Health Research Authority

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

February 2019

Present:

Name	Capacity	Items
Dr Tony Calland MBE	Chair	1.a.
Dr Martin Andrew	CAG Member	1.a.
Dr Liliane Field	CAG Member	1.a.
Mr Anthony Kane	CAG Lay Member	1.a.
Dr Simon Kolstoe	CAG Member	1.a.

Also in attendance:

Name	Position (or reason for attending)
Miss Kathryn Murray	Senior Confidentiality Advisor, HRA

1. NEW PRECEDENT SET REVIEW APPLICATIONS – NON RESEARCH

a) 19/CAG/0021 - Maternity Survey 2019

Context

Purpose of application

This application from Picker Institute Europe, CQC and NHS England on behalf of all acute Trusts running eligible maternity services, set out the purpose of service evaluation which will be achieved through a patient survey in order to build up a national picture of women's experiences of maternity care. This will be the seventh maternity survey carried out to date and forms part of the NHS Patient Survey Programme. Preparations for the survey will begin in March 2019, with fieldwork expected to commence from the end of April 2019.

Support under the Regulations is sought for the transfer of confidential patient information from participating Trusts to the survey coordination centre to enable the facilitation of the survey invitation process. The survey methodology remains unchanged from that which was supported by the CAG for the 2018 survey; however, some additional variables will be included in the data extract disclosed by Trusts to the coordination centre, including complete patient postcode, to be used for deprivation scoring. 129 Trusts are expected to participate and will be asked to draw a patient sample according to set criteria and use standardised materials and procedures for all stages of the survey.

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

Confidential patient information requested

Cohort

Patients who had a live birth in January or February 2019 and were aged 16 years or over at the time of delivery. Trusts are instructed to sample all eligible service users in February 2019. If this is fewer than 300 records they are asked to sample back from the last date in January to the beginning of January until they reach 350 records (in order to achieve a sample of 300 post-DBS checks). Trusts that do not have 300 eligible service users across February and January combined have the choice whether to participate in the survey. Specific exclusion criteria have been established which will be applied by the Trust prior to drawing the patient sample.

Administration of the Maternity Survey requires NHS Trusts to share two distinct sets of information with their approved contractor:

1. A **mailing file** which is used to address questionnaires to the appropriate person. It contains:

- A unique identifier,
- Title,
- First name,
- Surname,
- Address Fields,
- Full postcode.

2. A **sample file** which is used to link demographic data to the survey responses, to aid analysis and to enable checks to be carried out for any errors in how the sample was drawn. It will also be used to enable the identification of service users who received antenatal and postnatal care directly from the trust. This file contains:

- The unique identifier code (as above),
- Sex,
- Mother's year of birth,
- Mother's ethnic group,
- Delivery date (DD/MM/YY),
- Time of delivery (for multiple births, this will be the time that the last baby is born),
- Number of babies born at delivery,
- Place of birth: NHS site code,
- Actual delivery place,
- CCG code,
- Mother's full postcode.

3. An **attribution file** which includes the sample file fields above and additional information relating to the provision of antenatal care or postnatal community care as follows:

- Antenatal provider information,
- Postnatal provider information,
- Postcode sectors to which the Trust provides maternity services (ONLY if using the postcode method to complete the antenatal and postnatal provider information).

For clarity, please note that the Survey Coordination Centre does **not** receive any names or full addresses.

Confidentiality Advisory Group advice

Public interest

The CAG was assured that the application defined an appropriate medical purpose, which was the management of health and social care services. It was recognised that the ongoing evaluation of patient care via the NHS Patient Survey Programme was within the public interest.

Practicable alternatives

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

- Feasibility of consent

The applicant cited three central arguments to support why consent is not feasible for the survey process. Firstly, operation of a consent-based process would remove the benefits of the Trusts being able to employ a specialist contractor to facilitate the survey process as it would require them to arrange their own mailing to patients. Operation of a consent-based process would introduce a systematic bias in response rates by changing the nature of the survey from an opt-out system to an opt-in system. It was further noted that introducing a prior consent process for the survey would put an unrealistic burden on busy clinical staff. The Sub-Committee recognised that this rationale had previously accepted for the survey programme and remained valid for the proposed application. No queries were raised in this area.

- Use of anonymised/pseudonymised data

Access to confidential patient information was required to facilitate the survey programme.

Justification of identifiers

The CAG was assured that the items of confidential patient information requested were appropriate and proportionate to achieving the proposed activity. Members noted that this application had requested the inclusion of complete postcode to facilitate deprivation analysis.

Whilst it was recognised that applicants were ordinarily asked to reduce the identifiability of datasets, the applicants had requested access to complete postcode for analysis purposes. The Sub-Committee was assured by the applicant's rationale in this area around small pockets of deprivation which would be overlooked with this level of granularity and were content to provide support to the additional item of confidential patient information.

The applicant had also requested access to gender as part of the sample information, to ensure that the sampling approach was not systematically excluding individuals, such as those who self-identify as transgender. The Group was assured by the rationale provided to support this additional patient identifier, and was content to provide a recommendation of support on this basis.

Exit Strategy

It is generally a principle that steps should be taken to move away from this potential support; such as through the seeking of consent or removing identifiable information once completed. Confidential patient

information is required for a time-limited basis only to facilitate the survey distribution and analysis processes. This would be retained for a maximum of 12 months following which this would be destroyed. The CAG was assured by the exit strategy described and raised no concerns in this area.

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 an unconsented activity should go ahead. The applicant explained that, in the development phase for the 2019 iteration of the survey, they had undertaken a consultation where interviews were held with Expert stakeholders (such as organisational bodies, policy makers, Public Health England and women's interest groups such as Maternity Action) and with recent mothers (babies who have been born in the last 12 months). This development work enabled the feedback of data end users and maternity service users themselves to contribute to the overall content of the questionnaire to ensure that it was fit for best and best matched the experience of women who have recently used the services. Members were assured that the activity undertaken in this area was appropriate and proportionate. No further follow-up was requested.

Patient Notification and Dissent

It is a general principle of the CAG, when recommending support, for reasonable measures to be taken to inform the relevant population of the activity and to provide a right to objection and mechanism to respect that objection, where appropriate. This is known as patient notification. This is separate to the local obligation to comply with the principles of the General Data Protection Regulation and the Data Protection Act 2018. The applicant provided standardised information leaflets and posters which participating Trusts would be required to display. It was clarified that these documents would also be translated into the ten most commonly spoken languages to be displayed alongside the English text. Members agreed that the documentation provided clear information around the survey and offered a means of patient objection. No issues were raised in this area.

Confidentiality Advisory Group advice conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met and that there was a public interest in projects of this nature being conducted, and therefore advised recommending support to the Secretary of State for Health and Social Care, subject to compliance with the specific and standard conditions of support as set out below.

Specific conditions of support (Final)

1. Confirmation from the IGT Team at NHS DIgital of suitable security arrangements via Information Governance Toolkit (IGT) submission. **Confirmed - Picker Institute Europe, Quality Health and Patient Perspective – all have a published satisfactory reviewed grade on V14.1, 2017/18.**