Health Research Authority

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31 July 2018

Ms Jenny King
Chief Research Officer
Picker Institute Europe
Buxton Court
3 West Way
Oxford
OX2 0JB

Dear Ms King

Application title: **2018 NHS Adult Inpatient Survey**
CAG reference: **18/CAG/0098**

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 and Social Care 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 01 June 2018. The application was considered via the Precedent Set process under criteria 11 – Applications made by the Picker Institute Europe to administer surveys on behalf of the Care Quality Commission (CQC). The response to the provisionally supported outcome was considered in correspondence.

Secretary of State for Health and Social Care decision

The Secretary of State for Health and Social Care, having considered the recommendation from the Confidentiality Advisory Group as set out below, has determined the following:

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

Please note that the legal basis to allow access to the specified confidential patient information without consent is now in effect.

This letter should be read in conjunction with the outcome letter dated 20 June 2018.

Context

Purpose of Application

This non-research application from Picker Institute Europe, CQC and NHS England set out the purpose of carrying out the 2017 NHS Adult Inpatient Survey, using standardised methodology to build up a national picture of patient experiences. A set of aggregated statistical data is produced which is shared with individual Trusts, CQC, NHS England and the Department of Health and used to monitor and compare the performance of Trusts, and to drive improvements.

This survey would be the 16th carried out to date. The methodology is well established and has been approved in principle by the CAG via Precedent Set Sub-Committee. The applicants confirmed that the survey methods are unchanged from the 2017 survey.

Participating trusts identify the sample in line with the inclusion/exclusion criteria, and disclose names and addresses to approved contractors for the purpose of mailing out the surveys (this data is held in a mailing file along with the unique identifying code which is printed on the survey itself). Demographic information for each potential participant is collected in a separate sample file, linked by the identifying code.

Picker Institute is commissioned to manage and coordinate the surveys under the title of the Patient Survey Coordination Centre, carrying out checks across the samples submitted by trusts and disseminating aggregated results (identifiable information is not received by the Patient Survey Coordination Centre).

As part of the drive to improve response rates (RR) and possibly reduce response bias, and to explore a move to a mixed mode methodology using online methods within the NPSP, a pilot study is being proposed across 10 Trusts, which would each be asked to provide an additional 1,014 patient, and provide mobile telephone numbers for them, *to test the effect of a three separate interventions in the 2018 NHS Inpatient Survey (IP18):*

- *Administering the questionnaire online (instead of a postal survey).*
- *Sending SMS reminders.*
- *Using a shorter questionnaire.*

The control arm of the pilot will be the main sample. This pilot is aimed at testing the effects of three different methods of invitation which combine postal letters and text messages, and the use of an online questionnaire. Inclusion of mobile phone numbers was approved for last year's survey via full CAG review – as the proposed pilot does not require the disclosure of any additional items of confidential patient information, promotion to full CAG was not deemed appropriate at this stage. The interventions will be piloted as follows:

Intervention	Mailing 1 (M1)	Mailing 2 (M2)	Mailing 3 (M3)
Intervention 1	Postal letter with link to online questionnaire	Postal reminder with link to online questionnaire	Postal letter (no link) *and* hard copy of questionnaire
Intervention 2	Postal letter with link to online questionnaire, followed by SMS with link	Postal reminder with link to online questionnaire, followed by SMS with link	Postal letter (no link) *and* hard copy of questionnaire
Intervention 3	Same as main survey, with shorter questionnaire	Same as main survey	Same as main survey, with shorter questionnaire

It is noted that all pilot interventions will use the shorter version of the questionnaire.

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

Confidential Patient Information Requested

Cohort

- Inpatients aged 16 years old or over who were discharged from acute and specialist NHS hospitals in July 2018 (and earlier for smaller trusts), having had one overnight stay in hospital.

Exclusions:
- deceased patients,
- children or young persons aged under 16 years at the time of sampling,
- obstetrics/maternity service users, including spontaneous miscarriages,
- patients admitted for planned termination of pregnancy,
- psychiatry patients,
- day cases,
- private patients (non-NHS),
- any patients who are known to be current inpatients patients without a UK postal address,
- any patient known to have requested their details are not used for any purpose other than their clinical care, including those responding to posters displayed on hospital wards referring to the survey (the survey instructions request that all responses to posters are logged and used for this purpose).

