent question affect consent rates?

A higher proportion of participants consented to each of the requests when they were asked earlier (see Table 1). When the consent questions were asked early, 66.3% of participants agreed to all three requests. This agreement rate was 9 percentage points lower (57.2%) when the requests were made late in the survey. The individual requests show the same pattern, consistent with prior research.

Table 1: Consent to link or send kit, by placement of question

Consent to…	Early	Early, in context	Late	Difference (and p-value) early vs. in-context	Difference (and p-value) early vs. late
NHS data	75.6%	72.2%	68.4%	3.4 (0.001)	7.2 (<0.001)
Register data	74.4%	70.2%	66.5%	4.2 (<0.001)	7.9 (<0.001)
Send serology kit	81.6%	77.9%	78.4%	3.7 (<0.001)	3.2 (0.001)
All three requests	66.3%	60.0%	57.2%	6.3 (<0.001)	9.0 (<0.001)

Notes: P-values from Chi^2 tests. Cell sizes are documented in Appendix Table B3.

Also shown in Table 1 is the effect of asking consent in context (after the coronavirus vaccination module). Prior research would suggest that doing so would provide a rationale for the request, thereby increasing consent rates. We acknowledge that putting the consent questions in context (by definition) changes the placement of the request. Nonetheless, when the consents are asked in context (at around 4 minutes into the survey), the consent rate is significantly *lower* than when it is asked early in the survey before any of the health questions (around 1.7 minutes

in). This suggests that placement is more important than context. There is a caveat: respondents who are asked for consent early in the survey are more likely to break off (4.1%) than those asked early in context (2.7%) or late (2.1%) (See Appendix Table C1). The increase in the break off rate is smaller than the increase in the consent rate, though, so there still a net gain in consent, although there is a slight loss in completed (as opposed to partial) surveys.

The higher rate of consent from the early placement does not come at a cost of reduced understanding of the consent request. There was no difference between the three placement groups in their objective understanding of the linkage request (see Appendix A for the wording of the objective understanding questions).

RQ2: Does the order of consent questions affect consent rates? Is there an interaction between order and placement of consent questions?

Table 2 shows the main effect of order on consent rates. There is no difference in the consent to link to administrative data or to be sent a serology kit if the health consents are asked first, or serology is asked first.

Table 2: Consent to link or send kit, by order of linkage request

Consent to…	Health asked first	Serology asked first	Difference	P-value
NHS data	71.8%	72.3%	-0.5%	0.588
Register data	71.0%	69.7%	1.3%	0.140
Send serology kit	79.0%	79.6%	-0.6%	0.480
All three	60.7%	61.6%	-0.9%	0.333

Notes: P-values from Chi^2 tests. Cell sizes are documented in Appendix Table B4.

To test whether the effect of the placement of the consent request depends on the order of the requests, we test the interaction between the experimental treatments. For each of the consent requests, we estimate a logit model of the probability of consent, regressed on binary indicators for the placement of the request (early/late), the order of the request (health/serology first), and the interaction between the two, to test whether the effect of the early versus late treatment is different when health is asked first compared to when serology is asked first.

Table 3 shows the predicted probabilities of consent estimated from the logit models, for each request, by placement and order (the full models are presented in Appendix Table B5). If serology is asked first, asking consent questions early in the survey yields a consent rate for the NHS question that is 5.1 percentage points higher than asking late. If NHS linkage is asked first, asking early yields a consent rate that is 9.2 percentage points higher than asking late. The difference-in-difference estimate of 4.1 percentage is not significant.

For register data linkage and serology the interactions are not significant. In sum, asking consent early in the survey is always better than asking late; it may also be better to ask NHS data consent first.

