

23 November 2017

Ms Jenny King
Picker
Buxton Court
3 West Way
Oxford
OX2 0JB

Dear Ms King

Application title: 2018 Community Mental Health Survey
CAG reference: 17/CAG/0185

Thank you for your non-research application, submitted for approval under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process patient identifiable information without consent. Approved applications enable the data controller to provide specified information to the applicant for the purposes of the relevant activity, without being in breach of the common law duty of confidentiality, although other relevant legislative provisions will still be applicable.

The role of the Confidentiality Advisory Group (CAG) is to review applications submitted under these Regulations and to provide advice to the Secretary of State (SofS) for Health on whether an application should be approved, and if so, any relevant conditions. This application was considered at the precedent set CAG meeting held on 03 November 2017. The application was considered via the Precedent Set process under criteria 1 - Applications to identify a cohort of patients and subsequently to seek their consent (otherwise referred to as participant identification applications)

Secretary of State approval decision

The Secretary of State, having considered the advice from the Confidentiality Advisory Group as set out below, has determined the following:

1. The application is conditionally approved, subject to compliance with the standard and specific conditions of approval outlined below.

Please note support to process confidential patient information without consent is now in effect.

Context

Purpose of application

This non-research application from Picker, CQC and NHS England set out the purpose of administering the 2018 Community Mental Health Survey, to gauge patient experience and views of the service they received. A recommendation of support was requested to enable the transfer of patient identifiable data from mental health providers, to an approved survey contractor for the purpose of mailing out questionnaires. The vast majority of trusts involved were expected to opt to use an approved survey contractor, either: Picker, Quality Health, Patient Perspective, CAPITA Surveys & Research or Membership Engagement Services.

The end product from the survey would be a set of aggregate statistical data that did not contain patient identifiable information. This statistical dataset is used for a wide variety of purposes to support ongoing improvement in overall patient experience by NHS Trusts and CCGs and by CQC, to inform its regulatory functions.

NHS Patient Survey Programme

This survey is part of the NHS Patient Survey Programme, and as such follows the same methodology as other surveys within the programme. The methodology is approved in principle by the CAG, and applications are usually considered via the Precedent Set pathway.

New approaches are often piloted within the NHS Patient Survey Programme. The 2017 Adult Inpatient Survey (which is referred to throughout the application) trialed the use of text message reminders to complete the survey, and was escalated to full CAG meeting as there was no precedent for the use of text messages. Support was given at the meeting for this approach.

Breaches reported for the 2017 Adult Inpatient Survey were considered, as the same methodology and applicant were involved; any changes made to NHS Patient Survey Programme methodology as a result of breaches were considered relevant to this application despite the fact that the breaches occurred in a different survey.

For the current application (Community Mental Health Survey 2018), the following interventions would be added as part of a pilot:

Pilot Study

A shorter questionnaire

An online survey – link to be sent to patients in a text message

SMS (text message) reminders

No CQC Flyer

The aim was to increase response rates overall and from lesser heard groups

A recommendation for class 3 and 6 was requested in order to select and contact participants to seek their consent, and to allow access to an authorised user for the above purpose.

Confidential patient information requested

Access was requested to data from mental health providers in relation to people aged 18 and over who had been in contact with NHS mental health services in the three month period, 1 September to 30 November 2017, and who were receiving specialist care or treatment for a mental health condition, including those who received care under the Care Programme Approach (CPA).

The mailing file is used to address questionnaires to the appropriate person, and is sent to the Approved Contractor. It contains:

- Trustcode
- A standardised unique identifier code, to be constructed as survey identifier, trust code followed by a whole number (consecutive across the sample of 850 service users from each trust), e.g. MH18XXXnnnnn where XXX is the trusts 3 digit trust code and nnnnn is the 5 digit serial number relating to sampled service users
- Title (Mr, Mrs, Ms, etc.)
- First name
- Surname
- Address Fields
- Postcode

The sample data file 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 and is sent to the Coordination Centre. This file contains:

- Trustcode
- The unique identifier code (as above)
- Year of birth
- Gender
- Ethnic category
- Day of last contact
- Month of last contact
- Year of last contact
- CPA status
- CCG code

Mental Health Care Cluster Codes

The inclusion of mental health care cluster codes in the sample file was a deviation from the previous method, which had been to send this information to the coordination centre separately. This would simplify the process for trusts and avoid errors (previous errors included a Trust sending the care cluster code along with patient identifiers, and mismatching the care cluster code with the patient record, due to having separated it from the sample file).

There was precedent for a similar approach to be supported by the CAG in the Adult Inpatient Survey, where ICD-10 codes were included with the sample file.

Pilot study

As part of the pilot work, pilot trusts would also be asked to include the following:

- Indicator to show whether service users have a mobile phone number or not (main / control sample);
- Mobile phone number (for the pilot sample only)

Confidentiality Advisory Group advice

Public interest

The Sub-Committee agreed that there was an obvious medical purpose inherent in the application, and that a public interest was demonstrated in the stated purpose of seeking

patient experience and views of the service they received, particularly if this eventually influenced policy and practice.

Pilot study

Members noted that innovations and updates to the survey methodology had been implemented over time, and that the use of text message reminders had been previously supported by the CAG. Members raised no concerns about the current pilot study which would include a shorter questionnaire, text message reminders and SMS links to the survey. No additional identifiers would be transferred to the Coordination Centre as a result of the change.

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

Members accepted that obtaining consent would not be practicable, and could bias the outcomes, particularly from this type of survey.

