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02 August 2022

Tamantha Webster
Survey manager
151 Buckingham Palace Road,
London,
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Dear Ms Webster,

Application title: **The 2022 Urgent and Emergency Care Survey**
CAG reference: **22/CAG/0107**

Thank you for submitting a **non-research** application under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 ('section 251 support') to process confidential patient information without consent.

Supported applications allow the controller(s) of the relevant data sources, if they wish, to provide specified information to the applicant for the purposes of the relevant activity without being in breach of the common law duty of confidence. Support provides a lawful basis to allow the information to be processed by the relevant parties for the specified purposes without incurring a breach of the common law duty of confidence only. Applicants must ensure the activity remains fully compliant with all other relevant legislation.

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 for Health and Social Care on whether application activity should be supported, and if so, any relevant conditions. This application was considered at the precedent set CAG meeting held on 08 July 2022. The application was considered via the precedent set process under category 11: Applications made by the Picker Institute Europe to administer surveys on behalf of CQC.

Secretary of State for Health and Social Care decision

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

The application, to allow the disclosure of confidential patient information from NHS trusts to one of three approved contractors for the purpose of sending out questionnaires for the 2022 Urgent and Emergency Care Survey, and for disclosure of postcode to the Survey Coordination Centre for Existing Methods (SCCEM) at Picker for analysis purposes, is fully supported, subject to compliance with the standard and specific conditions of support.

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

Context

Purpose of application

This non-research application submitted by Picker Institute Europe, (on behalf of the Care Quality Commission), sets out the purpose of conducting the 2022 Urgent and Emergency Care Survey.

The 2022 Urgent and Emergency Care Survey will be the ninth carried out to date, and falls within the NHS Patient Survey Programme (NPSP). The NPSP was initiated in 2002 by the then Department of Health, and is now overseen by the Care Quality Commission (CQC), the independent regulator of health and social care in England. The CQC have commissioned the Survey Coordination Centre for Existing Methods (SCCEM) at Picker to manage and coordinate the survey programme under the title of the SCCEM. All eligible trusts will be asked to conduct the survey with preparations expected to begin in September 2022 and fieldwork expected to start from November 2022. All trusts will draw a sample of patients according to set criteria, and follow standardised materials and procedures for all stages of the survey.

The methodology for the 2022 survey is unchanged from the 2020 survey. The Same Day Emergency Care (SDEC) indicator will no longer be requested for the 2022 survey. The SCCEM will use an online sample checking platform for the 2022 survey.

NHS Trusts will submit the combined mailing and sample file to the approved contractor. The complete mailing data will then be removed, except for the full postcode, which will be sent to the SCCEM as part of the sample file. Both the approved contractors and the SCCEM will not open a sample file until a satisfactory sample declaration form has been received. Any outputs provided will be anonymous. This statistical dataset is used for a wide variety of purposes, with the ultimate aim of supporting the improvement of patient experience in England.

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	People aged 16 and over who attended a Type 1 emergency department in September 2022 or a Type 3 urgent care department in September 2022. Trusts can sample back to August 2022 if required to fulfil sample. For trusts with only Type 1 departments, the sample size will remain at 1250. Trusts who have both departments will have a sample size of 950 for Type 1 and 420 for Type 3. The applicants anticipate that 126 trusts will be involved.

	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 - Any attendances at Walk-in Centre's - Any attendances at Type 3 departments not wholly managed by the sampling trust. - Patients who attended or were streamed to a separate Same Day Emergency Care unit (i.e. not the A&E department or Urgent Treatment Centre).
Data sources	1. Electronic patient records within all eligible Trusts in England (126 trusts)
Identifiers required for contact purposes	1. A standardised unique identifier code, to be constructed as survey identifier, trust code followed by a whole number (consecutive across the sample of patients from each trust), e.g. UEC22XXXNNNN where XXX is the trusts 3 digit trust code and NNNN is the 4 digit serial number relating to sampled patients. 2. Title (Mr, Mrs, Ms, etc.) 3. First name 4. Surname 5. Address Fields 6. Full Postcode
Identifiers required for analysis purposes	1. The unique identifier code (as above) 2. NHS Trust code 3. Date and time of attendance 4. NHS Site code 5. Department type (Type 1 or Type 3) 6. Ethnicity 7. Gender 8. Year of birth 9. CCG code 10. Patients full postcode – to use to map to deprivation index

	11. Mobile phone indicator
Additional information	Trusts may also choose to collect additional sample variables outside of those detailed in the Survey Handbook. This can be valuable to trusts in enabling them to make greater use of their survey locally to target quality improvements. Sample and mailing data will be submitted by Trusts to approved contractors in a single file. The file which contains both mailing and sample information will be split into separate files by the contractor before submitting only the sample information to the SCCEM. Please note that the SCCEM does not receive any names or full addresses.