Table 3: Interaction effect of placement and order of consent requests on consent

	Early		Late						
	Pr(consent)	S.E.	Pr(consent)	S.E.	Diff.	S.E.	Diff-in-Diff	S.E.	P-value
NHS data									
Serology first	74.5	1.04	69.4	1.11	5.1	1.52			
Health first	76.6	1.00	67.4	1.10	9.2	1.48	4.1	2.12	0.052
Register data									
Serology first	72.5	1.07	65.8	1.14	6.8	1.56			
Health first	76.1	1.00	67.2	1.10	8.9	1.49	2.2	2.16	0.312
Send serology kit									
Serology first	80.8	0.95	78.8	1.00	2.0	1.38			
Health first	82.4	0.91	77.9	0.98	4.4	1.34	2.4	1.92	0.207

Notes: predicted probabilities of consent from logit model of consent, regressed on placement, order and their interaction. Diff-in-Diff: difference in differences between serology first and health first groups.

RQ3. Why does the placement of consent questions affect consent rates?

To examine why respondents are more likely to consent when the request is placed earlier in the questionnaire, we asked respondents about the reasons why they did or did not consent. For both questions, the order of the response options was randomized and respondents could select all answers that applied to them (see Appendix A).

For each consent request (health, registry, serology) and each reason for not consenting, we create an indicator variable with value 1 if the respondent mentioned this reason, and 0 if they did not mention it. For each of these binary indicators we estimate a pooled logit regression of the probability that the respondent mentioned that reason for not consenting, regressed on the placement indicator and a control for the consent question (health, registry, serology). The reason for pooling the three consent questions is that we are interested in identifying general patterns and mechanisms driving consent decisions, rather than in studying reactions to specific consent requests. Standard errors are adjusted for the clustering of observations in respondents using Taylor-series linearization (StataCorp 2021), since each respondent contributes up to three observations, one for each consent request they declined. Appendix Table C2 contains the logit models and Appendix Table C4 the predicted probabilities estimated from the logit models, for each reason for not consenting, by placement of the consent request. Figure 4 graphically represents the predicted probabilities. The most common reason stated is that the request was too personal, the respondent had already shared enough information with the study.

There are significant differences between placement groups for four of the six reasons for not consenting (Figure 4 and Appendix Table C4). Respondents in the late group were significantly more likely to say they were too tired than respondents in either of the other groups; more likely

to say they were unclear why they were being asked this than those in the early group; and more likely to say the information was too personal, they had shared enough information, than respondents in the early in context group. Respondents in the late group were, however, less likely to say they were worried their records might be lost, than respondents in either of the other groups.

Figure 4: Predicted probabilities of each reason for not consenting, by position of linkage request

