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**Understanding Society Microbiome Study:
Findings from qualitative research into the clarity, completeness
and accessibility of prospective participant materials for the
Wave 16 microbiome sample collection**

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Non-technical summary

To support the roll out of the microbiome collection under the Wave 16 of *Understanding Society: UK Household Longitudinal Study*, ISER commissioned Verian (formerly Kantar Public) to conduct in-depth interviews with *Understanding Society* participants to gather feedback on prospective survey materials. The specific aims of this research were to investigate whether participants understand what is being asked from them (clarity), whether they feel the information being provided is sufficient (completeness), whether they think they can do it (accessibility) and understand what additional information would make it easier for them to understand (have any recommendations for improvement). The study comprised 25 in-depth Zoom interviews. Participants were recruited from the *Understanding Society* Innovation Panel Sample following an opt-out exercise.

The research has highlighted some changes and recommendations that would improve the clarity, completeness and accessibility of the prospective participant materials. The specific changes were related to highlighting the purpose and wider benefits of the study throughout the documentation, streamlining the number of materials used, considering alternative methods of returning the sample, catering for differing needs (e.g. participants with EAL, visual impairments etc), and ensuring consistent design of materials used.

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Abstract: To support the roll out of the microbiome sample collection under the Wave 16 of *Understanding Society: UK Household Longitudinal Study*, ISER commissioned Verian (formerly Kantar Public) to conduct in-depth interviews with *Understanding Society* participants to gather feedback on prospective survey materials. The specific aims of this research included investigating clarity, completeness and accessibility of the information being provided in the participant materials and identify scope for improvement.

Generally, there was a high level of clarity, completeness and accessibility reported in relation to the participant documents used. There were also a number of specific changes recommended to the materials in order to them easier to understand. Findings from this study have been used by the research and study design teams at ISER to inform the design of study materials and protocols.

Keywords: sample collection, survey, participant materials

JEL classification:

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1. Introduction

Background

Understanding Society is a longitudinal study that follows the lives of individuals within 40,000 households in England, Scotland, Wales and Northern Ireland. It is an internationally recognised study led by the Institute for Social and Economic Research (ISER) at the University of Essex, and it is the largest study of its kind in the world. The overall purpose of *Understanding Society* is to provide high quality longitudinal data on topics such as health, work, education, income, family and social life. It provides vital evidence for scientists and policymakers on the causes and consequences of deep-rooted social problems.

ISER have already started to collect biomeasures (such as blood samples and body measurements) from participants, which has enabled many genetic and biomarker publications and will support cutting edge research in the biosocial research arena. ISER would like to collect a wider range of biological samples in future waves of the study – in particular, the collection of poo samples from the general population for microbiome analysis has the potential to provide novel and useful biosocial insight. Previous qualitative research by Verian (formerly Kantar Public) evaluated the acceptability of providing a sample of this nature. This research built on those insights and aimed to test prospective participant materials.

Aims

To support the roll out of the microbiome collection under the Wave 16 pilot, ISER commissioned Verian to conduct in depth interviews with *Understanding Society* participants to gather feedback on prospective survey materials. The specific aims of this research were to:

- Investigate whether participants understand what is being asked from them (clarity)
- Investigate whether participants feel the information being provided is sufficient (completeness)
- Investigate whether participants think they can do it (accessibility)
- Understand what additional information would make it easier for them to understand (have any recommendations for improvement)

The survey material to be tested included 8 documents:

- STIM A (document 1): Invitation letter UK Household Longitudinal Study Interview
- STIM B (document 2): Participant information sheet about health measures
- STIM C (document 3): Participant information sheet about microbiome sample
- STIM D (document 4): Consent question
- STIM E (document 5): Cover letter for sample collection kit
- STIM F (document 6): ISER instructions for sample collection kit
- STIM G (document 7): Supplier instructions for sample collection kit

- STIM H (document 8): Sample collection package – Questionnaire

Findings from this study have been used by the research and study design teams to inform the design of study materials and protocols for Wave 16.

Research methodology

This research comprised 25 in-depth online qualitative interviews via Zoom, which were designed to provide a forum to have detailed conversations about multiple documents with individuals from a wide range of different backgrounds and contexts. This allowed the research team to unpack the processes that participants use to engage with the study material. Interviews were conducted via video call, where participants could feel comfortable providing feedback from a familiar environment of their choosing. Interviews lasted approximately 45 minutes and participants received a £40 voucher or PayPal transfer in recognition of their time and to encourage participation. Consent was gained verbally. Fieldwork took place in February and March of 2023.

The interviews were semi-structured to facilitate a conversational interview style that put participants at ease. It also allowed space for spontaneous participant responses, alongside gathering the evidence needed to address the research questions effectively. Interviewers used a discussion guide (see Appendix A) and eight stimulus materials (Appendix B, Stim A – H) used during the interviews, and were shared with the participant in advance of their interview.

It is worth noting that there was a difference in the way that STIM A – D were delivered for this research, and how they would be used in *Understanding Society* interviews under normal conditions. To accommodate this research, which was undertaken via online qualitative interviews, STIM A, STIM B, STIM C and STIM D were sent via email to the participant with their Zoom invite. However when taking part in real *Understanding Society* interviews, participants would receive printed copies of STIM A and STIM B posted to their address. STIM C would also be in the form of a printed leaflet, but this would be handed over to participants by interviewers or linked to online. STIM D would be read out by the interviewer or would be viewed online.

STIM E, STIM F, STIM G and STIM H were delivered in a very similar way to how they would be used. They were printed and posted to the participant's home address in a package which also contained a stool sample kit, two toilet collection accessories, a return envelope and a pair of recyclable protective gloves.¹ This was done in order to provide a realistic test-environment which gave participants a clearer understanding of the context and sequence in which the documents would be viewed. Participants were not required to use the kit or provide a poo sample as part of this research.

¹ This was facilitated by Greens, a third-party supplier, who printed and assembled the packages. All but one of the participants successfully received their parcel before their interview. Only one participant, whose parcel did not arrive in time, viewed STIM E, STIM F, STIM G and STIM H online.

They were also not required to read the materials or open the package in advance of the interview but were invited to.²

Sampling

The sample for this study was drawn from *Understanding Society Innovation Panel*, a sample of 1,750 individuals which has already been used by *Understanding Society* to pilot innovative fieldwork procedures, methodologies and questionnaires. We selected 400 individuals from the eligible sample who were contacted with an opt-out email, inviting them to take part. Of those who did not opt out, we then recruited 25 participants according to the requirements of the agreed sample frame.

The sample frame for this research sought to cover a mixture of ages, genders and locations, with a particular focus on getting input from a range of ethnicities as this had previously been identified as underrepresented in previous work around acceptability of poo samples and medical research generally. There was also a need to recruit a number of people who have EAL (English as an Additional Language), in order to test that the documents were clear and easy to understand across diverse groups with different needs. An overview of the qualitative sample can be found in Appendix C, but is summarised in terms of gender, age and location below:

² In practice, the majority of participants opted to look over the materials and had opened the package in advance of the interview.

Table 1 Achieved sample summary

TOTAL	
25 DEPTHS	25
PRIMARY QUOTAS	
MALES AGED	
Males 18-24	2
Males 25-34	4
Males 35-44	3
Males 45-54	2
Males 55+	2
FEMALES AGED	
Females 18-24	3
Females 25-34	3
Females 35-44	2
Females 45-54	2
Females 55+	2
SECONDARY QUOTAS	
LOCATION	
London	6
South East	4
South West	2
West Midlands	1
East Midlands	2
Yorkshire and the Humber	0
North West	6
North East	1
Scotland	2
Wales	1
Northern Ireland	0

The sample, though reflective of a range of ages, genders and locations, did contain 5 participants who had a medical background: either those who worked in nursing, care homes, mental health roles or as pharmacists. However, this did not affect the usefulness of the research, as these groups often offered insight into the needs of the harder-to-reach groups that they worked with, as well as their own thoughts, but may be worth bearing in mind in future studies.

Analysis

The analysis process was iterative, drawing from interview audio recordings, interview notes, and researcher debriefs. A matrix mapping framework technique was used, whereby data is coded and systematically summarised into an analytical framework organised thematically. The framework was developed to reflect the research objectives and according to the themes emerging from the initial debrief session and data coding. The completed framework allowed us to easily review and sort the data by theme, by case and across groups of participants ensuring a thorough review of the data. We then interpreted the data by finding patterns and associations within the data, while also undertaking sub-group analysis. Researcher analysis sessions were also used to support interpretation of the data, during which the team came together to discuss, validate and test emerging themes and insights.

Reading this report

This report draws on findings from qualitative research. Due to the flexible and open nature of qualitative methods, this research does not seek to quantify or be generalisable to the overall population but reflects a range of attitudes and preferences of the participants we spoke to. Verbatim quotes are used throughout to illustrate findings. To provide additional detail, quotes are labelled with gender, age, location and ethnicity. Please note that these classifications are taken from the sample frame (see Appendix C). Some quotes also include labels showing whether the participant has English as an Additional Language (EAL). For example: *"Quote."* (Male, 25-34, London, Ethnicity, EAL).

2. Findings and recommendations

In the following sections, the findings for each document are shared in succession. They are split into part 1: covering documents A, B, C and D (which the participants viewed online); and part 2: covering documents E, F, G and H (which participants viewed as printed documents). Throughout, we cover the three research questions: whether participants understood what was being asked of them; whether participants felt that the information being provided was sufficient; whether participants felt that they would be able to complete the process based on the information provided; and what additional information would make it easier for them to understand. Before we discuss the documents, there are some observations that are relevant across all the prospective participant materials.

Participant typologies

It is worth noting that there were no significant differences in participants understanding and opinion across genders, locations, ethnicities, ages or other demographic variables. Instead, participants can be clearly grouped into those who preferred to skim-read (skim-readers) and those who engaged with the materials in depth (non-skim-readers). This distinction was found to offer valuable insight into how the materials resonated with different reader groups, and how best to accommodate to a wide range of participants. Throughout the analysis, therefore, we discuss these two participant typologies.

Document order

When reflecting on the prospective participant materials as a whole, participants felt the documents (STIM A – H) followed a logical flow and were happy with the order they were given in. One participant felt the documents in the sample collection kit could be better labelled to ensure participants were reading them in the intended order. They said:

*“There’s a lot of documents, am I reading the right thing in the right order?”
(Female, 35-44, South East, Chinese or other ethnic group)*

In regard to which documents are provided in the sample collection kit, one participant suggested it might also be helpful to include one or both informational leaflets (STIM B and STIM C), to remind participants of the study’s purpose and aims.

“I think the document C that explains what the research is used for I would probably include in this pack as well as in the initial and just to remind people of why it’s being used and what it’s going to be used for... probably just a reminder if nothing else.” (Male, 25-34, West Midlands, Any other white background)

Varied engagement with the documents

Participants tended to engage differently with each document provided to them. The most important information participants wanted to know was about the study’s purpose, aims and exactly what they would need to do to take part. For the majority of participants, the instructional documents (STIM F and STIM G) were the most

important to them as they included step-by-step instructions for collecting the sample.

Participants in the skim-reader group, and those who had carried out a poo sample before, engaged less with the informational leaflets and were happy with scanning over the information rather than reading in detail. They acknowledged that some participants, particularly those who had never collected a poo sample before, would benefit from the level of detail provided to them.

"Because I've done it before, it's self-explanatory...some people like to read into depth of why you're doing it." (Female, 35-44, Greater London, Mixed - White and Asian)

"I have a good idea about what to expect. Maybe someone doing it for the first time may need a lot of reading." (Male, 55+, Greater London, Asian or Asian British – Indian, EAL)

On the whole, the amount of information provided in the informational sheets is sufficient to accommodate to a wide range of participants. Participants felt having more information was far better than having insufficient information:

"I don't think there's anything such as too much information." (Male, 35-44, North East, Any other mixed background)

"It's better more information than less anyway...we choose what we read." (Female, 25-34, North West, Asian or Asian British - Pakistani)

Financial incentive

Two participants felt the £5 gift voucher was insufficient for what they were being asked to do.

"I'd probably need a little bit more incentive...it just seems a bit more of a psychological barrier...for an extra few quid I'd probably do it." (Male, 18-24, North West, White - British)

"The only thing that stands out is, you know that five-pound gift voucher sign, I think it's a bit big, as in like it's not really enough to like be so proud of exactly." (Female, 35-44, South East, Chinese or other ethnic group)

One of the participants suggested amending the value of the incentives for completing an online interview and collecting the poo sample. For example, instead of £20 for completing the interview and £5 for collecting the sample, offering £15 for the interview and £10 for the sample might encourage more participants to complete both activities, rather than just one.

Document accessibility

Some participants raised concerns about the accessibility of taking part in the study generally, both in regard to engaging with the informational sheets and collecting the poo sample. In some of the documents, particularly STIM B, STIM C and STIM G, the small font sizes could make it difficult for some participants to engage with the information. One participant suggested it would be helpful to have an option for participants to request materials with a larger font.

Several participants also felt that language could be a barrier to taking part in this study. Participants identified that individuals with EAL may find difficulty with engaging with the documents. Some suggested offering multi-lingual packs on request or translator support to better engage participants with EAL.

Accessibility of taking the sample

Additionally, some participants felt the process of collecting the sample may be difficult for those with mobility issues. To support participants with mobility issues, offering physical assistance from a healthcare worker may encourage them to take part.

“Sometimes the plastic on the testing kits might just be quite difficult for them to handle, especially when you’re trying to open things.” (Female, 35-44, Greater London, Mixed – White and Asian)

“The physical part of actually giving a sample, you’ve got to be quite steady on your feet.” (Female, 55+, Wales, Any other mixed background)

There was a suggestion that including an accessibility question in the *Understanding Society* survey could be used to identify accessibility needs and help *Understanding Society* to deliver additional support for those that would like to take part.

3. Prospective participant materials A, B, C and D

In this section, we report on participant's views and feedback on the documents they viewed online (STIM A, B, C and D). The findings are supported by quotes from our conversations with the participants. Before we discuss each document individually it is worth noting a few general points:

Design

Overall, there was very positive feedback about the design of these documents – particularly the leaflets (STIM B and STIM C). Whilst there are some feedback points detailed below, they were seen by the majority of participants as being professional, informative and appealing.