The mailing file sent to contractors contains the following information:

- A standardised unique identifier code (see application for full details of how this is constructed)
- Title (Mr, Mrs, Ms, etc.)
- First name
- Surname
- Address Fields
- Postcode (where available)
- Mobile telephone number for those patients included in the pilot, from a total of up to 10 Trusts**.**

The sample data file (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 contains:

- The unique identifier code,
- Admission/discharge dates,
- Length of stay (this is calculated from the admission and discharge dates),
- Whether admission from Treatment Centre,
- Route of admission,
- NHS Site code on admission and discharge,
- Ethnicity,
- Gender,
- Year of birth,
- Indicator of recorded mobile telephone number (all patients not included in SMS pilots),

- CCG Code: to enable analysis at this level by stakeholders for the production of relevant indicators,
- ICD10 code.

The sample file is also shared with the Coordination Centre to enable centralised checks on the appropriateness of samples drawn. For clarity, please note that the Coordination Centre do **not** receive any names or addresses.

Confidentiality Advisory Group advice

A Sub-Committee of the main CAG considered the below written response provided to the request for further information detailed in the provisionally supported in correspondence.

1. **Confirm whether an assessment was undertaken in relation to the number of contacts proposed for the pilot interventions and the potential for this to have a negative privacy impact on potential respondents. Clarify whether this potential risk was discussed with the Inpatient Survey Advisory Group.**

It was explained that, for all pilot interventions, each contact with the patient would provide the option to opt-out from receiving any further contacts regarding the survey. The postal letters included a helpline to call and opt-out, the SMS messages also included this helpline as well as the online version of the survey. Similar to this year's proposed pilot interventions, other pilot studies within the NHS Patient Survey Programme have had a maximum of five contacts to patients and no issues were identified. It was clarified that no complaints were received during the 2017 pilot study that ran alongside the 2017 Inpatient Survey where patients received a maximum of five contacts (including SMS messages).

The applicant confirmed that the move to incorporating digital means of contacting patients had been consistently requested by Advisory Groups across the Survey Programme as a solely paper based approach was considered outdated, cost inefficient and contributed to response bias. The Advisory Group also discussed the increase in using SMS to issue appointment reminders from Trusts and the Friends and Family Test, demonstrating that now is the right time to pursue these alternatives. It is worth noting that the Patient Survey Programme as standard uses two reminders to patients, but already other national surveys such as the GP Patient Survey use four as standard. At the 2018 Inpatient Advisory Group the proposal to issue SMS reminders was discussed and approved.

In addition, the applicants explained that as evidenced in other projects, patients generally do not mind being contacted by SMS. It was noted that from the 2017 pilot study that ran alongside the 2017 Inpatient Study, no complaints were logged to be specifically due to receiving SMS messages. Within a current audit being undertaken by the applicants, it was explained that a survey was sent to patients asking about the use of mobile numbers and email addresses for CQC surveys. Patients were happy with the idea of using mobile data, saying: 'I would definitely be more likely to respond to a request for feedback via text or email. I would be happy for my information to be passed on' and 'I really like this idea, it's much easier and less time consuming'.

The Sub-Committee received the response and no further issues were raised in this area.

2. **Confirm whether the number of paradata items which will be collected have been tested to ensure that, in conjunction with survey responses, to ensure there is no potential that a patient could be inadvertently identified from the information. Clarify whether the paradata sample has been assessed to ensure that this does not contain any markers which may be considered identifiable in relation to the GDPR or the DPA 2018.**

It was confirmed that the pilot contractor was Quality Health. This organisation is currently the contractor for the pilot study running alongside the 2018 Community Mental Health Survey which also included the use of SMS and an online survey. It was explained that the fieldwork had now ended for this study and Quality Health had confirmed that in providing paradata from their SMS and online survey systems (the same systems they will be using for the Inpatient Survey Pilot Study), no identifiable information was available as part of the paradata dataset. Quality Health also confirmed that this would also be true for the Inpatient Survey Pilot Study and therefore, there was no risk of breaching GDPR/Data Protection Regulations. A detailed overview of the paradata items which would be provided by Quality Health to the Survey Coordination Centre for each participant in the survey was provided for information purposes.

The Sub-Committee received the response and no further issues were raised in this area.

3. Provide details of the demographics and number of patients included within the Inpatient Survey Advisory Group.

Details were provided in relation to the demographics of the three members of the Inpatient Advisory Group.

Members received the details and whilst no issues were raised which required further information, it was recommended that the applicants consider increasing the number of group members moving forward as it was commented that this was a limited sample.

4. Clarify that Trusts would be advised in include both a telephone number and email address on the notification posters to facilitate opt-out.

The applicant explained that a webinar was held for Trusts on Thursday 21st June 2018 and 108 individuals attended. The project lead explained that both a telephone number and email address (if available) must be included on the dissent posters. Following the webinar, a document summarising all Q&A along with the webinar slides was published on the NHS Surveys website and links were sent via email to Trust contacts.