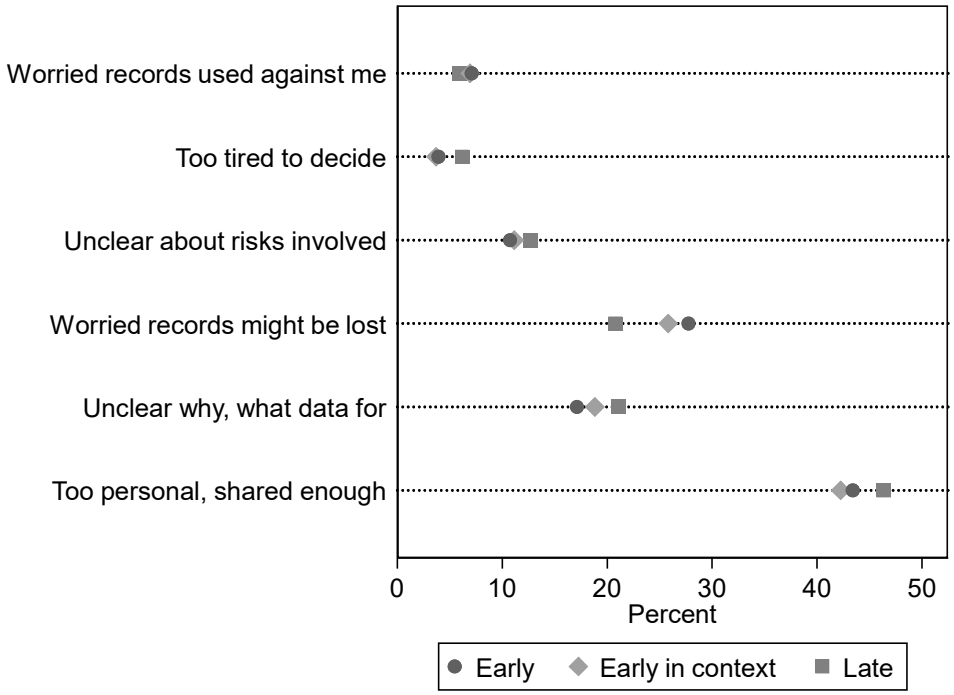
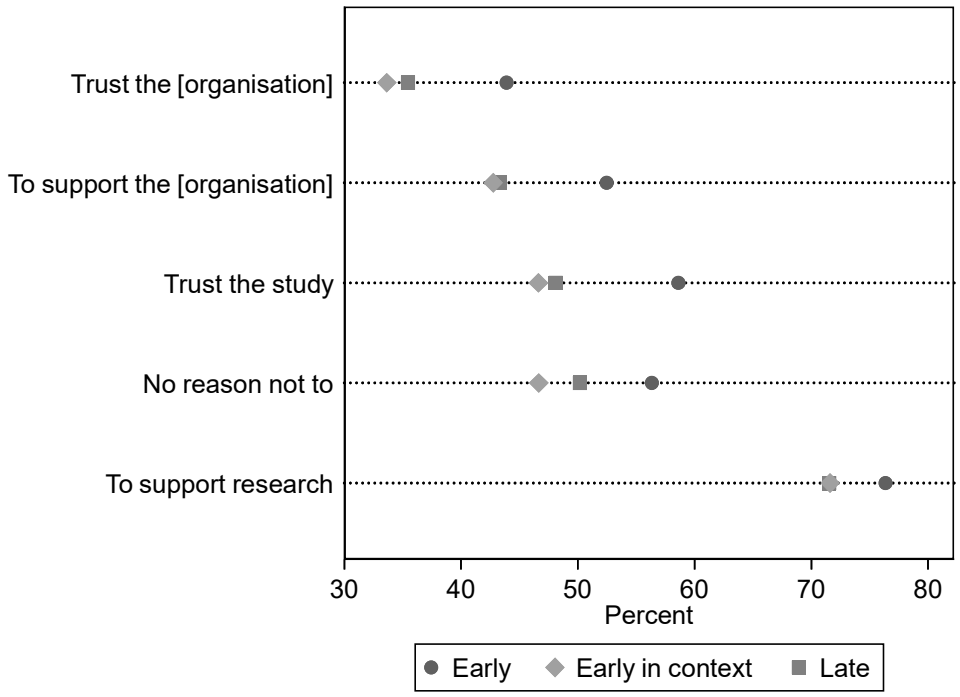


Figure 5 similarly represents the predicted probabilities of respondents in each placement group who gave each of the reasons for consenting. The most common reason given is to support research. For each of the five reasons for consenting, respondents in the early group were significantly more likely to report the reason than respondents in either of the other placement

groups. The early in context and late groups only differ significantly in the percentage who said they did not see any reason not to consent (Appendix Table C5).

Figure 5: Predicted probabilities of each reason for consenting, by position of linkage request



4. Discussion

We manipulated the placement and order of three consent requests in a web survey, to examine the effect on consent rates. We found that the placement of the request has a large effect on consent, with higher consent rates if asked early in the survey. This is consistent with several other recent studies using different modes (e.g. Jäckle et al. 2023 in a face-to-face survey; Sakshaug et al. 2019 in a web and a telephone survey), suggesting this is a robust finding. The finding that earlier placement of consent is associated with higher break-off rates, however, warrants further investigation. We also found that the order in which these requests were made

has no effect on consent rates. This is contrary to Beuthner et al. (2023) who asked seven consents across different domains, but consistent with Walzenbach et al. (2022) who asked five consents and did not find a consistent order effect. Further replications are needed. Our final finding was, contrary to our expectation, putting the request in context – after a module about coronavirus vaccination – *reduced* consent rates compared to asking the questions slightly earlier in the survey, though this was confounded with being slightly later in the survey.