Duplication

Some participants reflected on this first set of documents and queried whether it was necessary to have both leaflets (STIM B and STIM C) as they felt there was some duplication. They were not sure whether they would receive both, or just one, if they agreed to take part in the microbiome collection. However, this feedback should be taken in light of the fact that in practice *Understanding Society* participants would only receive STIM B alongside STIM A prior to their actual interview. At the interview, they would then be given STIM C by the interviewer. It is therefore unlikely that participants would immediately recall the information provided in STIM B when reading STIM C, as there would be a gap in between receiving each document.

Perceptions of clarity

Participants tended to associate 'clarity' with having fewer words on the page. As such, the leaflets (STIM B and STIM C) although generally positively viewed, were the documents with the most variation in feedback.

STIM A (document 1): Invitation letter UK Household Longitudinal Study Interview

Clarity: did participants understand what was being asked of them?

Overall, participants felt the invitation letter was concise and to the point, providing an overview of the health measures expected from them. Participants recognised the *Understanding Society* branding and felt the letter was consistent with previous communications they had received. Some participants had previously provided blood pressure or body measurements to *Understanding Society* and others had collected poo samples for medical tests, so they felt familiar and comfortable with what they were being asked to do.

"I've had to do it all before...absolutely fine." (Male, 35-44, North West, White – British)

Completeness: did participants feel that the information being provided was sufficient?

Most participants felt the information provided in the letter was sufficient and addressed their questions and concerns at this initial stage.

"It laid out everything I needed to know in a clear way." (Male, 18-24, Scotland, Asian or Asian British - Indian)

Participants in the skim-reader group focused on specific details, notably the purpose of the research, what the research hopes to achieve and what participants would have to do in practice.

"With stuff like this, I tend to skim read anyway. So, as long as all the important parts are in there...that's all for me that I need." (Male, 25-34, North West, White – British)

However, some participants felt the overall purpose of the study could be made clearer. In particular, they wanted to know what microbiome sampling aimed to achieve and what the wider impact of the study would be. This was especially prevalent among the skim-readers as this key information they were looking for was not emphasised.

"Just that overarching message...what they're trying to really achieve and why." (Male, 25-34, Greater London, Any other white background)

"Because they're more intimate samples, I'd kind of want to know what it's used for a bit more." (Female, 18-24, South West, Mixed – White and Asian)

Several participants expressed concern over the time constraints of participating in the study. For many who did not have the equipment to measure their blood pressure at home, they felt the process of going to a GP surgery to measure their blood pressure would be time consuming and a potential logistical barrier to participating. Participants wanted more information about where they could access these services – for example at their local pharmacy or GP surgery - and, importantly, an indication of how long the process of taking the samples and measurements would take.

"The easier it is to do, the more likely I am to do it...[this] seems like quite a lot of effort". (Male, 18-24, North West, White - British)

"It's going to be a bit long...Not to say I wouldn't do it...it just seems like a bit of a commitment." (Female, 25-34, North West, Asian or Asian British - Pakistani)

"I wouldn't say struggle with getting, but it's trying to get an appointment with a GP to be able to get your blood pressure, would be, might be a bit more difficult." (Female, 25-34, South West, White - British)

Some participants also wanted more information about the process of collecting the sample, as well as an indication of the next steps of the process after receiving the invitation letter.

"I'd just want to know a bit more about how they'd want me to collect the samples" (Female, 18-24, South West, Mixed – White and Asian)

"You'd need to have some kind of information about what exactly is the next step to take" (Female, 55+, Scotland, Any other white background)

Accessibility: are the materials easy to read and understand? Do people think they would be able to take part?

Participants found the letter easy to navigate and liked how the information was divided into different sub-sections. Some felt the bolded headings made it easier to find the information that they were looking for.

"It's wordy but not too wordy and the key bits are highlighted nicely." (Male, 18-24, North West, White - British)

Participants liked that the information was presented on one page, as it made the letter more digestible. Notably, participants who had English as an additional language (EAL) felt the language and terminology was straightforward and easy to understand.

"That's fairly clear to me...I don't feel I need any more information." (Male, 55+, Greater London, Asian or Asian British – Indian, EAL)

Key recommendations for improvement

- **Emphasise the purpose** and aims of the study, including what *Understanding Society* will gain from the results and why poo sampling, in particular, is important.
- **Include an indication of how long each part of the process will take** to give people a sense of the time commitment required, should they decide to take part. e.g. How long will collecting and returning sample take?
- **Clearly explain the next steps** e.g. *If you're willing to take part, you do not need to reply to this letter. We will follow up to confirm that you've agreed to participate and send out the sample collection kit with all the necessary steps to collect your sample or any additional assistance needed.*
- **Highlight key information** such as the purpose of the study and the time commitment so that skim-readers - or those who have limited time to engage with the materials - can easily and quickly make a decision about whether they might want to take part.

STIM B (document 2): Participant information sheet about health measures

Clarity: did participants understand what was being asked of them?

Regarding the clarity of the research aims, most participants understood the reasoning behind collecting different health measurements across the population. In particular, participants who had previously provided their health measurements to *Understanding Society* felt familiar with what they were being asked to do.

"We've done height and weight and things like that before...I didn't think it was out of place asking for these kinds of measurements." (Female, 45-54, North West, Black or Black British - African)

However, some participants thought the research aimed to understand people's lifestyles and diet or aimed to determine why certain diseases are more prevalent in certain societies, which was not completely accurate.

There was also some confusion amongst participants about receiving the results from their poo sample. Some participants expressed their willingness to participate because they believed they would receive their stool sample results, despite the document stating this would not be possible. In comparison, participants understood they would receive their blood sample results because this information was bolded.

"People might think they're going to get some kind of diagnosis out of it, but they won't - which is important to highlight." (Male, 45-54, London, White - British)

"If there was anything wrong with the results, would I be told about it, like, you know if there was something glaringly like health wise...would I be given the results?" (Female, 35-44, South East, Chinese or other ethnic group)

In regard to the clarity of the health measures, one participant suggested that illustrations would improve the clarity of the measurement instructions in the 'Measuring your waist' and 'Measuring your hips' subsections. This may benefit those who understand more visually. They said:

"A visual representation of where they need to measure on your waist, where you need to measure on your hip, might be really helpful for some people." (Female, 25-34, South West, White - British)

Completeness: did participants feel that the information being provided was sufficient?

Participants felt this document was detailed and informative, providing sufficient information about the purpose of the research and potential areas of concern, including data and information security.

"It answers everything that I would want to know." (Male, 35-44, North West, White - British)

Participants tended to be divided in their concerns about data and information security. Participants in the younger age groups, particularly the 18 - 24 and 25 - 34 brackets, were generally more data cautious than participants in the older age groups. Those who had concerns about data and information security felt reassured by the transparency of the 'how will we keep your information safe' subsection and the GDPR disclaimer - and also pointed to the fact that they had an existing relationship with *Understanding Society* so probably had higher trust levels. Several participants felt that their poo sample data could not be used maliciously and, therefore, had few concerns about the risks of taking part.

"If there's like financial stuff involved, I'd probably be more apprehensive... [with a] poo sample, who's going to want that and what are they going to do with it." (Male, 18-24, North West, White - British)

"How my data is used is really important to me...because it's anonymised...I don't really feel like there's any sort of risk." (Male, 18-24, Scotland, Asian or Asian British - Indian)

Some participants liked the emphasis on the voluntary nature of the research and how they could decide which of the measurements or samples to provide and that they could change their mind at any stage. In addition, participants felt reassured by their trust in *Understanding Society* as a reputable organisation, particularly those who had been involved for a longer period of time.

Notably, participants in the skim-reader group felt less engaged with this document as they thought it was too detailed. Several participants would have preferred for the key information about the study to be emphasised in a separate section. This may improve the engagement of skim-readers and increase their understanding of the study's aims and expectations.

"It almost feels like some of it could be dealt with in an FAQ section". (Male, 25-34, North West, White – British)

"Have sort of the key facts about in sort of more bullet point fashion." (Male, 25-34, West Midlands, Any other white background)

Some participants acknowledged the level of detail would be of benefit to those who would have more concerns or were more 'on the fence' for taking part.

"If you're more worried about it, it's probably quite good that there's a lot of information on there." (Female, 18-24, East Midlands, White – British)

Accessibility: are the materials easy to read and understand? Do people think they would be able to take part?

Participants found the document visually engaging, particularly as the colours and images contributed to an engaging read. One participant said:

"It's not dull and boring you know it's captivating and it makes you want to carry on reading." (Female, 18-24, South East, Mixed – White and Black, EAL)

On the whole, the language and terminology was simple enough for participants from medical and non-medical backgrounds. For example, the explanation of the microbiome was reported to be understandable for those who had not come across the terminology or concept before – although some did struggle to articulate what the microbiome was in their own words when prompted. However, two participants raised concerns over the use of 'HbA1c' and 'glycosylated glycated haemoglobin'. Instead, they suggested changing the phrasing to 'blood sugar' or 'blood glucose', as this may resonate with more people and be more widely understood.

The two main concerns participants expressed were regarding the layout of the document and the length of text. In relation to the layout, participants found the right to left format difficult to read. One participant said:

"The information is all over the place." (Male, 55+, Greater London, Asian or Asian British – Indian, EAL)

The layout was particularly challenging for participants who viewed the document on a mobile phone or tablet as the right to left format impacted the flow of the sections and made it harder to navigate the document as a whole. Again, this feedback should be considered in light of the fact that STIM B would, in reality, be viewed as a printed leaflet during face-to-face interviews. Participants would therefore find the leaflet easier to navigate as the sections follow a logical order in its printed form.

However, for participants accessing STIM B online, the format should be amended to a more accessible web format.

As previously mentioned, the quantity of text disengaged the skim-reader group, but also may pose challenges for participants with reading difficulties, like dyslexia. One participant with dyslexia stated that the length of text of text was, at first, overwhelming but the use of bolded subheadings helped them navigate the leaflet. Again, a brief summary section may be beneficial to engage a wider range of participants and ensure the key information is not missed by participants who may be more likely to skim-read.

"So, for me, first thing, it's quite a lot of text. Again, being dyslexic and I would almost kind of skip over some of it... the different subheadings do make it slightly easier." (Female, 25-34, South West, White – British)

Key recommendations for improvement

- **Amend the layout of the document for online viewing** i.e. ensure the document reads from left to right in its online format to make it accessible for those viewing the document on a mobile phone or tablet.
- **Bold the text 'We will not be able to provide any feedback on your sample'** to clarify that participants will not get their stool sample results.
- **Simplify some the scientific language** e.g. change 'HbA1c' and 'glycosylated glycated haemoglobin' to a more participant friendly term, like blood sugar or blood glucose.
- **Consider including a summary section of key information in a bullet point format** so that skim readers can pick up the key information, and those who want more detail can find it elsewhere. In practice, this would mean summarising information about the purpose of the study, what the health measurements are, what participants will have to do and whether they will be given results.

STIM C (document 3): Participant information sheet about microbiome sample

Clarity: did participants understand what was being asked of them?

Overall, participants seemed to prefer this document to STIM B, as it had less text and, therefore, more digestible. A few participants found this document repetitive as it included similar information from STIM B. However, on the whole, participants found it helpful that the information was reiterated in case they had missed it previously and because it re-emphasised the basis of the study.

"What I needed to know I'd already learned from the other one." (Female, 45-54, North West, Black or Black British - African)

"Obviously there is a lot less text, so it's a lot easier to, to read." (Female, 25-34, South West, White - British)

Completeness: did participants feel that the information being provided was sufficient?

Participants found this document informative and straightforward, particularly about the process of collecting the sample. One participant said:

"You're told exactly what you need to do." (Male, 18-24, Scotland, Asian or Asian British – Indian)

Some participants wanted to know more information about the 'why's' of poo sampling. They felt it would be useful to receive more context about poo sampling, an evidence base of what poo sampling has achieved in the past and how this has informed current research. Additionally, some participants wanted to know what the study hopes to achieve, and how it would develop, if the samples are found to be 'testable'.

"The 'why'...could be more prominent. I think that would give me more understanding of why I'm doing it and what you're getting from it." (Male, 25-34, North West, White - British)

"I imagine they've got some idea of what the research might be used for if the samples were testable, so maybe a little bit after there would kind of be interesting." (Male, 18-24, North West, White - British)

Notably, a few participants found 'The microbiome – what is it?' section confusing and felt they would have to research the topic to better understand it. One participant, who studied Biology and was familiar with the terminology used, suggested including definitions of 'microbe' and 'pathogens' as it was not clear in the explanation provided.

Accessibility: are the materials easy to read and understand? Do people think they would be able to take part?

In regard to the design and layout of the sections, participants responded positively, particularly about the use of colour and bolded headings as this made the information sheet an engaging read.

"I like when there's colours and little drawings, it helps keep me focused." (Female, 18-24, South West, Mixed – White and Asian)

"It's easy for you to quickly find what you want to know". (Female, 18-24, East Midlands, White - British)

Similar to STIM B, participants felt this document would be easier to read and navigate if the information was ordered from left to right.

Key recommendations for improvement

- **Amend the layout of the document** to ensure the document reads from left to right to improve the flow and make it accessible for those viewing the document on a laptop, mobile phone or tablet.
- **Emphasise the purpose of the research in relation to stool sampling** e.g. Why poo sampling? What has poo sampling achieved in the past? What would be the next steps in this research if the samples are found to be testable on a large scale?
- **Provide a definition list of key scientific terminology** e.g. Definitions of microbiome, microbe and pathogen.

STIM D (document 4): Consent question

Clarity: did participants understand what was being asked of them?

Participants felt the consent question document effectively summarised key information from the previous informational sheets, to help inform their decision to take part.

"Just a simple, black and white, this is what it is, are you happy to do this or not." (Male, 25-34, West Midlands, Any other white background)

Completeness: did participants feel that the information being provided was sufficient?

