Minutes of the meeting of the Sub Committee of the Confidentiality Advisory Group

10 February 2023 via correspondence

Present:

Name	Role	Items
Dr Sandra Duggan	CAG Member	2a
Dr Katie Harron	CAG Member	2a
Dr Murat Soncul	CAG Alternate Vice Chair	2a

Also in attendance:

Name	Position (or reason for attending)
Mr Dayheem Sedighi	HRA Approvals Administrator
Ms Caroline Watchurst	HRA Confidentiality Advisor

1. Expressions of interest

There were no conflicts of interest declared.

2.New Precedent Set Review Applications

a. 23/CAG/0022- Infant Feeding Survey 2023

Context

Purpose of application

This non-research application submitted by Ipsos UK on behalf of the Department for Health and Social Care (DHSC), sets out the purpose of conducting the 2023 Infant Feeding Survey, to understand how mothers in England feed their babies, where they get advice about feeding their babies, and about their pregnancy and lifestyle. 's251' support is only requested for the purposes of contacting participants to seek implied consent to take part. Any process after the return of the questionnaire, is undertaken with implied consent as the legal basis under common law.

The Infant Feeding Survey is a well-established survey that has been running since 1975. This will be the 9th wave of the survey, the last survey being 2010. DHSC have commissioned Ipsos UK to run the survey process. The purpose of this application is to inform DHSC's policy decision making processes, and will provide valuable information on infant feeding behaviours including breastfeeding, the use of foods and drinks other than breastmilk in infancy and other related matters. The survey is also a key commitment from government as part of the childhood obesity plan. It will provide vital information to monitor efficacy of current policies, and inform the development of new policies to ensure that all children are provided with the best start in life. The anonymised dataset will be made available on the UK Data Archive for other organisations to access to support DHSC, and other organisations develop public policy and programmes to support mothers to breastfeed.

The 2023 survey will be based on a representative sample from NHS England (previously NHS Digital), of mothers who are selected from all births in England registered during a set period. Three phases of data collection with the same sample of mothers will be conducted. Mothers will be asked to complete one questionnaire when their baby is ten to thirteen weeks, one questionnaire when their baby is four to six months, and one questionnaire when their baby is eight to ten months old. The applicants have built in a sample boosting strategy that aims to boost the sample amongst those ethnic groups who are less likely to respond to questionnaires. A small incentive will also be offered to those from the most deprived quintile, measured using the indices of social deprivation at a lower-level super output area (LSOA).

The survey will follow a similar mixed method approach as the Maternity Survey 2021 and 2022, which is also carried out by Ipsos UK, with the same population. The contacts will be as follows;

Contact	Type	Content of contact	Days from first mailing

1	Postal	Invitation letter inviting the patient to take part online, Multi-language sheet	1
1.1	SMS	SMS reminder (if phone number available), 3 days after mailing 1	4
2	Postal	Reminder letter, Multilanguage sheet	7
2.1	SMS	SMS reminder (if phone number available), 3 days after mailing 2	10
3	Postal	Reminder letter, Paper questionnaire, Freepost return envelope, Multi-language sheet	17
4	Postal	Reminder letter, Multilanguage sheet	24
4.1	SMS	SMS reminder (if phone number available), 3 days after mailing 4	27

A recommendation for class 5 and 6 support was requested to cover access to the relevant unconsented activities as described in the application.

Confidential patient information requested

The following sets out a summary of the specified cohort, listed data sources and key identifiers. Where applicable, full datasets and data flows are provided in the application form and relevant supporting documentation as this letter represents only a summary of the full detail.

Cohort	Mothers aged 16 years or over at the time of delivery, who gave birth under the care of an NHS trust (including home births), in a given month (specific month contingent on the DARS processing times). Approximately 26,483 people will have invitations sent. Detailed inclusion criteria are in the CAG application form.
Data sources	1. NHS England (previously NHS Digital); a. Maternity Services Dataset b. Personal Demographics Service
Identifiers required for purposes of identifying the cohort and sending invitation to consent	1. Name 2. Address Fields including postcode 3. Mobile phone number 4. Patient unique survey identifier 5. Date of birth 6. Date of death 7. Ethnicity
Identifiers required for analysis	1. Patient unique survey identifier 2. NHS Site code (of birth)

purposes (disclosed to IPSOS UK prior to implied consent in place)	3. Postcode – retained in full format for calculation of various variables (as per CQC surveys) 4. Mobile Phone indicator 5. Patient Date of Birth (Mother) 6. Patient Death Status (Mother) 7. Gender (Mother) 8. Ethnic group (Mother) 9. Actual delivery place 10. Delivery method 11. Maternal Critical Incident Indicator 12. Number of babies born at delivery 13. Patient date of birth (Baby / babies) 14. Baby phenotypic sex 15. Patient Death Status (Baby / babies) 16. Breast milk given for first feed (Baby / babies) 17. Baby admitted to neonatal critical care (Baby / babies) Analysis will be undertaken with implied consent

Confidentiality Advisory Group advice

The following sets out the Confidentiality Advisory Group advice which formed the basis of the decision by the Secretary of State for Health and Social Care.