The most frequent reason chosen for not consenting was "too personal, shared enough information". Our finding that this was selected as a reason for non-consent more frequently by those asked late in the survey points to some form of fatigue, as does the placement effect we find. More work is needed to understand the mechanism behind the consistent effect of placement on consent found in the literature.

The most common reason chosen for consenting was "to support research". Our finding that trust – whether in the organization (the National Health Service) or the study (*Understanding Society*) – is selected more often as a reason for consenting by those who got the consent questions early suggests that the prevailing belief that trust is built up over the course of a survey (used as justification for asking questions like these at the end of the survey) is not empirically supported in our study. Again, understanding how trust evolves or changes over the course of a survey is an area ripe for further exploration.

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Appendix

A. Full wording of consent questions, and other questions used in analysis (follow up of non-consenters, objective understanding)

Health data linkage consent

To complement the information Understanding Society collects, we would like to find out more about your health and treatment from data held by the NHS (in the four countries of the UK). This would allow researchers to investigate how your health and wider circumstances interact. If you agree:

- We would like to link to information the NHS has about your health including:
    - data from hospital care records (including dates of admission and consultations, treatments received, and referrals made)
    - primary care records (including doctor and nurse consultations, diagnoses received, treatments given, and referrals made)
    - data on prescriptions
    - information on COVID-19 infection notification and test results
- We will send NHS data holders your personal identifiers (including name, address, sex and date of birth) so that they can identify the records they have about you.
- The NHS data holders will anonymise your records: they will contain an anonymous identification number but not your personal identifiers (name, address, sex, date of birth or NHS number).
- The anonymised NHS records will be added to the answers you have given in this study.

- We will make the combined anonymous data available for academic and policy research purposes only.
- Access to the data will be restricted and controlled, to make sure that researchers use the information responsibly and safely.
- This will not affect the way that you deal with the NHS in any way.

Please read this leaflet and look at this diagram for further information.

Do you give permission for us to pass your personal identifiers (including name, address, postcode, sex and date of birth) to NHS data holders for this purpose?

1. Yes
2. No

(Link to leaflet: https://www.understandingsociety.ac.uk/participants/health-records and link to diagram: https://www.understandingsociety.ac.uk/participants/data-linkage)

Registry data linkage consent

We would also like to link to information about cancer registrations and the death registration records held by the General Registrars and Public Health bodies in each of the four countries of the UK.

Do you give permission for us to pass your personal identifiers (including name, address, postcode, sex and date of birth) to the NHS data holders for this purpose?

1. Yes
2. No

Serology consent

We would like to understand how many of our participants across the country have developed antibodies against the virus that causes COVID-19.

This is part of a national initiative where other research studies in the UK are also asking their participants to complete the same antibody test. Analysing the information from Understanding Society alongside these other studies will allow a greater understanding of the impact of COVID-19 on people's health and other aspects of life. You can take part even if you have recently been vaccinated.

- If you agree, we would like to send you a small kit which will allow you to take an antibody test.

- The test will involve pricking your finger with a small needle and collecting the blood in a small tube.
- You will then need to send the blood sample back in the pre-paid return envelope that will be included in the pack.
- The laboratory will test your blood for COVID-19 antibodies and, if you want it, you will receive a letter with your result within two weeks of posting your sample back to us.
- If you change your mind after you receive the kit, that is fine – you don't need to do anything.
- All the materials and full instructions will be included in the package.
- Your name and address will be used by Ipsos MORI to send you the kit, but no identifiable information will be sent to the laboratory.
- The results of your test will be added to your survey responses, and the data from the project will be available in **anonymised** format to other researchers, through the UK Data Service or other data repositories. **Anonymised** data and sample results may be shared with other bona fide scientists, including those from the Department of Health and Social Care (DHSC) and Public Health England (PHE).
- If you have certain health or medical conditions you will not be able to take part.

For more information, please click <here>.

To see a video of what is in the kit and what is involved, please click <here>.

May we send you the antibody testing kit through the post?