Participants felt this document reiterated key information from STIM B and STIM C. Some participants felt reassured that even if they had not read the previous documents in detail, they would have enough information from this document to make their decision about taking part. Notably, the skim-readers were positive about this document, as it presented the essential information in a clear and concise manner.

"It does like state everything that you know needs to be stated." (Female, 18-24, South East, Mixed – White and Black, EAL)

"If someone would have more concerns about this...there are many people they can reach out to." (Female, 25-34, South East, Any other white background, EAL)

Some participants expressed concerns over the time sensitivity of collecting and returning the sample. Participants wanted to know when they would need to collect the sample, whether immediately after consenting or within a given time period. In addition, they wanted to know how long after collecting the sample they would have to return it via the Post Office.

Accessibility: are the materials easy to read and understand? Do people think they would be able to take part?

Participants felt the repetition of 'poo (also known as faeces, stools or bowel movements)' was unnecessary and impacted the flow of the text. A few participants felt unsure what 'bowel movements' meant and would need to search the meaning online. On the whole, participants felt the terminology of 'poo' was the least confusing and would be the most commonly understood. Notably, some participants from a medical background preferred the use of 'stool' for being commonly used in a medical context.

"You'd need to keep the language as simple as possible...Not everybody knows what faeces is but everyone knows what poo is...I think using language like that helps." (Female, 55+, Scotland, Any other white background)

"Everyone calls it poo at the end of the day...it's probably the least confusing." (Male, 18-24, North West, White - British)

Key recommendations for improvement

On the whole, participants felt the consent question summarised key information about the study and what was expected from them. For the benefit of all participants, the consent question should also:

- **Remove the repetition** of 'poo (also known as faeces, stools or bowel movements)'
- **Provide information on the time sensitivity of the sample** i.e. How long after consenting to the study do participants have to collect the sample and once collected, how long do participants have to return the sample.
- **Consider only using 'poo' and 'stool' throughout** as they are the most widely understood terms.

4. Prospective participant materials E, F, G and H

In this section, we share the findings from the documents that were provided to the participant as part of a package that was sent to their home address prior to the interview. The parcel included: printed copies of STIM E, STIM F, STIM G and STIM H; a poo sample kit containing the manufacturer's instructions; two toilet collection accessories; a return envelope and a pair of recyclable protective gloves. Before discussing each document in turn, there are a few reflections which are relevant to multiple STIM documents:

Impressions of the sample collection kit

Participants felt the sample collection kit met their expectations after engaging with the first four documents.

"I think it's all fairly straightforward and somebody who's agreed to do this will I think expect all these sorts of things, and they would expect that they need to read some detailed instructions on how to do it." (Male, 25-34, West Midlands, Any other white background)

They felt generally positive toward the sample collection kit. Several participants who had collected poo samples in the past found the sample kit more substantive than kits they had previously used. When comparing this kit to NHS poo sample kits, participants said:

"I never got these gloves...so that's quite helpful." (Male, 25-34, Greater London, Any other white background)

"They give you everything you needed. The instructions are really clear, like how to actually use it." (Male, 18-24, Scotland, Asian or Asian British - Indian)

"It's got extra steps with better information." (Male, 55+, Greater London, Asian or Asian British – Indian, EAL)

Several participants felt the toilet collection accessories were a useful addition to the kit, especially as NHS collection kits tend to use cardboard utensils and toilet tissues, rather than vials and toilet covers. However, one participant felt the materials in the sample kit were too extensive and would be costly. She also explained that the extensive materials could have a negative environmental impact if participants weren't clearly told to recycle all the recyclable materials, and wondered whether

ISER could do more to mitigate potential environmental impacts of the process. She said:

"When you're looking to use less things these days [...] there was a lot of paper there." (Female, 55+, Scotland, Any other mixed background)

One or two participants mentioned this in relation to not knowing which documents to read first. They suggested that *Understanding Society* consider a way of labelling the documents in package to make it clear to participants which order they should be reading the documents.

Returning the sample

Only a few participants felt worried about the prospect of returning the sample. They had concerns over the packaging in particular – whether it would be discreet, smell-proof and sturdy. Two participants felt embarrassed at the thought their sample collection package would have a 'biohazard' warning on it. Notably, participants who had previously collected poo samples did not share these reservations. For those who are worried about this, you could consider a way of reassuring participants about the packaging e.g. reiterate somewhere in the prospective materials that packaging would be discreet, and the contents of the package would be unidentifiable.

Though it would not impact their willingness to take part, many participants felt it would be more convenient to return their sample via a post-box and a few suggested a courier collection option would be helpful.

STIM E (document 5): Cover letter for sample collection kit

Clarity: did participants understand what was being asked of them?

This letter was generally described as clear and concise. As with the other cover letter (STIM A) few participants mentioned a desire to have clear 'next steps' laid out within this letter, but did also acknowledge that that information is covered in subsequent documents.

Completeness: did participants feel that the information being provided was sufficient?

Generally, participants viewed this letter as one of the less important documents, because its function was more as a greeting and framing document, rather than instructional. Skim-readers in particular said they were likely to skip over a lot of the content in this letter and go straight to the instructional leaflets. Nevertheless, many participants said that the important information – the contact number and email, and the fact that they could change their mind about taking part – were clear. One participant, who self-identified as a skim-reader said:

"I think that's ok. It just needs to be matter of fact" (Male, 45-54, London, White - British)

Participants liked the personalisation but felt that the addition of their surname was not necessary. Instead, one or two participants said that the date would be a useful addition, so that people would be able to reference how long they had had the kit for if they didn't take the sample immediately.

"I don't think it needs to have, [name deleted], like it doesn't need my surname and looks a bit weird" (Female, 35-44, South East, Chinese or other ethnic group)

A few participants mentioned how important it was that the letter said 'thank you', since they felt that they were opting to do something potentially 'unpleasant' for very little personal or immediate gain. With this in mind, one person recommended putting the 'thank you' as the first sentence in the letter.

A handful of participants mentioned that the need to take the sample to a Post Office was referenced here, but perhaps needed more detail to specifically say that they should take it to a counter, and not to put it into a post-box. In addition, some participants wanted more information on the timescales around the sample – as mentioned already in relation for STIM D. Participants highlighted that this letter might be a good place to add this information and set clear expectations around when they should use the kit by and how long they have to return their sample.

Accessibility: are the materials easy to read and understand? Do people think they would be able to take part?

Participants highlighted that the familiar *Understanding Society* logo, the consistent design and the use of colour made the letter more visually appealing, and a few mentioned that they liked the 'personal touch' of including Michaela Benzeval's signature as it felt like it humanised the process. As with STIM A, they liked that the information was presented on one page, as it felt easily digestible. There were, therefore, no specific accessibility issues highlighted by participants here.

Key recommendations for improvement

Overall, sentiment towards this document was either positive or neutral, as this was perceived to be a simple framing document. There were a few minor changes suggested by participants:

- **Add the date of the letter** so that participants know when they first received it.
- **Re-order the first two sentences** so that the 'thank you' comes first, as this feels important to some participants.
- **Consider adding more detail on what people should do at the Post Office** as it's not immediately clear.
- **Explain how long people have to return the sample** to set clear expectations.
- **Consider removing the surname from the letter** and addressing participants using their first name only.

STIM F (document 6): ISER instructions for sample collection kit

Clarity: did participants understand what was being asked of them?

This document was highlighted by many participants as being one of the most important documents, yet one where the most changes were needed. Here, the most common feedback was that the formatting was inconsistent with the other documents, and therefore looked out of place. This was reported even by those who

said that this document was clear – they still noted that there was no logo³, no colour and a different font. Those who said it was unclear explained that there was an unclear messaging hierarchy between the sections, the title was small so it wasn't clear which side should be read first. Given that the design and layout was highlighted as a key predictor of participants' perception of the level of clarity (particularly in the two flyers and the two covering letters) this highlights a need for the layout to be reconsidered.

"This one, kind of, looks like a bit of an outlier, it's just a bit like, not the same as the other ones"

(Male, 35-44, South East, White - British)

Others mentioned that this document would be clearer if the document was set out like a 'tick-list', so that participants could ensure they had followed all the steps in the correct order.

In terms of the language, participants tended to report that this was clear. It was noted, however, that there was some unnecessary detail in the list of contents – one participant suggested cutting the brand name of the gloves, so that 'A pair of EnviroGlove recyclable gloves (latex and powder free)' would read '1 x pair of recyclable gloves (latex and powder free)'. It is also worth noting that the same participant did *not* feel that using the brand name 'OMNigene-GUT collection kit' was unnecessary detail, as she felt that including the brand name would help people identify the collection kit.

It was also flagged that there was overlap between ISER's instructions for sample collection and the manufacturer's which made these instructions feel confusing (STIM F and STIM G). One participant, who self-identified as a skim-reader, suggested:

"Maybe take out the collecting sample and just say, see instructions in the sample kit or whatever, the collection kit." (Male, 35-44, South East, White - British)

Because STIM F frames the process, from receiving the package, to taking the sample and returning the questionnaire, STIM G falls into the middle of that process. There is therefore a need to clearly demarcate where people should go to STIM G, and then come back to STIM F – as the participant above suggested.

Completeness: did participants feel that the information being provided was sufficient?

Although many participants thought this document was useful and praised the fact that the content was broken into sections, a few felt that these instructions would benefit from additional information about how long people have to get the sample to ISER. This was also mentioned earlier in relation to STIM D - people worried that

³ After feeding back this preliminary insight to the client, the logo was added to the pdf version of this document for the final few interviews. In practice, the final participants had all already received their packages (which included the printed version without the logo) so all interviewees were responding to the original version without the logo.

there might be a cut-off point which would render their contribution unusable. Sample wording here could be 'please return the sample to Understanding Society within x days of taking your sample'.

Accessibility: are the materials easy to read and understand? Do people think they would be able to take part?

The fact that there was a video link was praised by participants, although only one person reported having watched the video. Others mentioned that it might be difficult to type in a URL, so suggested a QR code that could be scanned on a mobile as an option that would make this more accessible to more people.

Some participants mentioned that as some people are visual learners, they might appreciate images of the kit included in the kit list so that they could easily match them up. There was a notable issue with the toilet collection accessories, as many participants either were not sure what that was, thought it was an information leaflet, or thought it was missing from the package. There is a need to clearly label the collection accessories, perhaps with a sticker, to help people identify them.

Key recommendations for improvement

- **Design the document** with consistent logos, fonts and layouts so that it looks like a coherent piece of the participant journey.
- **Clarify the messaging hierarchy** (e.g. make the title bigger and clearer so that it's obvious which side of the page should be read first).
- **Replace the URL** to the instructional video with a QR code for easier access.
- **Remove any unnecessary detail** from the equipment list (e.g. the glove brand name).
- **Consider adding a checklist element**, so that people can follow each step (including moving from this document to the supplier instructions and back) clearly.
- **Consider adding images of the different parts of the kit** to this document (e.g. to help people identify each of the contents of the package).

STIM G (document 7): Supplier instructions for sample collection kit

Clarity: did participants understand what was being asked of them?

Overall, many participants mentioned that this was one of the clearest documents. Frequently, this was because of the use of instructional images.

A participant who had done a stool sample previously, described these as being clearer than NHS sample instructions:

"It's got extra steps with better information" (Male, 55+, Greater London, Asian or Asian British – Indian, EAL)

As mentioned above, participants here mentioned the lack of clarity about what the toilet collection accessory was and how to use it. One participant, who had a medical background, explained that the collection accessory instructions were also unclear

because the symbols on these instructions are black triangles and squares, but that these are a different colour on the toilet accessory itself:

"You have to carefully peel open the edge with the triangles, but the triangles, the black triangles, they don't correspond with the white triangles on the black label, do you see? [...] the edge with black triangles. There are no black triangles." (Female, 35-44, South East, Chinese or other ethnic group)

Completeness: did participants feel that the information being provided was sufficient?

Participants reported that this information was thorough. Some participants, who had provided poo samples before, mentioned that sample kits from the NHS didn't provide gloves or a toilet accessory kit. This participant said that this process was far easier and more comprehensive than their previous experience. Nonetheless, participants sometimes reported that they couldn't locate the toilet accessory, or thought it was a set of paper instructions.

Accessibility: are the materials easy to read and understand? Do people think they would be able to take part?

On the whole, participants also said that this felt clear and accessible because of the use of images. One participant, who was dyslexic and identified as a skim-reader said:

"Yes, I think that's, that's a lot easier to follow" (Female, 25-34, South West, White - British)

"I'd say that the clearest piece is the [manufacturer's] instructions on how to collect a sample – because of the images. [...] a lot of us are like visual learners and like seeing things and this literally shows you step by step how to what to do, what not to do." (Female, 20, South East, Mixed – White and Black, EAL)

However, there were some minor issues raised – for example, one person suggested that number of languages and the small font makes these instructions feel overwhelming, and because the paper is thin, it looks slightly transparent and the text almost overlaps, making it harder to read.

Key recommendations for improvement

It is important to note that STIM G is the manufacturer's instructions for sample collection and so modifications are limited. However, for the purpose of sharing participant feedback and highlighting any possible issues, you could consider the following areas:

- **Label the toilet accessory clearly** as it was common that participants misidentified this, could not find it, or thought it was a leaflet. Participants felt that this could be done by adding an additional label.
- **Consider increasing the font size.** Although all participants in this study said that the font size was fine for them, many of them commented that elderly people or those with sight issues might struggle to read this document.
- **Consider allowing participants to request instructions in a preferred language,** rather than including all languages.

STIM H (document 8): Sample collection questionnaire

Clarity: did participants understand what was being asked of them?