Public interest

The CAG noted that this activity fell within the definition of the management of health and social care services and was therefore assured that the application described an appropriate medical purpose within the remit of the section 251 of the NHS Act 2006 and was in the public interest.

Practicable alternatives

Members considered whether a practicable alternative to the disclosure of confidential patient information without consent existed in accordance with Section 251 (4) of the NHS Act 2006, taking into account the cost and technology available.

- **Feasibility of consent**

The applicant has provided justification as to why consent is not practicable, which has been accepted across other national surveys;

- Attempting to consent every individual would have the potential to introduce bias into the survey findings, as the types of patients who proactively opt-in to surveys tend to be atypical of the general patient population and tend to hold more extreme views (both positive and negative).

- The evidence used to monitor or develop government policies and initiatives must be up to date and accurate. Therefore this data collected by Ipsos on behalf of DHSC on the infant feeding practices, behaviours, and attitudes of mothers in England must be representative of and generalisable to the maternal population to ensure its validity. Black and Asian women are at an increased risk of poor maternity outcomes and therefore may be less likely to give consent in the time immediately following birth, which is the only time frame during which it would be possible for consent to be sought. It is particularly important that the views and experiences of these mothers, as well as those in other demographic groups who are generally considered harder to reach, are captured and represented in this survey so that government initiatives and policies are evidence-based including in relation to addressing health disparities, and this methodology would allow this inclusion.
- Seeking consent would place a large burden on clinical staff, as this would be very difficult to manage.

The Sub-Committee was content that consent was not a practicable alternative.

- **Use of anonymised/pseudonymised data**

Confidential patient information is required to facilitate the distribution of the survey questionnaires and the invitation process which could not be otherwise achieved.

The Sub-Committee were content that using anonymous information was not a practicable alternative.

'Patient Notification' and mechanism for managing dissent

Before disclose:

IPSOS UK will work with National Infant Feeding Network (NIFN). Supported by UNICEF UK, the network shares and promotes evidence-based practice around infant feeding. UNICEF UK Baby Friendly Initiative (BFI) is part of the NHS Long Term Plan for Maternity Services and therefore most NHS Trusts employ an Infant Feeding Lead, the majority of whom are engaged with NIFN. They will help with dissemination of information about the survey prior to the breach – applicants are sharing information about the survey at the NIFN Leads meeting on 14th March 2023 as well as sharing updates at additional meetings when appropriate. Once the sample dates are confirmed with NHS England, NIFN Leads will share posters (with opt out information) with NIFN members asking them to display these in the most appropriate place within their NHS Trust. Information and notification posters will also be shared with NHS Heads of Midwifery to help promote the IFS, and put up posters in appropriate locations.

The survey will be publicised through posters (opt out information not included) on the social media platforms that Ipsos UK and DHSC have a presence on. To complement the social media activity there will be publicised Ipsos and DHSC Infant Feeding Survey webpages. Individuals will be able to get more information about the current and past Infant Feeding Surveys here and there will be a link to a short form for those who wish to opt out of being contacted. Potential participants will be able to opt out online by navigating to the opt out page and completing an online form that will collect the details necessary to ensure those who opt out are able to be removed from any sample data.

Application specific opt out has therefore been developed, prior to the breach and the National Data Opt Out will apply.

The Sub-Committee were broadly content with the notification methodology and content, however the Members noted that the proposed social media notification did not contain any mention of how patients could opt out. The Members therefore requested for the social media notification to refer to how a patient could opt out of this processing, and provide an updated version to CAG.

The Sub-Committee also requested that the applicant submit the wording of the website notification for review, prior to 's251' support being provided.

After disclosure:

A Questionnaire is sent, alongside an invite letter that links to longer privacy notice, which will be made available online. This is after the breach has occurred. These appear in line with the CQC surveys.