1. Yes

2. No
3. I have one of the health or medical conditions that means I cannot take part

(Link for additional information: www.understandingsociety.ac.uk/participants/serology

Link to video: https://www.youtube.com/watch?v=okTozcGMDlU)

Why not consented to health data linkage

Can you tell us why you did **not** give us permission to add records collected by the National Health Service, or NHS, to the answers you have given in this study?

Please select all that apply.

1. Too personal, I've shared enough information with this survey
2. I am unclear about the risks involved / don't understand what would be done
3. I'm worried that my health records might be used against me
4. I'm worried that my health records might be lost / hacked / stolen
5. I was too tired / didn't want to make a decision
6. Unclear why I am being asked for this / what the data would be used for
7. The NHS doesn't have any data about me
8. Other reason

(Order of items 1-6 randomized to minimize response order effects.)

Why not consented to Registry data linkage

Can you tell us why you did **not** give us permission to add records held by the General Registrars and Public Health bodies to the answers you have given in this study?

Please select all that apply.

1. Too personal, I've shared enough information with this survey
2. I am unclear about the risks involved / don't understand what would be done
3. I'm worried that my records might be used against me
4. I'm worried that my records might be lost / hacked / stolen
5. I was too tired / didn't want to make a decision
6. Unclear why I am being asked for this / what the data would be used for
7. The General Registrars and Public Health bodies don't have any data about me
8. Other reason

(Order of items 1-6 randomized to minimize response order effects.)

Why not consented to serology

Can you tell us why you did **not** give permission for us to send you the COVID-19 antibody testing kit through the post?

Please select all that apply.

1. Too personal, I've shared enough information with this survey
2. I am unclear about the risks involved / don't understand what would be done
3. I'm worried that my COVID-19 test result might be used against me
4. I'm worried that my COVID-19 test result might be lost / hacked / stolen
5. I was too tired / didn't want to make a decision
6. Unclear why I am being asked for this / what the data would be used for
7. I don't want to know whether I have had COVID-19
8. I don't want to prick my finger
9. Takes too much time
10. Other reason

(Order of items 1-6 randomized to minimize response order effects. Order of items 7-9 also randomized)

Why consented to health data linkage

Can you tell us why you gave us permission to add records collected by the National Health Service, or NHS, to the answers you have given in this study?

Please select all that apply.

1. I trust the study not to mishandle information
2. I trust the NHS
3. To support the NHS
4. To support research for the greater good of society
5. I didn't see any reason not to / I have nothing to hide
6. Other reason

(Order of items 1-5 randomized to minimize response order effects.)

Why consented to Registry data linkage

Can you tell us why you gave us permission to add records held by the General Registrars and Public Health bodies to the answers you have given in this study?

Please select all that apply.

1. I trust the study not to mishandle information
2. I trust the General Registrars and Public Health bodies
3. To support the General Registrars and Public Health bodies
4. To support research for the greater good of society
5. I didn't see any reason not to / I have nothing to hide
6. Other reason

(Order of items 1-5 randomized to minimize response order effects.)

Why consented to serology

Can you tell us why you gave permission for us to send you the COVID-19 antibody testing kit through the post?

Please select all that apply.

1. I trust the study not to mishandle information
2. I trust the NHS
3. To support the NHS
4. To support research for the greater good of society
5. I didn't see any reason not to / I have nothing to hide
6. I wanted to know if I have had COVID-19
7. Other reason

(Order of items 1-5 randomized to minimize response order effects.)

Objective understanding of health data linkage

To help us understand whether the explanation we gave you about linking NHS data and your answers to this study was clear or unclear, here are a few statements about how the linkage is done. Please specify whether you think each of the statements is true or false.

Please select one answer per row.