The majority of participants described this document as being very clear. Frequently people said that this was because of the small number of words and the descriptive images. The main pain points raised were around the medication questions. Firstly, a few people raised that themselves or others they know may need more space to specify medications:

"I suppose actually thinking of my dad, my dad is also on a lot of medication and I don't think it would actually fit in, in that space either" (Female, 25-34, South West, White - British)

Secondly, quite a few people also suggested that the wording of the medication question was too vague. This document would therefore benefit from more precise language to explain what to include. One participant, who had a healthcare background explained:

"That question, the one with medication, it always kind of throws people. They think 'do I need to put going on the pill' or - I know a lot of things say you don't need to kind of put, like the contraceptive pill. [...] You could put 'are you currently taking any prescribed medications?' or it could be 'have you taken any kind of medications, prescribed or non-prescribed in the last however many days' - depending on how that's going to maybe affect the study." (Female, 25-34, South West, White – British)

In addition, in the following question, there was a lack of understanding about what fell into the categories 'protein/amino acid supplement', 'probiotics' and 'prebiotics'. Some felt it would be helpful to give examples here to make this clearer – e.g. giving examples of probiotics or of 'protein supplements'. In particular, one participant queried whether 'protein supplements' included protein powder. A few participants also said they had not heard of prebiotics and reported finding this question confusing:

"Giving examples of each might be quite helpful." (Male, 25-34, Greater London, Any other white background)

A few participants also mentioned not being sure what 'bowel movements' meant, and one person said that they had to Google it to check that their understanding was right, so there is a need to either rephrase or provide a short explanation here.

"The only thing was I'd have to Google bowel movements just to be sure." (Female, 18-24, South West, Mixed – White and Asian)

Completeness: did participants feel that the information being provided was sufficient?

In the bowel movements question, one participant felt that there weren't enough options for those who had more frequent bowel movements.

Accessibility: are the materials easy to read and understand? Do people think they would be able to take part?

Some participants flagged that this could perhaps be printed on A5 paper, as there was a lot of empty space. Where people hadn't seen the Bristol stool chart before, they said they found the images really helpful and it would be easy to use. One

participant said her 6-year-old son had seen it and found it easy to use as a descriptive tool.

Key recommendations for improvement

- **Consider rewording ‘bowel movements’** or providing a definition to clarify this for participants.
- **Clarify the wording on the medication question** (e.g. specify the level of detail required) and leave more space for those who may be on a lot of medication.
- **Give examples of what is included** under ‘protein / amino acid supplements’, ‘probiotics’ or ‘prebiotics’ or an explanation to make this clear for people who either don’t know what these are, or haven’t heard of them.
- **Consider adding more multiple-choice options** on the bowel movements question for those who have more frequent bowel movements.

5. Conclusions

Overall, the findings of this research suggest that there is already a good level of clarity, completeness and accessibility in these documents. The suggestions outlined in this report should be seen as small tweaks to materials that participants generally described as easy to follow. The actions outlined in relation to each STIM document are outlined in previous chapters, but below is a summary of the key findings across the participants:

- Overall, participants were **positive about the level of detail** in the documents. Though some participants would have preferred less information, and had a preference to skim-read, there was a general acknowledgement that being over-informed would be better than being under-informed.
- Nevertheless, participants tended to associate documents having ‘more words’ with being ‘less clear’. **Perceptions of clarity** are therefore more positive when participants feel like there isn’t ‘too much’ information – and this is also related to **design and formatting**. It was frequently noted that the use of colour and sub headings made documents both clearer and more accessible.
- However, **perceptions of what constituted ‘too much’ information** varied according to whether participants were skim-readers or not. There are two distinct groups with different levels of interest and attention that need to be catered for.
- Across both skim-readers and non-skim-readers, some participants highlighted the **importance of humanising the research**. This was figured through the personalisation of the letters, wording that showed expressions of gratitude from *Understanding Society*; and naming representatives from the research team (Michaela Benzeval).
- Existing **trust in *Understanding Society*** means that brand recognition and familiarity is a strength. Where participants felt that there was consistent branding and design across materials, they were more likely to respond positively to them.
- **Key information cited by participants** included: why the samples are being collected, instructions on what to do and how long it would take. Additionally, detail on data privacy and the fact that they can decide to stop taking part was also seen as important. These are the messages that mattered most to participants, and should be front and centre.
- There was a **low level of existing knowledge or understanding about the microbiome** amongst the participant group, with the exception of those who had a medical background. Although the majority of participants tended to say the explanation of the microbiome was clear, this wasn’t always demonstrated in their understanding.
- The connection with **health and disease feels more meaningful** to people than the explanation of what the microbiome is, and is therefore more likely to emotionally connect with people and increase their likelihood of taking part. Currently the ‘why’ is not put front and centre in the materials and participants felt that this could be strengthened, as this is more of an incentive than the financial reward.

Overall recommendations for improvement

- **Emphasise the ‘why’ behind the research throughout to boost engagement**
This is one of the key pieces of information that people are looking for when they make the decision to take part. Currently participants feel that this could be clearer.
- **Streamline the number of materials where possible**
Although participants reported that the documents were clear, one option is to consider removing any materials that might be repetitive (e.g. in relation to STIM B and STIM C, a few participants felt that there was an option to create one leaflet, rather than two different ones with significant informational crossover; in relation to STIM F, there was also seen to be some crossover between that document and the STIM G – the manufacturer’s instructions). This could also help to address the points raised earlier about the volume of paper and perceptions of clarity related to the number of words and documents.
- **Consider the best way to cater for differing needs**
Although in this research there was no one interviewed who felt that they would have significant challenges understanding the process and taking part in the microbiome sample collection, many did point out groups that would. One person suggested that *Understanding Society* could include an accessibility question in the annual survey, where participants with EAL, visual impairments or other needs could be flagged in advance – and given the option to request large print, chosen-language documents, translator support or assistance with *Understanding Society* communications and activities more generally.
- **Consider different methods of returning the sample** – although the majority of participants said that having to take the sample to a Post Office wouldn’t change whether they were willing to take part, most of those, when prompted, said that they would prefer to drop the parcel into a post-box. This was seen as more convenient and anonymous, which they felt made the process easier and more pleasant.
- **Ensure design of materials is consistent** – participants know and trust *Understanding Society*, and the design of the leaflets and letters was often praised for the familiarity of its branding, as well as its professional look. This was shown to be very important to participants, and influenced their impressions of both clarity and accessibility, but currently there are a one or two documents that are not designed in line with this.

Following these recommendations participant materials were updated for the Wave 16 fieldwork starting in January 2024 (see Appendix D for examples of updated documents).

6. Appendix A – Topic Guide

ISER – Understanding Society Microbiome Pilot Interviews 2.0

Depth interview topic guide v2.0

Background

Understanding Society is a UK Household Longitudinal Study that follows the lives of thousands of individuals within households over time. It is an internationally recognised study led by the Institute for Social and Economic Research (ISER) at the University of Essex. It provides vital evidence for scientists and policymakers on the causes and consequences of deep-rooted social problems.

The collection of stool samples for microbiome analysis ('gut bacteria') has the potential to provide a novel and useful biosocial insight. Previously, Verian conducted a qualitative study into perceptions of the acceptability of collecting these kinds of samples across Understanding Society participants of all ages. This project builds on previous work, asking respondents from Understanding Society's Innovation Panel to review the clarity, completeness and accessibility of the information which will be provided to those who agree to provide stool samples in the future.

No biological samples will be collected at any point during this pilot study.

Research Aim

To get participant feedback on prospective documents and material that may be used for the study (from recruitment to sample collection protocols), to ensure all materials used are participant-friendly and provide the information participants would require in a clear and concise manner.

Stimulus list

- STIM A: Invitation letter UK Household Longitudinal Study Interview
- STIM B: Participant information sheet on Health measures and poo samples
- STIM C: Participant information sheet on poo samples & the microbiome
- STIM D: Consent question
- STIM E: Sample collection package - Cover letter
- STIM F: Sample collection package - Sample collection instructions from Understanding Society
- STIM G: Sample collection package - Sample collection instructions from the manufacturer
- STIM H: Sample collection package - Questionnaire

Note to Moderators

The participants for this research have been recruited from the Understanding Society Innovation Panel following an opt out email. Participants will have seen the stimulus

materials before attending the interview, but may need prompting so please have the stimulus materials ready to share as you talk through each of them.

Please note, this guide is not a script and is intended to be used flexibly, with participant responses guiding the flow of the conversation, topics covered in the order that they naturally arise, and probes used only when needed

Key contacts

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Project Associate: Avindri Chandraharan

Project recruitment lead: Paul Vousden



1. Introduction

(2 minutes)

Introduce research, reassure about confidentiality and set tone of discussion

- **Warm up and introduction**
 - Introduce yourself as a researcher at Kantar Public
 - **Client:** Research on behalf of University of Essex who run the Understanding Society Study that you're part of
 - **Oral consent:** explain to the participant –
 - **What you're taking part in:** You've been selected to participate in this research, where we'll be discussing your thoughts on the information provided to people as part of their participation in a health study run by Understanding Society.
 - **Purpose of the interview:** The purpose of this interview is to gather feedback on the instructions and the letters that Understanding Society will be using in future health studies, where they will be asking people to collect biological samples such as stool (poo) samples. Just to confirm, we do **not** need you to collect any biological samples as part of this research.
 - **Reassurances:** There are no right or wrong answers - we just want to hear about your feedback on a few documents.
 - **What the research is for:** Understanding Society can then use the findings to improve the experience for participants, and make sure

the process and the instructions are as clear and easy as possible for everyone who takes part in the future.

- **Anonymity and confidentiality:** Your participation in this is anonymous and confidential – there will be nothing fed back to Understanding Society that could identify you at all, and all your data is securely stored and not shared with anyone outside of the research team here at Kantar Public.
- **Voluntary:** Your participation is also voluntary - if you decide that you want to withdraw from the research that the team at Kantar Public is undertaking, you can do so at any time. You just need to let me know, or, if you decide to withdraw after this interview, contact the recruiter who will let us know to remove your data. *[if they want to withdraw from Understanding Society in general, then the need to contact Understanding Society directly]*
- **Interview length** – up to 45 minutes
- **Recording:** We also usually audio record these interviews, as this helps us accurately capture what's said. Again, those are just used for our own internal notes. Would that be ok? Yes – start recording and – confirm verbal consent.
- **Answer any questions or concerns:** Do you have any questions about the research that you would like to ask me? [Kantar Public's privacy policy can be accessed on our website: <https://www.kantar.com/uki/surveys>]
- **Audio recording:** check they are happy to be recorded. Audio files will be transcribed and anonymised for analysis.
- **Turn on the audio recorder and confirm consent to take part and to audio record the interview**
- **Introduce stim materials:** So today we'll be going through 8 documents – we sent 4 via email - documents A, B, C, D. And in the kit you received in the post, you should have 4 more documents – a cover letter, two instruction documents and a questionnaire. Did you receive that package, and are all of those documents in there?

2. Participant background (2 mins)

- **Understanding Society**
 - How long they've been involved in Understanding Society
 - What attracted them to the innovation panel in particular
 - How they first heard about it
 - Motivations for participating in Understanding Society
 - What they like about participating in Understanding Society
 - Did they take part in the collection of biological samples and other biomeasures as part of Understanding Society three years ago (a nurse/

interviewer may have come to their home or they would have completed online and been sent kit to take a blood/hair sample)? why/why not?

- Willingness to take part in the sample collection
 - Do you think you'd be willing to take part in this research in the future? (i.e. to collect a poo sample and send it to Understanding Society?)
 - Why / why not?
- **About them**
 - How they spend their time e.g. work, volunteering
 - What they do for work (where relevant)
 - Who's in their household / family context e.g. whether married, whether have children (ages of children)

3. Invitation (5 mins)

This section is about the participant's experience of STIM A, the advance letter that participants in the study would receive which introduces the health measures element of Understanding Society.

*Researcher to explain: **Now, we'll have a look at the documents you were sent over via email. We'll go through each one and talk through your thoughts about them.***

***We'll start with letter A where it talks about your next Understanding Society interview. In the letter it also tells you about the health measures that Understanding Society would like to collect from you.** (Ask participant to open document on their screen. If unsure/can't find, interviewer shares screen with document open)*

Reading options: Ask if participant read through document before interview. If not, offer participant to either read letter themselves and let you know when finished or read aloud to them.

- Initial reactions
 - Spontaneous
 - What stood out
 - How it makes them feel (e.g. reflect on the tone, design, wording – do they feel excited, apprehensive etc)
- Ask them to describe in their own words what they're being asked to do
 - Anything confusing or unclear?
- What questions or concerns, if any, do they have – note (but do not probe) if any of these relate to:
 - Purpose (e.g. why this data is being requested)
 - Process (e.g. sample collection, storage, delivery)

- Privacy (e.g. confidentiality, data security)
- Other (e.g. embarrassment, hygiene, personal benefit, such as diagnostic information)
- Whether this is enough information to make a decision about whether to take part
 - What further information, if any, they would like (if necessary, prompt in relation to questions raised earlier)
 - What is the main reason (reasons) why they would or wouldn't take part?
- What changes they would make to the letter to make it clearer or more appealing e.g. language, content, layout
 - Reasons for this

4. Participant information (10 mins)

This section is about the participant's experience of STIM B and STIM C, the participant information sheets. STIM B is general and covers giving health measurements in general as part of Understanding Society. STIM C is an information leaflet specifically about stool sample collection.

*Researcher to explain: **The next few questions are about document B where it talks about the health measures involved as part of the Understanding Society study.** (Again, offer reading options)*

Show participant the health measures participant information sheet (STIM B)

- Initial reactions (spontaneous)
- What stood out and why
 - Ask them to explain which bits of information they find the most useful
- How it makes them feel
 - Is there anything in there that would discourage them from taking part
 - Anything that made them feel encouraged to take part
- Anything confusing or unclear?
 - How could it be clearer / be improved?
 - Did they feel the information provided is sufficient

*Researcher to explain: **Next, we'll move onto looking at letter C, an information leaflet specifically about stool sample collection.** (Offer reading options)*

Show participant the microbiome sample participant information sheet (STIM C)

- Initial reactions (spontaneous)

- What stood out
- How it makes them feel
- Anything confusing or unclear?
- Any questions?

5. Giving consent (5 mins)

This section is about the participant's experience of STIM D, the consent question which would either read by the participant (if they are giving consent to provide samples for the study online) or by the interviewer (if they are giving consent face-to-face).