Patient and Public Involvement and Engagement

Meaningful engagement with patients, service users and the public is considered to be an important factor for the CAG in terms of contributing to public interest considerations as to whether the unconsented activity should go ahead.

As part of the survey development process for this survey, Ipsos UK has carried out cognitive testing with 28 mothers who represent the cohort. This involved reviewing the questionnaire and survey materials. As part of this process, applicants also asked for patient views on the use of confidential patient information without consent, for the purposes of sending invitations. None of the mothers expressed any reservations about their details being used to send them a survey through the mail, nor to send them reminders via SMS. Where minor concerns were raised by mothers, they were happy that they would be able to opt out from future communications regarding this survey or would ignore the letter. No mother has spontaneously noted a concern about their personal data being used for research purposes without consent.

Ipsos UK also carried out cognitive testing for the Maternity Survey 2021 and 2022, which forms part of the NHS Survey Programme, and involves the same cohort. The majority of patients were comfortable with the use of confidential patient information without consent, and cited it as being similar to customer experience surveys they are sent from their banks and dentists. A key consideration was reassurance about who was conducting the survey and there being a need for transparency.

Applicants have learnt from the cognitive testing processes of both the Infant Feeding Survey, and also the NHS Patient Survey Programme is that most patients considered SMS messages to be a mainstream method of communication, but have stated that they wanted the reassurance on who the SMS was from and cited that an SMS message that came from a mobile number rather than a name (for example, "Department of Health and Social Care Surveys") would raise some concerns for them on the validity of the contact.

The Sub-Committee felt that the patient and public involvement undertaken is reasonable and proportionate, and summarises a supportive view.

Exit strategy

Any data for analysis would be analysed with the consent of the patient. The exit strategy for 's251' support is therefore implied consent, on return of the survey.

For those who do not respond to the survey, the exit strategy will be deletion of identifiable information;

Identifiable information (used to send out the survey) will be destroyed by Formara & GOV.UK Notify Service two months after client sign off on the final report. This was originally planned for March 2024, but could potentially now be sometime in 2025. It is dependent on the receipt of the sample file.

All other items of confidential patient information for those who have not returned the questionnaire, for example postcodes, & dates of birth, will be retained in a sample data file by IPSOS UK. All sample variables will be held in the dataset for the period of analysis and reporting, as these items are required for the survey weighting, and for analysis of any non-response bias.

The Sub-Committee were generally content with the proposed exit strategy, however it was noted that it was still not completely clear how long identifiable information would be retained regarding those who do not return the questionnaire. The CAG noted that it will be destroyed after *'the period of analysis and reporting'*, but it is not clear how long this is planned to be. The Sub-Committee therefore requested clarification on the expected time period that confidential patient information will be retained by IPSOS UK before being destroyed, for mothers who do not return the questionnaire.

Confidentiality Advisory Group advice conclusion

The CAG agreed that there was a public interest in this activity, were supportive in principle of this activity proceeding, and therefore recommended to the Secretary of State for Health and Social Care that the activity be provisionally supported. However, further information and actions would be required prior to confirming that the minimum criteria and established principles of support have been adequately addressed.

In order to complete the processing of this application, please respond back to all of the request for further information, and actions required to meet the specific conditions of support where indicated, within one month.

Request for further information

1. Please update the social media notification with details of how to opt out, and provide the updated notification to CAG for review.

2. Please submit the wording of the website notification to CAG for review.

3. Please clarify the expected time period that confidential patient information will be retained by IPSOS UK before being destroyed, for mothers who do not return the questionnaire.

Specific conditions of support (provisional)

Once received, the information will be reviewed by a sub-committee of members in the first instance and a recommendation and decision issued as soon as possible. At this stage it may be necessary to request further information or refer to the next available CAG meeting. If the response is satisfactory, a final support outcome will be issued.

Specific conditions of support (Provisional)

The following sets out the provisional specific conditions of support. These may change in the final outcome letter depending on the responses to queries.

1. Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. See section below titled 'security assurance requirements' for further information. **Confirmed:**

   The NHS England **21/22** DSPT reviews for **NHS England, Ipsos UK, Formara Ltd and the Department of Health and Social Care (which covers GOV.UK Notify Service)** were confirmed as '**Standards Met'** on the NHS England DSPT Tracker (17 February 2023)

Minutes signed off as accurate by correspondence from		
Signed – Officers of CAG		Date
Dr Murat Soncul, CAG Alternate Vice Chair		*22/02/2023*
Signed – Confidentiality Advice Team		Date
Dayheem Sedighi, HRA Approvals Administrator		*20/02/2023*