Health Research Authority

Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 7972 2557
Email: HRA.CAG@nhs.net

28 August 2018

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

Dear Ms King

Application title: **2018 Urgent and Emergency Care Survey**
CAG reference: **18/CAG/0110**

Thank you for your service evaluation 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 29 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 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 18 July 2018.

Context

Purpose of application

This application from the Picker Institute Europe set out the purpose of carrying out the 2018 Urgent and Emergency Care Survey, sponsored by the Care Quality Commission. The findings of the survey are used by NHS Trusts and CCGs to facilitate local improvement, by the CQC as part of its regulatory activities and to support other relevant functions and will be shared in a non-identifiable format with NHS England, the Department for Health and Social Care and wider NHS Organisation to gain understanding of patients' experiences of NHS services and to drive improvements to them.

The 2018 survey will be the seventh carried out to date. The title of the survey has been revised for this year's proposed survey (from the previously titled 2016 Emergency Department Survey) to reflect changes in terminology and increased focus on urgent care as well as emergency care. All emergency department surveys prior to 2016 included patients attending Type 1 services only. The sampling approach was changed in 2016 to include Type 3 services. Broadly, these services are defined as:

- Type 1 - A major, consultant-led A&E department with full resuscitation facilities operating 24 hours a day, seven days a week.
- Type 3 - Other A&E / minor injuries unit / urgent care centre treating minor injuries and illnesses. Can be doctor or nurse-led and accessed without an appointment.

Participating Trusts will be asked to begin preparations for the patient sample to be drawn in September 2018. Confidential patient information will be shared with the approved contractors facilitating the survey to enable the standardised to be followed across the full programme of activities.

Some minor changes to the study methodology are proposed for the 2018 survey as follows:

- A separate survey questionnaire is under development for patients who attended a Type 3 Department (Urgent Care Department),
- The sample size for patients attending a Type 3 Department has been increased from 300 to 420 to enable benchmarking across Trusts. This is in addition to the 950 patient sample for Type 1 Department attendances (Emergency Department), as per the 2016 survey. For Trusts without a Type 3 Department, the sample size for Type 1 Department attendances will remain at 1250, as per the 2016 survey.

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

Confidential Patient Information Requested

Cohort

- People aged 16 and over who attended a Type 1 emergency department in September 2018 or a Type 3 urgent care department in September 2018. Trusts will be instructed to contact the Survey Coordination Centre if they are unable to draw the required sample size from their Type 3 department in which case they will be instructed to also sample back to August 2018.

The Sampling Instructions will ask Trusts to exclude:

- deceased patients,

- children or young persons aged under 16 years at the date of their attendance at the emergency department,
- any patients who are known to be current inpatients ,
- planned attendances at outpatient clinics which are run within the Emergency Department (such as fracture clinics),
- patients without a UK postal address,
- patients attending primarily to obtain contraception (e.g. the morning after pill), patients who suffered a miscarriage or another form of abortive pregnancy outcome whilst at the hospital, and patients with a concealed pregnancy*,
- any patient known to have requested their details are not used for any purpose other than their clinical care,
- any patients who were admitted to hospital via Medical or Surgical Admissions Units and therefore have not visited the emergency department,
- For the type 3 sample, any services which are mainly or entirely appointment-based.

*As per 2016, Trusts will be advised to check ICD-10 codes, or obstetric or gynaecology codes. If the use of these codes will not enable identification of women who should be excluded, the Trust would then be required to check notes on their records to ascertain reason for attendance.

Administration of the 2018 Urgent and Emergency Care Survey requires NHS trusts to share two distinct sets of information with their approved contractor:

The **mailing file** is used to address questionnaires to the appropriate person. It contains:

- A standardised unique identifier code,
- Title (Mr, Mrs, Ms, etc.),
- First name,
- Surname,
- Address Fields,
- Postcode.

The **sample 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. This file contains:

- The unique identifier code (as above),
- Date and time of attendance,
- NHS Site code,
- Department type (Type 1 or Type 3),
- Ethnicity,
- Gender,
- Year of birth,
- CCG code.

The two sets of information listed above will be submitted by participating Trusts to approved contractors as one file. Approved contractors will split the data out and only the sample data will be provided to the Survey Coordination Centre to enable centralised checks on the appropriateness of samples drawn. The Survey Coordination Centre does **not** receive any names or full addresses.

Confidentiality Advisory Group advice

The Chair considered the below response to the request for further information detailed in the provisionally supported outcome in correspondence.

1. **Provide copies of the finalised poster and flyer, together with any wider patient-facing documentation which has been revised, which will be used within the 2018 survey programme for consideration.**

The applicants provided finalised dissent posters, one for Type 1 departments and one for Type 3 departments. It was also explained that, since the initial submission of the application, it had been confirmed that both posters will be developed in the nine other most commonly spoken languages in England, which were currently under development. Trusts would be required to display the posters in English in all the relevant areas. Those in other relevant languages would be displayed alongside the English-text version.

The applicant also explained that it had been decided to remove the CQC flyer from the first and third mailing packets following the Community Mental Health 2018 pilot where the CQC flyer was found to add no benefit on the overall response rate and potentially impacts response rate negatively for patients age 18 to 35. It was clarified that all of the information on the CQC flyer was already included on the covering letters meaning patients would still receive all relevant information. The removal of the CQC flyer would also reduce paper waste and cost; therefore it was felt that removing it from the mailing was the best direction moving forward considering it had no statistical benefit to the survey. Due to the removal of the CQC flyer, it had not been included as an attachment with the response.