- Use of anonymised/pseudonymised data

It was observed that the process of administering the surveys was well-established and efficient, from identifying those to whom questionnaires were sent to the receipt, linkage, analysis and validation of the data. Pseudonymised data was used where appropriate and data was anonymised at the earliest possible point.

The addition of Mental Health cluster codes to the pseudonymised data sent to the Coordination centre and used for validation of the data was noted and no concerns were raised in relation to the change.

Justification of identifiers

Members accepted that identifiers were required in order to send out surveys.

It was agreed that there were no other practicable alternatives.

Additional points

Public involvement

Members commented that user involvement was not extensive – however, there was evidence that patient views and suggestions had been taken account of, not least in the development of the pilot study. This was deemed adequate and overall, no concerns were raised.

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 and mechanism to respect objection, where appropriate. This is known as patient

notification. This is separate to the local obligation to comply with the principles of the Data Protection Act 1998.

Instructions to individual trusts contained a 'recommendation' to display a poster with contact details to enable patients to opt out. Members were of the opinion that this should be more strongly worded in order to comply with the CAG principle of support. Rather than 'recommended', the instructions should state that this was a 'request' or an 'expectation'. Although not all patients would see the poster, this was not an adequate reason for failing to display the poster, and the profile of the survey could be raised via trust newsletters and websites.

The Sub-Committee stressed that these actions were important in order to retain public trust in the use of patient data without consent.

Breaches

Breaches reported over the previous year for the NHS Patient Survey programme were considered as part of the application, whether or not they originated from the Mental Health Survey, as the methodology and applicant were the same.

There had been several breaches, many resulting from a failure by individual trusts to follow the instructions provided. The applicant had, as a result, simplified the manuals and supporting documentation with clearer explanations of Section 251 support and the importance of following the process.

The Sub-Committee was therefore satisfied that steps had been taken to reduce the risk of error.

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, subject to compliance with the specific and standard conditions of support as set out below.

Specific conditions of support

1. Please ensure that instructions to individual trusts go beyond 'recommending' that they display patient notifications, making clear that they are requested to ensure patients are aware of the survey and can opt out if they so wish. Please report back on this at annual review stage, including numbers of patients who have opted out.
2. Confirmation from the IGT Team at the Health and Social Care Information Centre of suitable security arrangements via Information Governance Toolkit (IGT) submission.

Annual review

Please note that your approval is subject to submission of an annual review report to show how you have met the conditions or report plans, and action towards meeting them. It is also your responsibility to submit this report on the anniversary of your final approval and to report any changes such as to the purpose or design of the proposed activity, or to security and confidentiality arrangements. An annual review should be provided no later than 23 November 2018 and preferably 4 weeks before this date. If at any stage you no longer require support under the Regulations

as you will cease processing confidential patient information without consent you should inform the Confidentiality Advice Team of this in writing as soon as possible.

Reviewed documents

The documents reviewed at the meeting were:

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|--|----------------|-----------------|
| CAG application from (signed/authorised) [Non-research Application Form] | 1 | 23 October 2017 |
| Other [Instruction Manual for Trusts Using a Contractor] | 1 | |
| Other [Sample Declaration Form for Trusts using an Approved Contractor] | 1 | |
| Other [Model Service Contract] | 1 | |
| Other [Multilanguage sheet] | 1 | |
| Other [Community Mental Health Services questionnaire] | 1 | |
| Patient Information Materials [CQC Flyer] | 1 | |
| Patient Information Materials [Dissent Poster] | 1 | |
| Research protocol or project proposal [Sampling Instructions] | 1 | 18 August 2017 |

Membership of the Committee

The members of the Confidentiality Advisory Group who were present at the consideration of this item or submitted written comments are listed below.

Yours sincerely

Rachel Heron
Confidentiality Advisor

Email: HRA.CAG@nhs.net

Enclosures:

*List of members who considered application
Standard conditions of approval*

Confidentiality Advisory Group sub-committee meeting 03 November 2017

Group Members:

| <i>Name</i> | <i>Profession</i> | <i>Present</i> | <i>Notes</i> |
|--------------------|-------------------|----------------|--------------|
| Dr Tony Calland | | Yes | |
| Mr Anthony Kane | | Yes | |
| Mr Andrew Melville | | Yes | |

Also in attendance:

| <i>Name</i> | <i>Position (or reason for attending)</i> |
|-----------------|---|
| Ms Rachel Heron | Confidentiality Advisor |

Standard conditions of approval

The approval provided by the Secretary of State for Health is subject to the following standard conditions.

The applicant will ensure that:

1. The specified patient identifiable information is only used for the purpose(s) set out in the application.
2. Confidentiality is preserved and there are no disclosures of information in aggregate or patient level form that may inferentially identify a person, nor will any attempt be made to identify individuals, households or organisations in the data.
3. Requirements of the Statistics and Registration Services Act 2007 are adhered to regarding publication when relevant.
4. All staff with access to patient identifiable information have contractual obligations of confidentiality, enforceable through disciplinary procedures.
5. All staff with access to patient identifiable information have received appropriate ongoing training to ensure they are aware of their responsibilities.
6. Activities are consistent with the Data Protection Act 1998.
7. Audit of data processing by a designated agent is facilitated and supported.
8. The wishes of patients who have withheld or withdrawn their consent are respected.
9. The Confidentiality Advice Team is notified of any significant changes (purpose, data flows, data items, security arrangements) prior to the change occurring.
10. An annual report is provided no later than 12 months from the date of your final confirmation letter.
11. Any breaches of confidentiality / security around this particular flow of data should be reported to CAG within 10 working days, along with remedial actions taken / to be taken.