

Retaining participants in the UK COVID-19 Infection Survey (CIS)

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12 June 2023



Background – The COVID-19 Infection Survey

What is the COVID-19 Infection Survey (CIS)?

- The CIS was considered the Gold standard COVID-19 surveillance survey, stood up at pace in April 2020.
- 448k active participants by October 2021 – a nationally representative sample of UK households
- 3,000 study workers travelling door to door to take swab samples, blood samples and complete a questionnaire on the doorstep, with each household member every month.

Why was participant retention important?

- The longitudinal sample has been valuable in understanding the impact of vaccines over time and infection rates of symptomatic and asymptomatic individuals.
- The CIS is the only longitudinal COVID-19 study so is an extremely valuable asset
- It costs significantly more to recruit new participants to replenish sample (extra print and postage costs)

The problem statement: Needed to significantly reduce budget due to reduced funding:

- Needed to reduce sample size but maintain representativity,
- Reducing compensation from 21st March (from £25 to £20)
- Move to a more cost-effective remote approach but would require participants to ‘opt in’

How did we identify problems for our participants?

Gathering feedback from participants through:

- Feedback from study workers about pain points (15 qualitative interviews and general feedback)
- Learning from key participant complaints/queries to the call centre
- Findings from the quantitative user feedback survey about general experience >30k responses
- Findings from 13 in-depth qualitative participant interviews

We found:

Lack of flexibility in when they take part was reducing response rates – especially since return to work

Feeling rushed to take samples whilst someone waits on their doorstep

Study workers were paraphrasing the questionnaire reducing consistency

Awareness of the huge costs and environmental impact of study workers travelling

How did we improve the experience to retain participants?

Removal of study workers and F2F design to a digital-first design:

- Be more flexible around when participants take part (14 day window)
- Reduce CO2 emissions (from 10k tonnes per year)
- Be more cost-efficient, by removing the travel time and costs of (circa 3,000) SWs going door to door
- Reduce risk of infection for both participants and SWs through remote data collection
- Reduce interviewer bias by questionnaires being completed primarily online
- Removing time pressure to conduct their biosample tests quickly whilst someone waits

Conducted vast amounts of user research to shape the new design to user needs, make it accessible, and to gather ongoing feedback to iterate and improve:

- 75 qualitative interviews – feedback about questionnaire wording, design, and materials
- 2,356 responses to quantitative feedback surveys to test favourability of different concepts
- Over 20,000 free text responses from the main CIS questionnaire to explain specific issues

How did we ensure success during the transition?

- **Used behavioural insights to improve participant materials**

Used a more personal tone, emphasising individual contribution and importance and relevance.

- **Demonstrated commitment to improvements**

By allowing participants to report issues/feedback at the bottom of each page of the questionnaire on an ongoing basis

- **Implemented reminder emails**

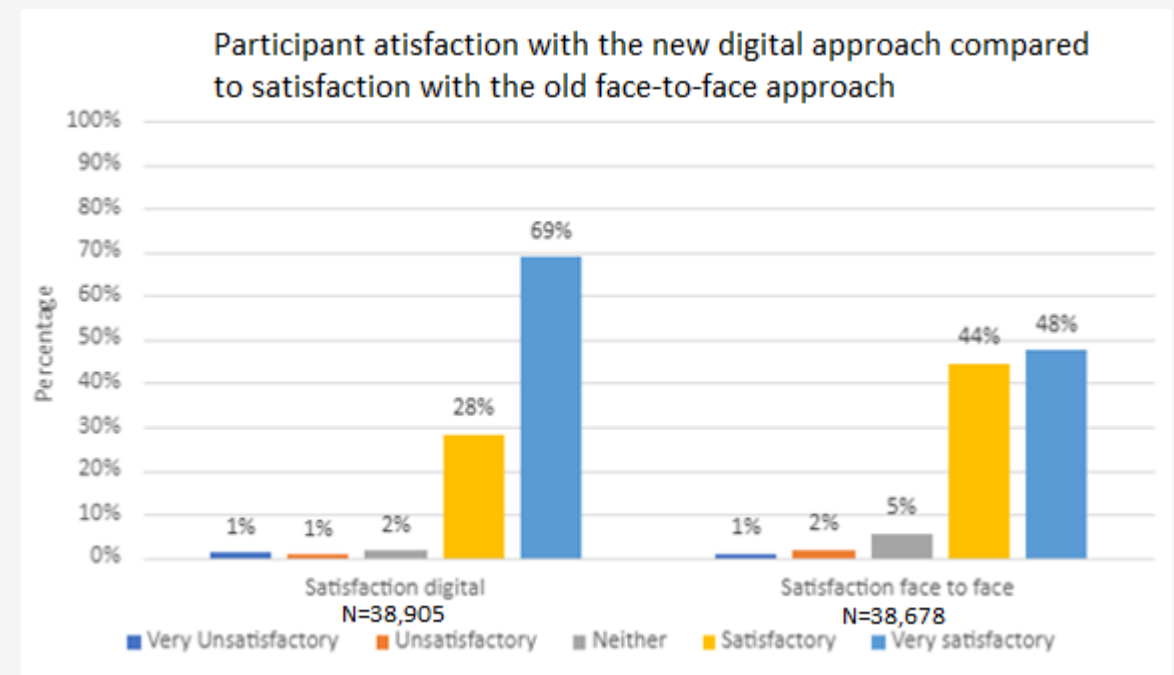
To increase initial opt-in and monthly response rates.