Researcher to explain: *The next few questions are about letter D, which is the consent question document. This would either be read by the participant (if they are giving consent to provide samples online) or by the interviewer (if they are giving consent face-to-face)*

- **(Offer reading options) Explore understanding of consent form**
 - Initial reactions
 - Anything confusing or unclear?
 - What questions, if any, do they have

Returning the sample

Researcher to explain: *As it says in this consent wording, the sample would then need to be returned to Understanding Society. This needs to be done via Royal Mail special delivery, which means that you would need to go to the Post Office. Understanding Society would provide the label and postage materials.*

- **Explore preferences for returning sample**
 - Whether they would be open to posting the sample at the post office
 - Reasons for views
 - What questions, if any, do they have
 - What concerns, if any, would they have about this
 - Would this affect their likelihood of taking part?

Future of the programme

Researcher to explain: *As it says in this consent wording, because scientific findings about microbiomes are still developing, we do not now know all the ways in which your contribution might be valuable to researchers.*

- **How do you feel about this?**
 - Initial reactions
 - Probe that this may mean that their sample may be stored, frozen, and then analysed at an unknown future date.
 - Any questions or concerns about that?

6. Sample collection (10 mins)

This section is about the participant's experience of STIM E, STIM F, STIM G and STIM H, the documents that arrived in the sample collection package they received.

Researcher to explain: Now we'll be looking at the kit you received in the post. In here, there should a cover letter that arrives with the sampling kit, the two instruction sheets and the questionnaire. If you could think back to opening the package and looking at all the information inside.

(If haven't opened: Could you please open the package now and have a look at the contents inside)

Show participant the sample collection kit cover letter (STIM E)

Researcher to explain: First, if you can have a look at the sample collection kit cover letter.

- **Sample collection kit cover letter**
 - Initial reactions
 - Anything confusing or unclear?
 - What questions, if any, do they have at this stage
 - Anything that's missing from the letter that they think is important
 - What changes, if any, would they make?

Show participant the sample collection instructions provided by ISER (STIM F)

Researcher to explain: Next, could you have a look at the sample collection instructions provided by ISER. This is named 'How to collect and return your poo sample'.

- **Sample collection instructions provided by ISER**
 - Initial reactions
 - Anything confusing or unclear?
 - Do they think they would be able to easily do this
 - If not, why not
 - Anything that would make the process easier to understand (e.g. format of the instructions, language etc)
 - What questions, if any, do they have at this stage

Show participant the sample collection instructions provided by the supplier (STIM G)

Researcher to explain: Now, could you look at the sample collection instructions provided by the supplier. This has the Omnigene-gut logo on the top.

- **Collection instructions provided by the supplier**
 - Initial reactions
 - Anything confusing or unclear?
 - Do they think they would be able to easily do this
 - If not, why not

- Anything that would make the process easier to understand (e.g. format of the instructions, language etc)
- What questions, if any, do they have at this stage

Show participant the stool sample questionnaire that was included with the package (STIM H)

*Researcher to explain: **Finally, could you have a look at the poo sample questionnaire.***

- **Stool sample questionnaire**
 - Initial reactions
 - Anything confusing or unclear?
 - Do they think they would find it easy to fill out?
 - Are the contents of the survey clear?
 - If not, why not
 - Is there anything that needs more explanation? Anything that would make it clearer to understand (e.g. format of the instructions, language etc)
 - What questions, if any, do they have at this stage

7. Overall reflections (10 mins)

This section is about the participant's experience of reading all of the research materials and instructions.

- **Overall views on study materials**
 - Most important information to communicate
 - What information, if any, is missing
 - Do they think others would find all of the letters, information sheets, consent form and kit instructions easy to follow?
 - Which part of the process was clearest? Which was the least clear?
 - Can they think of anyone in their life who might not find this easy to understand? How could we change it to make it clear for that person?
 - What would they change? (e.g. formats, order they're delivered in, the volume of reading material etc)
- **Willingness to take part in the sample collection**
 - Based on reading all of these documents, and knowing more about the process, do you think you'd be willing to take part in this research in the future? (i.e. to collect a poo sample and send it to Understanding Society?)
 - Why / why not? What specifically would deter you / what makes you feel that you would take part?

- Any other final thoughts or reflections

8. Close (1 mins)

- Reminder of incentive for taking part in this interview (£40 – Love2shop voucher or cash transfer)
 - You will receive £40 as a thank you for your participation in this research. Within 7 - 10 working days of completing the research, you will receive an email from either Paul or directly from Merit (noreply-kantar-rewards@meritincentives.com) containing a code to access your incentive. This can be either:
 - a **LOVE2SHOP voucher** that will be emailed to you
 - a **PAYPAL** payment to an account of your choice
 - **RESEARCHER:** confirm and clearly note participant's full name and email address for receiving MERIT reward. Double-check all info with participants.
- Thanks, and close

7. Appendix B – Stimulus documents

STIM A (document 1): Invitation letter UK Household Longitudinal Study Interview



FinalSerialNum
FF_personno/ff_P10

Contact us:

Participant helpline: 0800 252 853
Web: www.understandingsociety.ac.uk/participants
Email: contact@understandingsociety.ac.uk
For details of the study's privacy policy, please see
<https://www.understandingsociety.ac.uk/participants/gdpr>

RESP Name
ff_RESP Name
ff_Address1
ff_Address2
ff_Address3
ff_Address4
ff_Address5
ff_PostCode

Postal_Date

It's time for your Understanding Society interview

Dear [Participant's Full Name]

Thank you for being part of Understanding Society.

It's been a few years since we last contacted you and a lot has happened since then. In your last interview in 2019 we asked you to provide some health measures - we are collecting some of these again this year. Interviewing you every few years helps us see what's changed and what's stayed the same in your life, so please complete your interview again this year.

This year we'd like to ask you more about your health

Blood pressure: We would like to ask you to have your own blood pressure measured before completing the online questionnaire. You can take your blood pressure at home, if you have the equipment available, or you can visit your local pharmacy or GP surgery where this service is offered for free. If you are able to obtain your blood pressure readings, please use the enclosed card to record the measures, as well as where and when the readings were taken. We will ask you to report these readings to us during your interview.

Body Mass measures: We are also interested in body shape - included in this letter is a tape measure. If you are willing, please measure your waist and hips, following the instructions in the enclosed leaflet, and write down the measurements on the card. You will be asked to enter the measurements during your interview.

Blood and poo samples: During your interview we will ask if you agree for us to send you kits to take a small sample of blood and a small sample of poo. The kits contain everything you need to collect the samples and instructions on how to use them. You do not have to provide any of the measures or samples if you don't want to. Even if you don't want to take part in this part of the survey, please complete your annual interview as normal.

Thank you!

We're very grateful that you take part in Understanding Society. To say thank you, we've enclosed a £20 gift card which is ready to use. If you're able to complete your interview online by Early_bird_date we will send you an extra £10 gift card. If you send us your blood and poo samples we will send you an extra £5 per sample.

With many thanks,

Professor Michaela Benzeval
Director, Understanding Society.

Understanding Society is being conducted in accordance with the Data Protection Act. This means your personal details will be kept strictly confidential and you and your household will not be identifiable from the data.

4h.Understanding Society - the UK Household Longitudinal Study Wave 10_Advance letter_Web mode_recruited 2008_with microbiome_v1
1 October 2022
IRAS Project ID: 319149

Taking part

1. Visit the website
www.understandingsociety.ac.uk/society

2. Enter your
user name: XXXXXXXXX
and password: XXXXX

We may send you a SMS text to your phone with a personalised link to your survey.

3. Answer the questions
in your own time.

If you can't complete the survey online that's fine - we can arrange for an interviewer to visit you instead.

STIM B (document 2): Participant information sheet about health measures

What if I change my mind during the study?

Your participation is entirely voluntary. You have the right to change your mind about any measurement or withdraw from the study at any time without explanation.

What if I have concerns about the way the study was carried out?

Please contact Nicola Berraval, the Director of Understanding Society
 01236 873945 njberr@u.ac.uk
 Paul Clark, the Research Director of ILS
 01236 873746 paul.clark@u.ac.uk
 Sarah Manning-Pear, the Research Governance and Planning Manager
 at the University of Essex
 01236 873661 sarahm@u.ac.uk

Any questions?

If you would like to contact us at any point please use the contact information below
 at the University of Essex
 0800 262 853 contact@understandingsociety.ac.uk

If you are interviewed face-to-face, the interviewer will try to answer any questions you have.

Why are you collecting poo samples?

Poo sample collection has not yet been done on a large representative study before – Understanding Society is the first study to try to do this. Research suggests that analysing poo samples can provide valuable information about the health of the population by looking at our highly microflora.

The microflora is the community of bacteria, fungi and viruses that live in and on our body. Our bodies carry around trillions of these microbes which are invisible to the naked eye. They live in our gut, on our skin, in our nose and mouth. Each area of the body has a different community of microbes.

Our microbes act as a link between our body and the environment we live in. Like our fingerprints, the make-up of our microbes is unique to us. The microbes in our microflora are they – but they have a big impact on our health. They protect us against bad pathogens, help our immune system, and work as part of our digestive system. It develops and changes over time, as a response to what we eat, our lifestyle, the environment we live in, and the medications we take. It even changes depending on the people we live with.

The difference in our microflora appear to have an impact on whether we become unwell with certain illnesses. And our environment can affect our microflora, making it more likely that we will develop some health conditions like the obesity, cardiovascular disease, allergies, or inflammatory bowel disease.

What do I have to do if I agree to give a poo sample?

If you agree to take part, we would ask you to provide us with a poo sample and complete a short questionnaire about your health on the day the sample was taken. At the end of the survey we will ask you for your consent to send you a poo sample collection kit.

This includes everything you need to collect this sample, as well as detailed instructions of how to collect it. The whole process is very straightforward and should take you just a few minutes.

Will I be given any results?

We will use your poo sample to study the microflora of your gut. We will not be able to provide any feedback on your sample.

Who is carrying out the research study?

Researchers at the Institute for Social and Economic Research (ISER) at the University of Essex are running the study. Kate Pickett and Maccos Social Research, our research partners, will use your name and contact details as they can include you in the study and carry out follow-up. If you take part in the blood sample collection, then, the kit carrying out the analyses, will use your contact details and your date of birth and gender so that they can send you a collection kit, analyse your blood sample, and send you the results of your blood analysis. If you wish to receive these.

Do I have to take part?

Like every other part of Understanding Society, this part of the project is completely voluntary. You do not need to have any measurements (eg, blood pressure, height, weight, waist and hips circumference) taken or samples (blood or poo) collected if you do not wish to, but we hope you will agree to them as they are a very important part of this survey. If the survey results are to be useful to us, it is important that we obtain information from different people in all states of health. If you are happy to take part in some measurements and sample collections but not others, this is absolutely fine.

Are there any risks involved in participating?

There are no risks associated with taking any of these measurements or collecting any of these samples.

How will we keep your information safe?

In this research study we will use information from you. We will only use information that we need for the research study. Kate Pickett and Maccos Social Research, our research partners, will use your name and contact details as they can include you in the study and carry out follow-up. If you take part in the blood sample collection, then, the kit carrying out the analyses, will use your contact details and your date of birth and gender so that they can send you a collection kit, analyse your blood sample, and send you the results of your blood analysis. If you wish to receive these.

Everyone involved in this study will keep your data safe and secure. The results of the study will never include any names or addresses. The information collected is used for research purposes only and will be dealt with according to the principles of the Data Protection Act and General Data Protection Regulation (GDPR).

At the end of the study, anonymized data are made available from the UK Data Archive and other secure data repositories to genuine and registered researchers. All research reports are written in a way that no-one can work out that you took part in the study.

Health Measures

Information about what we would like to collect during and after your interview.

This leaflet tells you more about the part of your survey which involves collecting some health measures and biological samples.

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

What health measurements do you want to collect?

We would like to collect:

- Your blood pressure
- Your waist and hip measurements
- Your height and weight
- A blood sample
- A stool poo sample

We would like you to take a measurement of your blood pressure before the interview. If you complete your interview with an interviewer, they will also ask to measure your blood pressure.

Why your consent, we would also like you to take a measurement around your waist and hip using the tape measure included with this letter.

If you complete your interview with an interviewer, they will ask to measure your blood pressure, waist and hip measurements, and your height and weight. They will only collect these measurements with your consent.

The codes that the interviewer will use will also provide additional measures of body fat and water percentage.

We will also ask you for some measures that best at memory and reasoning.

Why are we collecting health measurements?

Physical measurements, such as height, weight, waist and hip circumference, and blood pressure, are important factors in our health.

Taking these measurements in a large number of people can help to predict certain health patterns within a population. Change in these measures within a population reflect the changes in the society's diet and lifestyle. We are interested in the relationship between height, weight, waist and hip measurements and other health outcomes.

Waist and hip measurements

The waist and hip circumference are measures of the distribution of our body fat (both subcutaneous and intra-abdominal). There has been increasing interest in the distribution of body fat as an important indicator of increased risk of cardiovascular disease. Research suggests that waist circumference is a predictor of health risk like the body mass index (BMI).

Body fat percentage

A person's body fat percentage is the total weight of the person fat divided by the person's weight. Some scientists regard the body fat percentage as the better measure of an individual's fitness level, as it is the only body measurement which directly calculates the body composition which is not affected by the individual's height or weight.

Blood pressure

Changes in blood pressure can tell us about someone's health and are risk factors for future health issues. A person's blood pressure is influenced by their age. It can also vary from day to day with our emotions, the food we eat, the temperature around us, whether we smoke, drink alcohol, take medication, or whether we are fit and active.

What do I have to do if I agree to provide the health measurements?

Taking measurements during your interview

Before your interview, we would like you to measure your blood pressure and write the results on the measurement card provided. This can be done at home, at a local pharmacy or a GP surgery that offers this service. If you are willing to get your blood pressure measured, you will be asked to provide the measurements in your interview.

We would also like you to measure your waist and hip, using the tape measure provided and the instructions given below. You will be asked to provide the measurements in your interview. If you are able to do this.