The NHS will be able to see the answers you have given in this study. [FALSE]

The NHS data holder will send us the information they have about you. [TRUE]

Your name, address, sex, and date of birth will be saved with the linked data. [FALSE]

We will send your name, address, sex, and date of birth to the NHS data holder. [TRUE]

B. Background tables

Table B1: Participation rates by experimental group

	Non-response	Response	Response rate	n
Early, health-first	883	1,846	67.6%	2,729
Early, serology-first	928	1,772	65.6%	2,700
Early-in-context, health-first	877	1,843	67.8%	2,720
Early-in-context, serology-first	910	1,808	66.5%	2,718
Late, health-first	887	1,848	67.6%	2,735
Late, serology-first	949	1,761	65.0%	2,710
Total	5,434	10,878		16,312

Pearson $chi^2(5) = 8.4253$ Pr = 0.134

Table B2: Analysis sample

	N	Analysis sample (N)
Issued sample	19,280	
- Non-respondents	-6,600	
- Treatment group 7*	-1,802	
Eligible respondents	10,878	
Health consent question	-121 break-offs before Q	10,757
Registrar consent question	-127 break-offs before Q	10,751

Serology test kit question	-185 break-offs before Q -208 ineligible due to health condition	10,485
Asked at least one consent question	10,771	

*Note: Respondents allocated to a 7th treatment group that is not relevant to our research questions are dropped from our analysis sample (n=1,802).

Table B3: Cell sizes for Table 1

	Early	Early, in context	Late	Total
NHS data	3,586	3,637	3,534	10,757
Register data	3,580	3,636	3,535	10,751
Send serology kit	3,487	3,550	3,448	10,485
All three	3,473	3,548	3,447	10,468

Table B4: Cell sizes for Table 2

	Health asked first	Serology asked first	Total
NHS data	5,489	5,268	10,757
Register data	5,485	5,266	10,751
Send serology kit	5,348	5,137	10,485
All three	5,347	5,121	10,468

Table B5: Full models with coefficients and fit statistics for tests of interaction of placement and order

Models estimated: $\ln(\Pr(\text{Consent}=1|X)) = \beta_0 + \beta_1\text{Order} + \beta_2\text{Placement} + \beta_3(\text{Order x Placement})$

	NHS data		Register data		Send serology kit	
	b/(se)	p	b/(se)	p	b/(se)	p
(Omitted category: Serology first)	.	.	.	.	.	.
Health first	-0.095	0.190	0.064	0.370	-0.053	0.526
	(0.072)		(0.071)		(0.083)	
(Omitted category: Late position)	.	.	.	.	.	.
Early position	0.253	0.001	0.318	0.000	0.125	0.144
	(0.076)		(0.074)		(0.086)	
Health first x Early	0.207	0.052	0.125	0.231	0.155	0.199
	(0.106)		(0.105)		(0.120)	
Constant	0.820	0.000	0.653	0.000	1.314	0.000
	(0.052)		(0.051)		(0.060)	
AIC	8402.7		8583.0		6935.3	
N	7,120		7,115		6,935	

C. Full tables of results

Table C1: Break off rates by consent placement

	N	Break off before closing module (%)	Break off in consent module (%)
Early	3,618	4.1[AB]	2.6[AB]
Early in context	3,651	2.7[A]	1.0[AC]
Late	3,609	2.1[B]	0.3[BC]
Total	10,878	3.0	1.3
		Pearson $Chi^2(2) = 24.61$, P<0.001	Pearson $Chi^2(2) = 78.40$, P<0.001

Notes: Break off in the consent module includes breakoffs in the health consent module, the serology consent module, or the module of consent follow up questions. [A B C] denote break off rates that are significantly different from each other in pairwise Pearson Chi^2 tests ($P \leq 0.001$).

Table C2: Full models for Figure 1, reasons for not consenting

Models estimated: $\ln(\Pr(\text{Reason}=1)|X) = \beta_0 + \beta_1(\text{Consent domain}) + \beta_2(\text{Placement})$. Standard errors estimated using Taylor-series linearization (also referred to as Huber/White/sandwich estimator) to account for clustering of observations in respondents (StataCorp 2021).