In addition to the above clarifications, the applicant explained that additional patient-facing documents had been updated and developed since the initial application and had been included as part of the response to the provisional outcome letter. This included the following documents that had since finished three rounds of cognitive testing and were in the process of sign off:

- UEC18_Type 1 First Covering Letter_V1,
- UEC18_Type 1 Second Covering Letter_V1,
- UEC18_Type 1 Third Covering Letter_V1,
- UEC18_Type 3 Frist Covering Letter_V1,
- UEC18_Type 3 Second Covering Letter_V1,
- UEC18_Type 3 Third Covering Letter_V1,
- UEC18_Type 1 Questionnaire_V1,
- UEC18_Type 3_Questionnaire_V1,
- UEC18_Sampling Instructions_V1,
- UEC18_Survey Handbook_V1.

The Chair received the response and supporting documentation. The rationale for the removal of the CQC leaflet was noted. No further issues were raised in this area.

2. **Trusts should be advised to include a postal address to facilitate patient objection where possible – confirm that this guidance has been disseminated to participating Trusts.**

The applicants clarified that the dissent posters had been developed to include space and specific guidance on including a postal address where available (see both Type 1 and Type 3 dissent posters attached). Once these are published on the NHS Surveys website, an email would be sent to survey leads at all participating Trusts announcing the availability of the posters and providing instructions on where, when and how to display them. This will be the first opportunity to directly inform Trusts to include a postal address if available. The applicant also planned to include this information in the UEC Survey Trust webinar where all participating Trusts would be invited to attend an hour long presentation on changes made to the survey and specific Section 251 requirements.

The Chair received the response and noted that participating Trusts should be strongly advised to include a postal address as a means of raising objection to inclusion in the survey.

Additional Point – Faster Distribution of Reminder Letter

The applicant also advised of a change to the methodological approach for the sending of the three mailings to patients as part of the provisional response. It was proposed to reduce the timeframe between the first, initial mailing and the second mailing (first reminder letter) from 10 days to 5 working days. This follows a methodological pilot which was undertaken alongside the 2017 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 3 percentage points when the time gap was reduced to 5 days between these mailings, compared to the advised 10 days (current methodological approach). This modification to the timing of the mailings has been confirmed with both NHS Trusts who participate in the survey, and the approved contractors who implement the survey on behalf of some of the trusts. It was clarified that this modification did not constitute a change to the information being provided by the Trust for the purpose of mailing nor did 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 the timings of mailings. As per usual, Trusts will be required to conduct local checks for deceased patients prior to the second mailing (as is standard on the programme).

The Chair received the additional information and recognised that this change was also proposed and supported in relation to the 2018 Adult Inpatient Survey (18/CAG/0098) and content to provide a recommendation of support to this revised methodology here also.

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 – Version 14.1, 2017/18 satisfactory reviewed grade for the following organisations: Picker Institute Europe, Quality Health, Patient Perspective, Capita Business Services Ltd. and Member Engagement Services**).

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 **28 August 2019** 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) [ED18 S251 precedent set application]	1	
Covering letter on headed paper [UEC18 Provisional outcome Applicants response]	1	
Other [ED18 CAG advice form SCC response]	1	
Other [ED16 Instruction manual]	1	
Other [ED18 Survey handbook]	1	
Other [ED18 Supplementary GDPR information]	1	
Other [ED18 Type 1 Questionnaire]	1	
Other [ED18 Type 3 S15. ED18_Type 3 Questionnaire]	1	
Other [UEC18 Sampling Instructions]	1	09 August 2018
Other [UEC18 Survey Handbook]	1	08 August 2018
Other [UEC18 Type 1 Questionnaire]	1	
Other [UEC18 Type 3 Questionnaire]	1	
Patient Information Materials [ED16 Dissent Poster]	1	
Patient Information Materials [ED18 Type 1 First Covering letter]	1	
Patient Information Materials [ED18 Type 1 Second covering letter]	1	
Patient Information Materials [ED18 Type 1 Third covering letter]	1	
Patient Information Materials [ED18 Type 3 First covering letter]	1	
Patient Information Materials [ED18 Type 3 Second covering letter]	1	
Patient Information Materials [ED18 Type 3 Third covering letter]	1	
Patient Information Materials [UEC18 Type 1 dissent poster]	1	
Patient Information Materials [UEC18 Type 1 First covering letter]	1	
Patient Information Materials [UEC18 Type 1 Second covering letter]	1	
Patient Information Materials [UEC18 Type 1 Third covering letter]	1	
Patient Information Materials [UEC18 Type 3 dissent poster]	1	
Patient Information Materials [UEC18 Type 3 First covering letter]	1	
Patient Information Materials [UEC18 Type 3 Second covering letter]	1	
Patient Information Materials [UEC18 Type 3 Third covering letter]	1	
Research protocol or project proposal [ED18 Sampling flowchart]	1	

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.

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

Standard conditions of support

Support to process confidential patient information without consent, given by the Secretary of State for Health and Social Care, is subject to the following standard conditions of support.

The applicant and those processing the information will ensure that:

1. The specified confidential patient 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, in addition to other national guidance.

4. All staff with access to confidential patient information have contractual obligations of confidentiality, enforceable through disciplinary procedures.

5. All staff with access to confidential patient information have received appropriate ongoing training to ensure they are aware of their responsibilities.

6. Activities remain consistent with the General Data Protection Regulation and 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. Any significant changes (for example, people, purpose, data flows, data items, security arrangements) must be approved via formal amendment prior to changes coming into effect.

10. An annual review report is submitted to the CAG every 12 months from the date of the final support letter, for the duration of the support.

11. Any breaches of confidentiality around the supported flows of information should be reported to CAG within 10 working days of the incident, along with remedial actions taken / to be taken. This does not remove the need to follow national/legal requirements for reporting relevant security breaches.