If you are pregnant, unable to stand up, and/or have a cast or bandage which would make measuring your waist and hip difficult, we are not asking you to provide the measurements.

Measuring your waist

Stand up straight.

Find, on the side of your body, the bottom of your ribs and the top of your hips.

Place the tape measure around your middle at a point halfway between them, just above your belly button. The tape should be snug but not too tight. You should be able to fit your little finger under the tape comfortably.

Take the measurement.

Write the measurement on the health measures card provided. Please write in the centimetre (cm) and millimetre (mm) of your measurement (like between two millimetres, please write in the nearest millimetre).

Measuring your hips

Stand up straight.

Place the tape measure around the widest part of your buttocks. Make sure that the tape is not around your waistband, or where your hands fall when you "put your hands on your hips".

The tape should be snug but not too tight. You should be able to fit your little finger under the tape comfortably.

Take the measurement.

Write the measurement on the health measures card provided. Please write in the centimetre (cm) and millimetre (mm) of your measurement (like between two millimetres, please write in the nearest millimetre).

Measurements taken by your interviewer

If you are being interviewed in-person, your interviewer will measure your blood pressure using an inflatable cuff that goes around the upper arm. If you would like to know the result, the interviewer will tell you your blood pressure along with an indication of its meaning, but a clinical diagnosis cannot be made by measurements taken on a single occasion.

If you are being interviewed in-person, your interviewer will also measure your standing height. They will ask you to measure your weight (with your clothes on). The code that the interviewer will use will also generate additional measures for body fat and body water percentage. The interviewer will also provide you with a tape measure and ask you through the process of taking your waist and hip measurements.

What biological samples do you want to collect?

If you are willing to, we would like you to collect a finger-prick blood sample and a poo sample. We will send you collection kits for these samples after your interview.

Why are you collecting blood samples?

Many studies routinely collect biological samples, including blood. Analyses of these samples can tell researchers a lot about the health of the population. These samples are usually collected by a nurse or at a research clinic. However, for some large studies like Understanding Society, where participating households are spread across the country, this is not always possible. We are carrying out this study to find out if we can measure the tests in blood samples collected by participants themselves in the same way as if a nurse collected the samples.

What do I have to do if I agree to give a blood sample?

This part of the survey involves a small quantity of blood being obtained by a finger prick and collected in a tube. This would involve pricking your finger and allowing the blood drops to drip into the tube. During your interview we will ask you for your consent to send you a blood sample collection kit. This includes everything you need to collect this sample, as well as detailed instructions of how to collect it. The whole process is very straightforward and should take you just a few minutes.

Will I be given any results?

We will be providing feedback on your blood results.

Your blood sample will be analysed for cholesterol (total cholesterol and HDL), triglycerides and (highly) lipoprotein-related haemoglobin (HbA1c). C-reactive protein, interleukin-6 and testosterone. We will also analyse levels of the following substances related to nutrition (folate, ferritin, vitamin C, vitamin B12 (cobalamin), vitamin B2 (riboflavin), vitamin B6 (pyridoxine), vitamin B12 (cobalamin) and folic acid (folate), vitamin A and related compounds, vitamin E and vitamin D). We will provide feedback on your cholesterol and HbA1c results.

STIM C (document 3) : Participant information sheet about microbiome sample

Understanding Society is very excited to be carrying out new research, looking at the microbiome that live in different people. In particular, we hope to learn how microbiome are influenced by differences in people's lifestyle and environment.

This leaflet tells you more about this part of the study which involves collecting a small poo sample. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve.

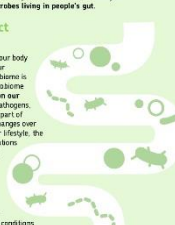
The microbiome – what is it?

The microbiome is the community of microbes that live on and in our bodies. These microbes can include bacteria, fungi and viruses. They live in our gut, on our skin, in our nose and mouth. Each area of the body has a different community of microbes. Each area of the body has a different community of microbes. We are interested in the microbes living in people's gut.

How do microbes affect your body?

Our microbiome acts as a link between our body and the environment we live in. Like our fingerprints, the make-up of our microbiome is unique to us. The microbes in our microbiome are tiny – but they have a big impact on our health. They protect us against bad pathogens, help our immune system, and work as part of our digestive system. It develops and changes over time, as a response to what we eat, our lifestyle, the environment we live in, and the medicines we take. It even changes depending on the people we live with.

The differences in our microbiomes appear to have an impact on whether we become unwell with certain illnesses. And our environment can affect our microbiome, making it more likely that we will develop some health conditions like obesity, cardiovascular disease, allergies, or inflammatory bowel disease.



15 Understanding Society – the UK Household Longitudinal Study Wave 18 Participant information sheet_Microbiome sample_v1
1 October 2022
RAG Project ID: 31919

What if I have concerns about the way the study was carried out?

Please contact Michaela Benzeval, the Director of Understanding Society:

01204 873988

mbenzeval@essex.ac.uk

Paul Clarke, the Research Director of ISER:

01204 873740 ext 404

pclarke@essex.ac.uk

Sarah Manning-Press, the Research Governance and Planning Manager at the University of Essex on:

01204 873545

sarahm@essex.ac.uk

Any questions?

For more information on the poo sample collection go to

www.understandingsociety.ac.uk/health/microbiome

If you would like to contact us at any point you can email or speak to one of us:

0800 252 803

info@understandingsociety.ac.uk

If you are interviewed face-to-face, the interviewer will try to answer any questions you may have.



Understanding Society



Microbiome sample collection

Information for participants

Why are we carrying out this study?


Understanding Society is the first large representative study in the UK to collect poo samples. Because of the size of the study and the rich information we collect from participants, we are in a unique position to make an important contribution to research in this area.

Most studies that have collected poo samples have been small and carried out in a clinic. The aim of this study is to assess whether participants can collect and return their own poo samples to us.

What samples are we collecting for the study?

If you are willing to, we would like you to collect a poo sample following the instructions provided.

As a token of appreciation for collecting the sample we will send you a £5 voucher after the sample is returned to us.



Who is carrying out the research study?

Researchers at the Institute for Social and Economic Research (ISER) at the University of Essex are running the study. Kantar Public and NatCen Social Research will be working with us to conduct fieldwork. Funding has been provided for the study by the Economic and Social Research Council (ESRC). If you return a poo sample the University of Essex will send it to Quadram Institute for analysis. More information about the Quadram Institute can be found on their website: <http://quadram.ac.uk>. Ethics approval for the study has been provided by the XXXX NHS Research Ethics Committee REC Number XXXX.

What do I have to do?

If you agree to take part we would like you to provide us with a poo sample and complete a short questionnaire about your health on the day the sample was taken.

Along with this leaflet, we will send you a poo sample collection kit that you can use at home. The kit contains everything you need to collect the sample, as well as detailed instructions on how to collect your sample. The whole process of collecting your poo sample is straightforward and should take you just a few minutes.

The instructions include information on how to return the sample to us. Please return the sample and the completed questionnaire in the pre-paid envelope.

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1 October 2022
RAG Project ID: 31919

Is it hygienic?

Yes. The kit includes a toilet accessory that attaches securely to the toilet and is simple and clean to use. We have also provided a pair of gloves to use when collecting your sample.

Do I have to take part?

Like every other part of Understanding Society, this part of the study is completely voluntary. You do not need to provide a poo sample if you do not wish to. We recognise that providing a poo sample is different from asking you to answer questions on a survey, but we hope that you will take part in this new and important part of the study.

Will I be given my results?

We will use your poo sample to study the microbiome of your gut. We will not be able to provide any feedback on your sample.

What are the benefits of taking part?

Your participation will help us to assess the feasibility of participants collecting and returning their own poo sample. If participants can collect their own poo sample, this could have a positive impact on research in this area.

Are there any risks to me?

On a practical level, there is very low risk of skin contamination during the collection process. Wearing the gloves provided in the collection kit will minimise this risk.

How will you use information about me?

We will need to use information from you for this study.

This information will include your name and contact details. Kantar and NatCen, our fieldwork partners, will use your name and contact details to carry out the study and to send you the poo sample collection kit, if you agree to this.

If you return a poo sample, the only information that the University of Essex staff receiving the sample and the Quadram Institute, the lab carrying out the analysis, will see is the sample and the barcode. They will not be able to see your name or contact details.

We will keep all information about you safe and secure. The results of the study will never include any names or addresses. The information collected is used for research purposes only and will be dealt with according to the principles of the Data Protection Act and General Data Protection Regulation (GDPR).

Once we have finished the study, the anonymised data are made available from the UK Data Archive and other secure data repositories to genuine and registered researchers. All research reports are written in a way that no-one can work out that you took part in the study.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, and can request that your information is removed. We can remove any information that you have given us which has not yet been deposited with the UK Data Archive, but we are not able to remove data which has already been made available to researchers.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to change the data we hold about you. If you wish to see the data we hold about you, you can make a data subject access request.

Where can I find out more about how my information is used?

You can find out more about how we use your information at www.understandingsociety.ac.uk/health/privacy

What if I change my mind during the study?

Your participation is entirely voluntary. You don't have to do any part of the study that you don't want to. You have the right to withdraw from the study at any time – you do not need to give a reason.



STIM D (document 4): Consent question

Microbiome sample consent question

MBIOMECONSENT [Microbiome consent]

Universe: If (((WAISTANDHIPCAPI.WHEXCLUDE = 2 | 3) | (WHEXCLUDEWEB = 2)) & CURRENTPREGNANCIES.PREGOCP <> 1 & ANTIBIOT = 2) // No colostomy/ileostomy, not pregnant and no antibiotics/antifungal

Text: We would also like to ask you for a sample of your microbiome. The "human microbiome" refers to the vast number of microorganisms that coexist with the human body, particularly in the gut. Research has shown that the microbiome plays an extremely important role in human health and disease. We are asking you to participate in this research by contributing a sample of your poo (also known as faeces, stools or bowel movements). Because scientific findings about microbiomes are still developing, we do not now know all the ways in which your contribution may be valuable to researchers. We recognise that this is very different from asking you to answer questions on a survey, but it is only with your contribution that Understanding Society can be used to help answer cutting-edge and valuable questions about the human microbiome.

We would like to send you a collection kit to use on your own and send back to us. This kit will have everything you need to collect a poo (also known as faeces, stools or bowel movements) sample.

The kit will contain full instructions on how to collect the sample and return it to us. To return it to us, you will need to take your sample to the post office. These kits will also be sent to our lab partner the Quadram Institute to analyse for sample quality.

To thank you for your time and effort, we will send you a £5 voucher for returning the sample to us.

Do you consent to provide a sample that will be analysed by the Quadram Institute for sample quality?

Interviewer Instruction:

PLEASE HAND MICROBIOME PARTICIPANT INFORMATION SHEET TO RESPONDENT.

PLEASE REFER TO YOUR INTERVIEWER INSTRUCTIONS TO ANSWER ANY RESPONDENT QUESTIONS.

IF YOU ARE UNABLE TO ANSWER THE QUESTIONS ON THE SPOT, RING THE OFFICE AFTER THE INTERVIEW AND THEN BE SURE TO CONTACT THE RESPONDENT WITH THE INFORMATION.

1. Yes, kit accepted
2. No, kit accepted

29.Understanding Society - the UK Household Longitudinal Study Wave 16_Consent questions_Microbiome sample_v1
3 October 2022
IRAS Project ID: 319149

STIM E (document 5): Cover letter for sample collection kit



FinalSerialNum
FF_personno/ff_PID

Poo sample collection kit

Dear NAME

Your Understanding Society poo sample collection kit is enclosed. Thank you for agreeing to participate in the biological sample collection part of the study.

Please make sure you read the enclosed collection instructions carefully before collecting the sample. Once you have collected the sample please take it to the Post Office in the pre-paid addressed envelope provided following the instructions.

If you change your mind about participating, please return the unused kit using the pre-paid addressed envelope provided.

For more information on the poo sample collection go to

www.understandingsociety.ac.uk/health/microbiome

If you have any further questions please contact us on **0800 252 853**.
Once again, thank you for agreeing to help Understanding Society in this way.

Yours sincerely



Professor Michaela Benzeval

Director, Understanding Society.
Institute for Social and Economic Research, University of Essex

STIM F (document 6): ISER instructions for sample collection kit



How to collect and return your poo sample

This leaflet explains how to collect and return your poo sample. Please read all the instructions before you begin.

What's in your poo sample collection kit?

Everything you need for collecting your poo sample is enclosed. Your kit contains:

- Sample box
- A pair of EnviroGlove recyclable gloves (latex and powder free)
- Two toilet collection accessories
- OMNIgene-GUT collection kit, containing:
 - Instructions sheet
 - Sample tube with a barcode label on
 - Spatula
- Specimen bag
- Pre-paid addressed envelope

We have also enclosed a short questionnaire about your health which we would like you to complete after collecting your sample.

The barcode on your sample tube and questionnaire is unique to you. If other members of your household are also providing a poo sample, it is very important that you do not get these mixed up.

Important information before you begin

- If you need to urinate, please do so before collecting your sample.
- Avoid collecting urine or water (from the toilet) with the sample. We have provided two toilet collection accessories in case you need to use a second one.

Collecting the sample

1. Take the collection kit to the toilet.
2. Put on the gloves provided.
3. Follow the instructions sheet provided in the kit on how to collect the poo sample.

DNA Genotek, the supplier of the kit, has also produced an instruction video which you can watch online at <https://tinyurl.com/stoolvideo>

4. Once you have collected your sample, place the sample tube into the specimen bag. Seal the bag.
5. Dispose of the gloves in your normal recycling.
6. Now wash your hands thoroughly.

36. Understanding Society - the UK Household Longitudinal Study Wave 16_Sample collection instructions_Microbiome sample_v2
16 December 2022
IRAS Project ID: 319149

Completing the questionnaire

1. Please complete the questionnaire after collecting your sample.
2. Please write your initials at the top of the questionnaire. For example, John Smith would have **JS** initials. **PLEASE DO NOT WRITE YOUR NAME.**

Packing the sample

1. Put the specimen bag inside the box. Then close the box and seal it.
2. Put the box into the pre-paid addressed envelope, along with your completed questionnaire. Seal the envelope.
3. Take the envelope to the Post Office and hand it to a cashier to be scanned.