	Used against me		Too tired		Risk uncertain		Lost records		Unclear why		Too personal	
	b/se	p	b/se	p	b/se	p	b/se	p	b/se	p	b/se	p
(Omitted: Health)	.		.		.		.		.		.	
Registry	-0.007	0.882	0.074	0.239	0.113	0.003	-0.074	0.002	0.134	0.000	-0.130	0.000
	(0.045)		(0.063)		(0.038)		(0.024)		(0.033)		(0.023)	
Serology	-1.172	0.000	0.033	0.772	-0.927	0.000	-1.630	0.000	-0.786	0.000	-0.769	0.000
	(0.130)		(0.116)		(0.098)		(0.076)		(0.074)		(0.049)	
(Omitted: Early)	.		.		.		.		.		.	
Early in context	-0.023	0.881	-0.064	0.743	0.043	0.724	-0.104	0.257	0.118	0.238	-0.049	0.546
	(0.154)		(0.196)		(0.121)		(0.092)		(0.100)		(0.081)	
Late	-0.193	0.210	0.474	0.008	0.190	0.101	-0.401	0.000	0.259	0.007	0.122	0.120
	(0.154)		(0.179)		(0.116)		(0.092)		(0.096)		(0.078)	

Constant	-2.362	0.000	-3.233	0.000	-1.987	0.000	-0.620	0.000	-1.469	0.000	-0.025	0.682
	(0.117)		(0.152)		(0.093)		(0.068)		(0.078)		(0.062)	
AIC	3961.1		3114.6		5838.9		8725.1		7951.3		11197.4	
N	8301		8301		8301		8301		8301		8301	

Notes: Coefficient estimates from six separate logit models, represented in the columns. The 8,301 observations are clustered in 4,174 respondents who did not consent to at least one of the requests and answered the question about reasons for not consenting. For the first model, the dependent variable is the probability that the respondent stated “Worried records used against me” as a reason for not consenting. For the second model the dependent variable is the probability that the respondent stated “Too tired” as a reason, etc.

Table C3: Full models for Figure 4, reasons for consenting

Models estimated: $\ln(\Pr(\text{Reason}=1)|X) = \beta_0 + \beta_1(\text{Consent domain}) + \beta_2(\text{Placement})$. Standard errors estimated using Taylor-series linearization (also referred to as Huber/White/sandwich estimator) to account for clustering of observations in respondents (Stata Corp 2021).

	Trust organisations		Support organisations		Trust study		Why not		Support research	
	b/se	p	b/se	p	b/se	p	b/se	p	b/se	p
(Omitted: Health)	.		.		.		.		.	
Registry	-0.297	0.000	-0.488	0.000	0.018	0.220	0.037	0.009	-0.031	0.112
	(0.018)		(0.020)		(0.015)		(0.014)		(0.020)	
Serology	-0.321	0.000	-0.231	0.000	-0.453	0.000	-0.306	0.000	-0.037	0.157
	(0.019)		(0.020)		(0.020)		(0.021)		(0.026)	
(Omitted: Early)	.		.		.		.		.	
Early in context	-0.436	0.000	-0.395	0.000	-0.489	0.000	-0.391	0.000	-0.247	0.000
	(0.050)		(0.047)		(0.049)		(0.048)		(0.052)	
Late	-0.356	0.000	-0.372	0.000	-0.429	0.000	-0.249	0.000	-0.251	0.000
	(0.050)		(0.048)		(0.050)		(0.049)		(0.053)	

Constant	-0.038	0.281	0.337	0.000	0.505	0.000	0.352	0.000	1.195	0.000
	(0.035)		(0.035)		(0.036)		(0.036)		(0.040)	
AIC	30997.2		32200.5		32165.9		32433.8		27377.4	
N	23613		23613		23613		23613		23613	

Notes: Coefficient estimates from five separate logit models, represented in the columns. The 23,613 observations nested are clustered in 9,416 respondents who consented to at least one of the requests and answered the question about reasons for consenting

Table C4: Predicted probabilities of reasons for not consenting, by consent placement