The response was received by the Sub-Committee and no further issues were raised.

5. Clarify whether there are any plans to include private patients within any future Inpatient Surveys.

The applicant confirmed that, as the present time, there were no plans to include private patients within any future iterations of the Adult Inpatient Survey. This was in line with the current purposes of the data collected by the national survey and the current regulatory needs of CQC.

The response was received and no further issues were raised in this area.

<u>Additional Amendments</u>

The applicants detailed two proposed amendments to the project methodology within the response letter as follows:

1. Faster reminder Letter

The applicants proposed reducing the time frame between the first, initial mailing and the second mailing (first reminder letter) from 10 days to five working days. This follows a methodological pilot undertaken alongside the 2017 iteration of the Adult Inpatient Survey. For this pilot, the impact of reducing the time gap between the first and second mailing on overall response rates was investigated. This pilot found that there was a significant

increase in response rate of three percentage points when the time gap was reduced to five days between these mailings, compared to the advised 10 days (current methodological approach). This modification did not constitute a change to the information being provided by the Trust for the purpose of mailing nor does it introduce a change to the data flow of information or increase the number of contacts made with patients. This change will only result in a change to timings. As standard, Trusts will be required to conduct local checks for deceased patients prior to the second mailing (as is standard on the programme).

The Sub-Committee received notification of the change and no issues were raised.

2. Mobile Phone Number Indicator

It was referenced within the initial application that mobile phone indicator would be submitted for the control arm (i.e. their main 1250 sample) from Trusts involved in the 2018 pilot study. The applicants confirmed that this would be extended to cover the mainstage survey, i.e. this will be provided for all Trusts participating in the survey and not limited to just the pilot trusts. Trusts would be asked to provide this information in the same way as instructed for pilot Trusts, namely that only an indicator needs to be assigned to each patient to note they have a mobile phone number recorded, or they do not. The Trusts would not be providing mobile phone data for any of the patients in their mainstage samples. The applicant explained that this change would enable better understanding the availability and coverage of mobile telephone information held by NHS trusts on patient records.

The Sub-Committee received notification of the change and no issues were raised.

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. Confirmation from the IGT Team at NHS Digital of suitable security arrangements via Information Governance Toolkit (IGT) submission (**Confirmed – NHS Digital review of Version 14.1, 2017/18, Capita Business Services Ltd., Membership Engagement Services and Patient Perspectives by email 18 July 2018**).

As the above conditions have been met, this letter provides confirmation of final approval. I will arrange for the register of approved applications on the HRA website to be updated with this information.

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 **31 July 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:

Document	*Version*	*Date*
CAG application from (signed/authorised) [Section 251 Form]		13 April 2018
Covering letter on headed paper [IP18 Provisional approval Applicant response]	1	
Other [Response to CAT Advice Form]		30 May 2018
Other [IP18 Main Questionnaire]	Final	
Other [IP18 Shorter Questionnaire]	Final	
Other [IP18 Supplementary GDPR Information]	1	
Patient Information Materials [IP18 Pilot First Covering Letter]	Final	
Patient Information Materials [IP18 Second Covering Letter]	Final	
Patient Information Materials [IP18 Pilot Second Covering Letter]	Final	
Patient Information Materials [IP18 Third Covering Letter]	Final	
Patient Information Materials [IP18 Dissent Poster]	Final	
Patient Information Materials [IP18 Flyer]	Final	
Patient Information Materials [IP18 First Covering Letter]	Final	
Research protocol or project proposal [IP18 Sampling Flowchart]	Final	
Research protocol or project proposal [IP17 Sampling instructions]	8	18 August 2017
Research protocol or project proposal [IP18 Pilot Sampling instructions]	1	29 May 2018
Research protocol or project proposal [IP18 Main Sampling instructions]	1	18 May 2018
Research protocol or project proposal [IP17 Survey Handbook]	10	06 July 2017
Research protocol or project proposal [IP18 Dissent]	Final	

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.

There were *no* declarations of interest in relation to this item.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

Yours sincerely

Miss Kathryn Murray
Senior Confidentiality Advisor

On behalf of the Secretary of State for Health and Social Care

Email: HRA.CAG@nhs.net

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

Confidentiality Advisory Group Sub-Committee Meeting in Correspondence

Group Members:

Name	*Present*	*Notes*
Dr Martin Andrew	Yes	
Dr Tony Calland MBE	Yes	Chair

Also in attendance:

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

Standard Conditions of Approval

The approval provided by the Secretary of State for Health and Social Care 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 2018.

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.