- **Highlighted the value of their participation**

By sharing latest study findings with participants in quarterly newsletter

- **Continued to collect feedback through a quantitative survey in a quarterly newsletter**

To measure and compare satisfaction pre and post transition and on an ongoing basis(>162k responses).



How did we measure success?

- Retained approximately 90% of our sample
 - February 2022 before voucher reduction = 441,266 active participants
 - July 2022 post transition = 397,354 active participants

- Measuring changes in representativity of our sample:

Participants providing samples through remote data collection and study worker home visits share generally very similar profiles, both when unadjusted and when adjusted, with the majority of differences between these population samples being below 1 percentage point.

Absolute difference in percentage points	Age	2 to 7 years	8 to 11 years	12 to 15 years	16 to 24 years	25 to 34 years	35 to 49 years	50 to 59 years	60 to 64 years	65 to 69 years	70 to 74 years	75 to 79 years	80 years and above
	Unadjusted		0.0	0.3	0.4	0.1	-0.8	-0.4	0.0	0.5	0.4	0.2	-0.1
Adjusted		-0.3	0.1	0.3	0.0	-0.1	0.0	-0.3	0.2	0.0	0.4	0.1	-0.4

Absolute difference in percentage points	Sex	Male	Female
	Unadjusted		0.2
Adjusted		0.0	0.0

Absolute difference in percentage points	Ethnicity	White	Asian	Black	Other	Mixed
	Unadjusted		0.3	0.0	-0.1	0.0
Adjusted		0.9	-0.4	-0.3	-0.1	-0.2

The latest challenge for retention

- The CIS has been paused whilst UKHSA review their approach to surveillance, and consider future funding.
- **Any further surveillance would need to further reduce costs:**
 - smaller sample size (but still needs to be representative)
 - removal of compensation – concerning impact on representativity
- **If we stop collecting data from this valuable longitudinal cohort:**
 - likely disengagement of the sample
 - a data gap, reducing the overall value of the dataset in future

How are we retaining participants right now?

- The ONS have funded a temporary questionnaire-only study called the **COVID-19 and Respiratory Infections (CRIS)**, from April-June 2023 whilst decisions around the future of the CIS are ongoing.
- The problems CRIS is trying to solve:

Make the questionnaire more relevant to participants and analytically

Continue to monitor symptoms, understand the impact of all respiratory infections on daily life, absence from work and use of medical services, and understand the prevalence of long-COVID

Maintain participant engagement from the valuable longitudinal cohort

Prevent a large data gap

Move from household to individual sampling to maintain representativity despite a smaller sample

To test, iterate and improve the new questionnaire, in new in-house technology

- Setting up a separate questionnaire-only study meant that we could proceed at pace through the National Statistician's Data Ethics Advisory Committee (NSDEC) , without the need to secure a new Chief Investigator and resubmit a new medical ethics protocol.

What next?

- CRIS survey has been running since 11 April. Most participants have completed their first questionnaire, some are onto their second.
- Collecting feedback and implementing improvements or adding to a backlog.
- First analysis, including results about representativity and sample size will be published in July 2023.
- Awaiting decisions on continuation or closedown of the study at end of June.

Any Questions?

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