Reason for not consenting	Consent position	Predicted Probability	S.E.	95% C.I.	
Worried records used against me	Early	7.1	0.74	5.6	8.5
	Early in context	6.9	0.67	5.6	8.3
	Late	5.9	0.57	4.8	7.1
Too tired	Early	3.9 [A]	0.55	2.9	5.0
	Early in context	3.7 [B]	0.47	2.8	4.6
	Late	6.2 [AB]	0.61	5.0	7.4
Unclear about risks involved	Early	10.7	0.83	9.1	12.4
	Early in context	11.2	0.81	9.6	12.7
	Late	12.7	0.82	11.1	14.3
Worried records might be lost	Early	27.7 [A]	1.25	25.3	30.2
	Early in context	25.8 [B]	1.14	23.6	28.1
	Late	20.8 [AB]	1.00	18.8	22.7
Unclear why	Early	17.1 [A]	1.05	15.1	19.2
	Early in context	18.8	0.99	16.9	20.8

	Late	21.0 [A]	0.98	19.1	23.0
Too personal, shared enough	Early	43.4	1.42	40.6	46.2
	Early in context	42.2 [A]	1.31	39.7	44.8
	Late	46.3 [A]	1.25	43.9	48.8

Notes: Predicted probabilities calculated from the logit estimates in Appendix Table C3. [A B] denote predicted probabilities that are significantly different at the level $p<0.05$, based on pairwise z-tests.

Table C5: Predicted probabilities of reason for consenting, by consent placement

Reason for consenting	Consent position	Predicted Probability	S.E.	95% C.I.	
Trust the NHS / General Registrars and Public Health bodies	Early	43.9 [AB]	0.83	42.3	45.5
	Early in context	33.6 [A]	0.81	32.1	35.2
	Late	35.5 [B]	0.84	33.8	37.1
To support the NHS / General Registrars and Public Health bodies	Early	52.5 [AB]	0.81	50.9	54.1
	Early in context	42.8 [A]	0.82	41.1	44.4
	Late	43.3 [B]	0.84	41.7	45.0
Trust the study not to mishandle information	Early	58.6 [AB]	0.83	57.0	60.2
	Early in context	46.6 [A]	0.85	45.0	48.3
	Late	48.1 [B]	0.88	46.4	49.8
Didn't see any reason not to / nothing to hide	Early	56.3 [AB]	0.83	54.7	58.0
	Early in context	46.7 [AC]	0.84	45.0	48.3
	Late	50.2 [BC]	0.87	48.5	51.9
To support research for the greater good of society	Early	76.4 [AB]	0.68	75.0	77.7
	Early in context	71.6 [A]	0.73	70.2	73.0

	Late	71.5 [B]	0.76	70.1	73.0

Notes: Predicted probabilities calculated from the logit estimates in Appendix Table C3. [A B C] denote predicted probabilities that are significantly different at the level $p<0.05$, based on pairwise z-tests.

Appendix Table D: PRICSSA Checklist

PRICSSA: Preferred Reporting Items for Complex Sample Survey Analysis (Seidenberg, Moser and West, 2023)

PRICSSA item	Description
1.1 Data collection dates	March 1− April 9, 2021
1.2 Data collection modes	Online
1.3 Target population	Adults age 16+ in the United Kingdom who participated in the Understanding Society panel study and who had not opted out.
1.4 Sample design	Understanding Society is a panel survey using a complex stratified multistage probability cluster design (ISER, 2021)
1.5 Survey response rate(s)	65.8% using RR5 (see AAPOR, 2023)
2.1 Missingness rates	Rates of missingness are <0.2% for all three consent questions
2.2 Observation deletion	Observations with missing data on the consent questions were deleted
2.3 Sample sizes	10,771 responses were used in the analyses. Sample sizes are reported in Appendix Tables B1 and B2

PRICSSA item	Description
2.4 Confidence intervals/standard errors	Simple random sampling (SRS) standard errors are reported
2.5 Weighting	All analyses are unweighted
2.6 Variance estimation	Simple random sampling (SRS) variance estimates were used
2.7 Subpopulation analysis	Not applicable
2.8 Suppression rules	None
2.9 Software and code	StataSE version 15. Code enabling replication of the analyses can be found at https://osf.io/g8t7d/?view_only=bfb7232bf2b7472fbc1bde12a4fc26ff
2.10 Singleton problem (as needed)	Not applicable
2.11 Public/restricted data (as needed)	Public use version

PRICSSA item	Description
2.12 Embedded experiments (as needed)	The embedded experiments are the focus of these analyses