PLEASE DO NOT WRITE YOUR NAME OR ADDRESS ON THE SAMPLE, QUESTIONNAIRE OR RETURN ENVELOPE. THE BARCODES AND YOUR INITIALS ON THE QUESTIONNAIRE WILL LET US KNOW WHO THESE ARE FROM. THANK YOU.

36. Understanding Society - the UK Household Longitudinal Study Wave 16_Sample collection instructions_Microbiome sample_v2
16 December 2022
IRAS Project ID: 319149

STIM G (document 7): Supplier instructions for sample collection kit



Collection of the fecal sample using the OMNigene®-GUT device and the OM-AC1 toilet accessory

The OM-AC1 toilet accessory is used with the OMNigene®-GUT kit to facilitate the collection of fecal samples.
Read all instructions prior to collection.

Procedure:	
	1. Two toilet accessories are provided in the event that you are unable to collect a sample on the first attempt. Caution: Do NOT allow toilet water, urine, detergent or fragrance to come in contact with the toilet accessory.
	2. Empty your bladder before beginning the collection. Collect fecal sample free of urine or toilet water. Toilet paper or tissues may be required.
	3. Carefully peel open edge with ▲; repeat for edge with ■.
	4. Attach adhesive surface of accessory to BACK of toilet seat with adhesive close to the outer edge of the seat and press firmly.
	5. While holding the yellow tube top, unscrew ONLY the purple cap and set aside for later use. Important: Do NOT remove the yellow tube top. Do NOT spill the stabilizing liquid in the tube.
	6. Use the spatula to collect a small amount of fecal sample. Actual size of fecal sample.
	7. Transfer the fecal sample into the top portion of the yellow tube top. Repeat until the sample fills the yellow tube top. Important: Do NOT push sample into the tube.
	8. Scrape horizontally across the tube top to level the sample and remove any excess. Wipe exterior of tube and top with toilet paper or tissue as needed.

Procedure (continued):	
	9. Pick up the purple cap and screw onto the yellow tube top until tightly closed.
	10. For a minimum of 30 seconds , shake the sealed tube as hard and fast as possible in a back and forth motion.
	11. The fecal sample will be mixed with the stabilizing liquid in the tube; not all particles will dissolve. Important: Continue shaking if large particles remain as shown in Figure A.
	12. Drop used accessory into toilet. Wait 1 minute for paper to become soft, then flush. Alternatively, discard in garbage.
	13. Place spatula in original packaging or wrap in toilet paper and discard in garbage. Important: Send the sample for processing following the delivery instructions supplied separately by the kit provider.

Technical support is available Monday to Friday (9h00 to 17h00 ET):

- Toll-free (North America): 1.866.813.6354, option 6
- All other countries: +1.617.723.3757, option 6
- Email: support@dragenotek.com

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DRAGENOTEK

STIM H (document 8) : Sample collection package – Questionnaire



Please write your initials here: _____

Poo sample questionnaire

Are you currently taking any antibiotics?

- ☐ Yes
☐ No

Are you currently taking any other medications?

- ☐ Yes
☐ No

If you are taking medication and if possible, could you tell us what those medications are?

Have you taken any of the following in the past four weeks? Tick all that apply

- ☐ Vitamins
☐ Cod liver oil
☐ Protein/amino acid supplement
☐ Probiotics
☐ Prebiotics
☐ None of the above

How many bowel movements have you had in the last 7 days? Tick one box only

- ☐ None
☐ One
☐ 2-3
☐ 4-6
☐ 7 or more

Using the Bristol stool chart (below) please indicate what type of poo (stool) you had for the sample you collected

- ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Bristol stool chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely liquid

Time you collected the poo sample: ____:____ AM/PM

Date you collected the poo sample: ____/____/____ DD/MM/YY

PLEASE STICK THE BARCODE LABEL HERE

68_Understanding Society - the UK Household Longitudinal Study Wave 16_Microbiome sample questionnaire_v01 | 3 October 2022 | RRG Project ID: 319149

68_Understanding Society - the UK Household Longitudinal Study Wave 16_Microbiome sample questionnaire_v01 | 3 October 2022 | RRG Project ID: 319149

8. Appendix C – Final sample frame


	TARGET	RECRUITED
TOTAL		
Depths	25	25
PRIMARY QUOTAS		
AGE 18 - 24		
Gender		
Male	2	2
Female	2	3
AGE 25 - 34		
Gender		
Male	2	4
Female	2	3
AGE 35 - 44		
Gender		
Male	2	3
Female	2	2
AGE 45 - 54		
Gender		
Male	2	2
Female	2	2
AGE 55+		
Gender		
Male	2	2
Female	2	2
SECONDARY QUOTAS		
Ethnicity		

White - British	mix and monitor	8
White - Irish		0
Any other white background		4
Mixed - White & Black Caribbean		1
Mixed - White & Black African		0
Mixed - White & Asian		2
Any other mixed background		2
Chinese or other Ethnic group - Chinese		1
Chinese or other Ethnic group - Any other		0
Black or Black British - Caribbean		0
Black or Black British - African		2
Any other Black background		0
Asian or Asian British - Indian		2
Asian or Asian British - Pakistani		1
Asian or Asian British - Bangladeshi		0
Any other Asian background		2
Refused		0
Location		
Greater London	mix and monitor	6
South East		4
South West		2
West Midlands		1
North West		6
North East		1
Yorkshire and the Humber		0
East Midlands		2
East of England		0
Scotland		2
Wales		1

Northern Ireland		0
English as an Additional language (EAL)		
EAL		5
Non-EAL		20


9. Appendix D – final W16 Fieldwork materials updated following recommendations from the qualitative study

W16 Invitation letter (i.e. updated STIM A above)



FF_PersonalID

Contact us:
Participant helpline: 0800 252 853
Web: www.understandingsociety.ac.uk/participants
Email: contact@understandingsociety.ac.uk
For details of the study's privacy policy, please see <https://www.understandingsociety.ac.uk/participants/gdpr>



RESP_Name
ff_Address1
ff_Address2
ff_Address3
ff_Address4
ff_Address5
ff_PostCode

XX/XX/XXXX

It's time for your Understanding Society interview

Salutation
Thank you for being part of Understanding Society.
Every time you're interviewed it helps us understand more about life in the UK today. Interviewing you every year helps us see what's changed and what's stayed the same in your life – this is why we'd like you to complete your interview again this year.
We may also send you an SMS message to your phone with a personalised link to your survey to make it easier for you to access it from your phone. If you are not able to complete your interview in the first week or so, we may send you a reminder in the form of an SMS message.

This year we'd like to ask you more about your health

As part of your interview, we'd like you to give us a few simple health measurements. This is completely voluntary – you don't have to do this part of the interview, but we hope that you will. Collecting health measures on a large study from a variety of people will help researchers better understand the health of the UK population. There is more information in the leaflet accompanying this letter.
Blood pressure
We would like to ask you to have your own blood pressure measured before completing the online questionnaire. You can take the blood pressure measure at home, if you have the equipment available, or alternatively you can visit your local GP surgery, or a pharmacy where this service is offered for free.
If you are able to obtain your blood pressure readings, please use the enclosed card to record the measures as well as where and when the readings were taken. We will then ask to report those readings to us during your interview. If you are pregnant we are not asking you to get your blood pressure measured. If you cannot obtain your blood pressure readings, we would still like you to take part in the interview.
Body Mass measures
We are also interested in body shape – included in this letter is a tape measure. If you are willing, please measure your **waist and hips**, following the instructions in the leaflet enclosed, and write down the results on the enclosed card. You will be asked to enter the numbers during your interview.
Blood and poo samples
During your interview we will ask you if you agree for us to send you a kit so you can take a small sample of your blood and another kit so you can collect a small sample of your poo. The kits will contain everything you need to collect the samples including detailed instructions on how to use them. You do not have to do both, or either, of these – this is completely voluntary. If you do not want to take either of these samples, then we would still be grateful if you could complete your normal survey.

Thank you for your support

We're very grateful that you take part in Understanding Society. To say thank you for your help, we've enclosed a **£20 gift card** which is activated and ready to use. If you're able to complete your interview online by **Early_bird_date** we will send you an **extra £10 gift card** as a thank you for completing your survey early.
If you send us your blood and stool samples we will give you an **extra £5** per sample.
Have questions or want more information?
Call our participant helpline on 0800 252 853 or email us contact@understandingsociety.ac.uk. We'll be pleased to hear from you and answer any questions you have.
With many thanks,
Professor Michaela Benzeval
Director, Understanding Society.

Taking part 1
Visit the website
www.understandingsociety.ac.uk/society

2
Enter your
user name: username
and password: password
We may send you a SMS text to
your phone with a personalised
link to your survey.

3
Answer the
questions in your
own time.
If you can't complete the survey
online that's fine – we can
arrange for an interviewer
to visit you instead.

Understanding Society is being conducted in accordance with the Data Protection Act. This means your personal details will be kept strictly confidential and you and your household will not be identifiable from the data.

262400907 / W16 Letter 2

2

W16 Participant Information Sheet about Health Measures (i.e. updated STIM B above)

Everyone involved in this study will keep your data safe and secure. The results of the study will never include any names or addresses. The information collected is used for research purposes only and will be dealt with according to the principles of the Data Protection Act and General Data Protection Regulation (GDPR).

At the end of the study, anonymised data are made available from the UK Data Archive, the European Genome-Phenome Archive, other secure data repositories or by the study team to trusted researchers. All research reports are written in a way that no-one can work out that you took part in the study.

What if I change my mind during the study?

Your participation is entirely voluntary. You have the right to change your mind about any measurement or withdraw from the study at any time without explanation. You can withdraw your consent to store your blood at any time, without giving a reason, by asking us in writing for your blood to be removed from storage and destroyed.

What if I have concerns about the way the study was carried out?

Please contact Michaela Benoud, the Director of Understanding Society

0206 873983 mbeoud@essex.ac.uk

Paul Clarke, the Research Director of ISER

0206 873740 pclarke@essex.ac.uk

Martina Gordinas, the Research Governance and Planning Manager at the University of Essex

0206 876320 mg21994@essex.ac.uk

If you would like to contact us at any point please use the contact information below:

0800 252 853 contact@understandingsociety.ac.uk

If you are interviewed face-to-face, the interviewer will try to answer any questions you have.



Combining this genetic data with information about your environment, lifestyle, and health allows researchers to investigate the complex interaction of people's health and circumstances. Over time, how genes function can be changed either naturally or by our environment. One measurement of this is known as methylation, and we will also measure this so researchers can explore if and how this puts people at increased risk of health problems.

Will I be given any results?

We will provide feedback on your cholesterol and HbA1c results.

Why are you collecting poo samples?

Poo sample collection has not yet been done on a large representative study before - Understanding Society is the first study to try to do this. Research suggests that analysing poo samples can provide valuable information about the health of the population by looking at our body's microbiome.

The microbiome is the community of microbes that live in and on our body. Our bodies carry around trillions of these microbes which are invisible to the naked eye. They live in our gut, on our skin, in our nose and mouth. Each area of the body has a different community of microbes.

Our microbiome acts as a link between our body and the environment we live in. Like our fingerprints, the make-up of our microbiome is unique to us. The microbes in our microbiome are tiny - but they have a big impact on our health. They protect us against toxic pathogens, help our immune system, and work as part of our digestive system. It develops and changes over time.

as a response to what we eat, our lifestyle, the environment we live in, and the medications we take. It even changes depending on the people we live with. The differences in our microbiomes appear to have an impact on whether we become unwell with certain illnesses. And our environment can affect our microbiome, making it more likely that we will develop some health conditions like obesity, cardiovascular disease, allergies, or inflammatory bowel disease.

What do I have to do if I agree to give a poo sample?

If you agree to take part, we would ask you to provide us with a poo sample and complete a short questionnaire about your health on the day the sample was taken.

At the end of the survey we will ask you for your consent to send you a poo sample collection kit. This includes everything you need to collect this sample, as well as detailed instructions of how to collect it. The whole process is very straightforward and should take you just a few minutes.

There are no risks associated with measuring your blood pressure, waist and hip, and height and weight.

Your finger may be a bit sore from the finger prick used to collect the blood sample. As you would with any small cut, the area should be kept clean to avoid infection. The blood collection kit is sterile and following the instructions provided in the kit will minimise risk of infection. There is a very low risk of skin contamination during the poo sample collection. Wearing the gloves provided in the collection kit will minimise this risk.

How will we keep your information safe?

In this research study we will use information from you. We will only use information that we need for the research study. Verian and NatCan, our fieldwork partners, will use your name and contact details so they can invite you to the study and carry out fieldwork. If you take part in the blood sample collection, then, the lab carrying out the analysis, will use your contact details and your date of birth and sex so that they can send you a collection kit and analyse your blood sample. Verian will send you the results of your blood analysis, if you wish to receive these.

If you agree to have your blood stored for future research, your name and address will not be attached to the sample and so your sample will remain confidential. Before being used in future research, some of the information we have collected in this survey (but not any details which would identify you) may be attached to the sample.

Will I be given any results?

Your poo sample will be analysed to identify the collection of bacteria and other microbes living in your digestive system. We will do this by extracting DNA from your poo sample and testing it to identify the microbes that may be present. We will look at the DNA of the microbes living in your body, not your DNA. We will not be able to provide any feedback on your sample.

Who is carrying out the research study?

Researchers at the Institute for Social and Economic Research (ISER) at the University of Essex are running the study. Verian (formerly Kantar Public) and National Centre for Social Research (NatCan) will be working with us to conduct fieldwork and collect the measurements. Ethical approval for the study has been provided by the NHS Health Research Authority, East of England - Essex Research Ethics Committee, reference: 22/E02030.

Do I have to take part?

Like every other part of Understanding Society, this part of the project is **completely voluntary**. You do not need to have any measurements (e.g., blood pressure, height, weight, waist and hips circumference) taken or samples (blood or poo) collected if you do not wish to, but we hope you will agree to them as they are a **very important part of this survey**. If the survey results are to be useful to us, it is important that we obtain information from different people in all states of health. If you are happy to take part in some measurements and sample collections but not others, this is absolutely fine.

Are there any risks involved in participating?

There are no risks associated with measuring your blood pressure, waist and hip, and height and weight.

Your finger may be a bit sore from the finger prick used to collect the blood sample. As you would with any small cut, the area should be kept clean to avoid infection. The blood collection kit is sterile and following the instructions provided in the kit will minimise risk of infection. There is a very low risk of skin contamination during the poo sample collection. Wearing the gloves provided in the collection kit will minimise this risk.

How will we keep your information safe?

In this research study we will use information from you. We will only use information that we need for the research study. Verian and NatCan, our fieldwork partners, will use your name and contact details so they can invite you to the study and carry out fieldwork. If you take part in the blood sample collection, then, the lab carrying out the analysis, will use your contact details and your date of birth and sex so that they can send you a collection kit and analyse your blood sample. Verian will send you the results of your blood analysis, if you wish to receive these.

If you agree to have your blood stored for future research, your name and address will not be attached to the sample and so your sample will remain confidential. Before being used in future research, some of the information we have collected in this survey (but not any details which would identify you) may be attached to the sample.

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

We would like to collect:

- your blood pressure
- your waist and hip measurements
- your height and weight
- a blood sample
- a small poo sample

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Understanding Society

Health Measures

We would like to collect:

- your blood pressure
- your waist and hip measurements
- your height and weight
- a blood sample
- a small poo sample

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Understanding Society

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We would like to collect:

- your blood pressure
- your waist and hip measurements
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Understanding Society

Health Measures

We would like to collect:

- your blood pressure
- your waist and hip measurements
- your height and weight
- a blood sample
- a small poo sample

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Understanding Society

Health Measures

We would like to collect:

- your blood pressure
- your waist and hip measurements
- your height and weight
- a blood sample
- a small poo sample

Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve.

Understanding Society

Health Measures

We would like to collect:

- your blood pressure
- your waist and hip measurements
- your height and weight
- a blood sample
- a small poo sample

W16 Participant Information Sheet about Microbiome Sample Collection (i.e. updated STIM C above)

Understanding Society is very excited to be carrying out new research, looking at the microbiome that live in different people. In particular, we hope to learn how microbiome are influenced by differences in people's lifestyle and environment.

The microbiome – what is it?

The microbiome is the community of microbes that live on and in our bodies. They live in our gut, on our skin, in our nose and mouth. Each area of the body has a different community of microbes. We are interested in the microbes living in people's gut.

How do microbes affect our body?

Our microbiome acts as a link between our body and the environment we live in. Like our fingerprints, the make-up of our microbiome is unique to us. The microbes in our microbiome are tiny – but they have a big impact on our health. They protect us against toxic pathogens, help our immune system, and work as part of our digestive system. It develops and changes over time, as a response to what we eat, our lifestyle, the environment we live in, and the medications we take. It even changes depending on the people we live with.

The differences in our microbiomes appear to have an impact on whether we become unwell with certain illnesses. And our environment can affect our microbiome, making it more likely that we will develop some health conditions like obesity, cardiovascular disease, allergies, or inflammatory bowel disease.



What if I have concerns about the way the study was carried out?

Please contact Michaela Benzeval, the Director of Understanding Society:

01206 873783

mbenzeval@essex.ac.uk

Paul Clarke, the Research Director of ISER:

01206 873740

pclarke@essex.ac.uk

Mantelena Sotiriadou, the Research Governance and Planning Manager at the University of Essex:

01206 876320

ms21994@essex.ac.uk

Any questions?

For more information on the poo sample collection go to

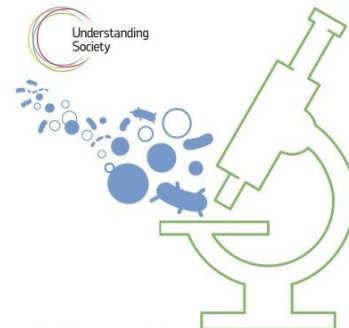
www.understandingsociety.ac.uk/projects/health/microbiome

If you would like to contact us at any point you can email or speak to one of us:

0800 252 853

contact@understandingsociety.ac.uk

If you are interviewed face-to-face, the interviewer will try to answer any questions you may have.



Microbiome sample collection

Information for participants



Why are we carrying out this study?

Understanding Society is the first large representative study in the UK to collect poo samples. Because of the size of the study and the rich information we collect from participants, we are in a unique position to make an important contribution to research in this area.

What samples are we collecting for the study?

If you are willing to, we would like you to collect a poo sample following the instructions provided.

As a token of appreciation for collecting the sample we will send you a £5 voucher after the sample is returned to us.



Who is carrying out the research study?

Researchers at the Institute for Social and Economic Research (ISER) at the University of Essex are running the study. Verian (formerly Kantar Public) and National Centre for Social Research (NatCen) will be working with us to conduct fieldwork. Funding has been provided for the study by the Economic and Social Research Council (ESRC). If you return a poo sample the University of Essex will send it to Quadram Institute for analysis. More information about the Quadram Institute can be found on their website: <https://quadram.ac.uk>. Ethics approval for the study has been provided by the NHS Health Research Authority, East of England – Essex Research Ethics Committee, reference: 22/EE/0260.

What do I have to do?

If you agree to take part we would like you to provide us with a poo sample and complete a short questionnaire about your health on the day the sample was taken. Along with this leaflet, we will send you a poo sample collection kit that you can use at home. The kit contains everything you need to collect the sample, as well as detailed instructions on how to collect your sample. The whole process of collecting your poo sample is straightforward and should take you just 15 minutes. The instructions include information on how to return the sample to us. Please return the sample and the completed questionnaire in the pre-paid envelope.

Is it hygienic?

Yes. The kit includes a toilet accessory that attaches securely to the toilet and is simple and clean to use. We have also provided a pair of gloves to use when collecting your sample.

How long do I have to collect and return the sample?

Once you receive the kit, you can collect the sample whenever is most convenient for you in the next couple of weeks. To return the sample to us, you will need to take your envelope to the post office counter within two weeks of collecting it.

What will happen to the poo sample I provide?

We would like to use your poo sample to study the microbiome of your gut. By combining this data with information about your environment, lifestyle and health, we hope to learn how our microbiome is affected by other factors in our life.

Are there any health or medical reasons why I should not give a poo sample?

We advise people with certain conditions do not collect a poo sample. These are:

- Participants who are pregnant
- Participants who have a colostomy or ileostomy
- Participants who have taken antibiotics or anti-fungals in the past six months

Do I have to take part?

Like every other part of Understanding Society, this part of the study is completely voluntary. You do not need to provide a poo sample if you do not wish to. We recognise that providing a poo sample is different from asking you to answer questions on a survey, but we hope that you will take part in this new and important part of the study.

What analyses will be done on the poo sample?

Your poo sample will be analysed to identify the collection of bacteria and other microbes living in your digestive system. We will do this by extracting the DNA from the microbes in your poo sample. This is how we identify which microbes are present. We will look at the DNA of the microbes in your body, not your DNA.

Will I be given my results?

We will not be able to provide any feedback on your sample.

What are the benefits of taking part?

Your participation will help us to learn about the microbiome in different people. We hope that knowing more about the microbiome will help us to understand and treat diseases, as well as improving our general health.

Are there any risks to me?

On a practical level, there is very low risk of skin contamination during the collection process. Wearing the gloves provided in the collection kit will minimise this risk.

How will you use information about me?

We will need to use information from you for this study. This information will include your name and contact details. Verian and NatCen, our fieldwork partners, will use your name and contact details to carry out the study and to send you the poo sample collection kit. If you agree to this.

If you return a poo sample, the only information that the University of Essex staff receiving the sample and the Quadram Institute, the lab carrying out the analysis, will see is the sample, the barcode, and the poo sample questionnaire. They will not be able to see your name or contact details.

We will keep all information about you safe and secure. The results of the study will never include any names or addresses. The information collected is used for research purposes only and will be dealt with according to the principles of the Data Protection Act and General Data Protection Regulation (GDPR).

Once we have finished the study, the anonymised data are made available from the UK Data Archive and other secure data repositories to trusted researchers. All research reports are written in a way that no-one can work out that you took part in the study.

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason. In the unlikely event of you losing capacity, we would withdraw you from the study. You, or a representative on your behalf, can request that your information is removed. We can remove any information that you have given us which has not yet been deposited with the UK Data Archive, but we are not able to remove data which has already been made available to researchers. Any personal information held by us, such as your contact details can be removed at any time.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to change the data we hold about you. If you wish to see the data we hold about you, you can make a data subject access request.

Where can I find out more about how my information is used?

You can find out more about how we use your information at www.understandingsociety.ac.uk/projects/health/privacy

What if I change my mind during the study?

Your participation is entirely voluntary. You don't have to do any part of the study that you don't want to. You have the right to withdraw from the study at any time – you do not need to give a reason.



W16 Cover letter for Microbiome sample collection kit (i.e. updated STIM E above)

Poo sample collection kit

DATE

Dear NAME

Thank you for agreeing to participate in the biological sample collection part of the study. Your Understanding Society poo sample collection kit is enclosed.

Please make sure you read the enclosed collection instructions carefully before collecting the sample. You can collect the sample whenever is most convenient for you in the next couple of weeks.

Once you have collected the sample please take it to the Post Office in the pre-paid addressed envelope provided following the instructions and hand it in at the counter. Please return the sample to us within two weeks of using the kit, if possible.

For more information on the poo sample collection go to

www.understandingsociety.ac.uk/projects/health/microbiome

If you have any further questions please contact us on **0800 252 853**.
Once again, thank you for agreeing to help Understanding Society in this way.

Yours sincerely

Professor Michaela Benzeval
Director, Understanding Society
Institute for Social and Economic Research, University of Essex

W16 ISER instructions for Microbiome sample collection kit (i.e. updated STIM F above)



How to collect and return your poo sample

Please read all the instructions before you begin

What is in your poo sample collection kit?

Everything you need for collecting your poo sample is enclosed. Your kit contains:

- 1 x sample box
- 1 x pair of gloves (latex and powder free)
- 2 x toilet collection accessories
- 1 x OMNI-gene-GUT collection kit containing an instruction sheet, sample tube with a barcode label and a spatula
- 1 x specimen bag
- 1 x pre-paid addressed envelope



We have also enclosed a short questionnaire about your health which we would like you to complete after collecting your sample.

! The barcode on your sample tube and questionnaire is unique to you. If other members of your household are also providing a poo sample, it is very important that you do not get your sample collection kits mixed up.

Collecting the sample

- ☐ Put on the gloves.
- ☐ Go to the instruction sheet provided in the kit on how to collect the poo sample.
- ☐ Come back to these instructions. Place the sample tube in the specimen bag and seal the bag.
- ☐ Dispose of the gloves in your normal rubbish bin.
- ☐ Wash your hands thoroughly.



Toilet collection accessory



Collection kit and instructions



Specimen bag

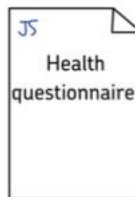
Completing the questionnaire

Please complete the questionnaire after collecting your sample.

Please write your initials at the top of the questionnaire. For example, John Smith would have JS initials.



Do not write your name on the questionnaire.



Packing the sample

Put the specimen bag inside the box. Close the box and seal it.

Put the box in the pre-paid addressed envelope, along with your completed questionnaire. Seal the envelope.

Take the envelope to the Post Office and hand it in at the counter.



Please return the sample within two weeks of using the kit.



Please do not write your name or address on the sample, questionnaire or the return envelope. The barcode and your initials on the questionnaire will let us know who these are from.



Specimen tube in bag



Packed envelope, ready for posting

Thank you for donating a poo sample - we really appreciate it.

W16 Microbiome sample questionnaire (i.e. updated STIM H above)



Thank you for your help. Please place the questionnaire in the pre-paid envelope provided and take it to the Post Office, together with the sample.

68. Understanding Society - the UK Household Longitudinal Study Wave 16, Microbiome sample questionnaire_v2 | 11 September 2023 | IRAS Project ID: 319149



Please write your initials here: _____

Completing the questionnaire

The questions can be answered by putting an 'x' in the box next to the answer you want to give, like this: ☒

Please complete the questionnaire in black or blue ink, keeping your answers within the boxes. If you change your mind about an answer you have given, completely block out the box you have crossed like this, ☒ and then put a cross in your preferred box.

Some questions may not apply to you and you will be taken to the next one that does by following an arrow and question number like this: → 4

Poo sample questionnaire

1. Are you currently taking any antibiotics or antifungals?

- ☐ Yes
☐ No

2. Are you taking or using any of the following prescribed by a doctor or nurse? Cross all boxes that apply.

- ☐ Pills/tablets
☐ Lotions/creams/ointments
☐ Injections/implants
☐ Inhaler/puffer
☐ Drops (eye, ear)
☐ Patches/gels
☐ Suppositories
☐ Other medication
☐ None of the above → 4

Please turn over

3. Can you tell us the names of all the medications that you are taking or using, prescribed by a doctor or nurse?

4. Have you taken any of the following supplements in the past four weeks? Cross all boxes that apply.

- ☐ Vitamins
☐ Cod liver oil
☐ Protein/amino acid supplement (for example, tablets, powder, bars, shakes)
☐ Probiotics
☐ Prebiotics
☐ None of the above



5. How many times have you had a poo (bowel movement) in the last 7 days? Cross one box only.

- ☐ None ☐ 7-8
☐ One ☐ 9-13
☐ 2-3 ☐ 14 or more
☐ 4-6

6. Using the Bristol stool chart (right) please indicate what type of poo (stool) you had for the sample you collected

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Bristol stool chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. Entirely liquid

7. Write in the time you collected the poo sample:

Hour _____ Minutes _____ AM/PM (delete as appropriate)

8. Write in the date you collected the poo sample:

Day _____ Month _____ Year _____

Please turn over