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.

The CAG noted that the methodology has been tried and tested, the survey has a clear medical purpose and is 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

There are three central arguments as to why consent is not practicable, and which have been accepted across the National Survey Programme:
• Trusts will not benefit from the expertise of a specialist survey contractor,
• Potential to introduce bias into the survey findings,
• Potential burden on clinical staff through the requirement to take consent.

The CAG were content with the justifications provided.

- Use of anonymised/pseudonymised data

The applicants advised that the approved survey contractors required confidential patient information in order to send questionnaires to selected patients. The CAG agreed that this could not be done without the use of confidential patient information. The CAG also noted

that phone number itself is not collected, only if the mobile number was available or not, and were content with this proposal.

'Patient Notification' and mechanism for managing dissent

It is part of the CAG responsibility to support public confidence and transparency in the appropriate sharing and use of confidential patient information. Access to patient information without consent is a privilege and it is a general principle of support for reasonable measures to be taken to inform the relevant population of the activity and to provide a right to object 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 Data Protection Act 2018.

Posters will be displayed in participating Trusts throughout the sampling period to inform patients that they may be approached to participate in the survey and provide a means for prior dissent to be raised. These have been produced in English and translated into 14 other languages to improve accessibility. Trusts are asked to think carefully about where to place them appropriately. Although the provision of posters is the primary method of informing the study population of the survey, the Survey Handbook will also recommend that trusts issue a local press release prior to mailing questionnaires out, to raise awareness of the survey and to gain publicity. This will contain a helpline number and email address, should people wish to opt out or have any questions. The content of these documents is the same as for the fully supported 2020 survey.

The poster provides information about how a patient can opt out of the survey. Trusts are also asked to remove any records where existing dissent has been recorded. Contractors and those trusts that administer the survey themselves, will provide a freephone telephone line, email address and postal address on survey materials and posters (which must be displayed in trusts throughout the sampling period) for people to call for advice, assistance or to opt-out of future mailings. The surveys have a policy exemption from the national data opt out. It is suggested that the National Data Opt-Out exemption should be explained in the patient notification materials. This should include an explanation that the exemption had not been granted by CAG, but via policy consideration. A link to the information around the exemption on the NHS Digital website, 7. Policy considerations for specific organisations or purposes - NHS Digital also should be included on the patient notification materials.

The Members were content with the methodology and content of the patient notifications and opt out mechanism. However it was commented that the poster on how to opt out is available in 14 languages, but it seems unlikely that any emergency Department would have room to display all of the posters relevant to the local community. It would seem sensible to say that is available in other languages on the poster and have a QR code or straightforward web link to a page with all of the available languages, or translated leaflets available on request. The CAG are not making this a condition of support, but merely recommend that the applicants re-visit the approach to investigate if there are better ways of displaying the multiple language options. It is commented that the applicants and the individuals they discuss the surveys with, will likely be able to develop a better way of doing this. This is a comment for future iterations of the survey.

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.

The applicants explained that the methodology used in the 2022 survey is broadly similar to that used since the NHS Patient Survey Programme was established in 2002. The first Emergency Department survey was developed in 2003. Consultations with relevant policy stakeholders and patient involvement was undertaken when designing the questionnaire. Where possible, questions are kept the same to facilitate year-on-year comparisons. However, the questionnaire content is reviewed before each survey to consider if any questions are not working and if new questions are needed to ensure the questionnaire is up to date and in line with current policy and practice. Questionnaire development is underway, and the applicant has involved a significant number of patients and the public.

The use of confidential patient information without consent was also discussed. The applicant undertook focus groups with patients who had attended an A&E department or Urgent Treatment Centre in the last 6 months. Four focus groups were held with 15 patients from different geographical areas across England (London, South West, South East, Midlands, North East), ages (26 to 56 year olds), and ethnic backgrounds (White, Black/Black British, Asian/Asian British). Overall, patients did not hold any concerns or worries with confidential patient information being shared without their consent for the purposes of completing a questionnaire.

The Members were content with the patient and public involvement undertaken, noting that it has been ongoing for several years, and has appeared quite effective.

Exit strategy

The mailing file, containing patient names and addresses, is to be kept encrypted at all times and destroyed when the survey is complete. The original data drawn from trust records may need to be reviewed if any anomalies or errors are identified at any stage throughout the course of the survey, up to the point by which the survey response data is checked and finalised. For this reason, the mailing files may be kept until the reporting stage of the survey. This will be no longer than 6 months after the end of fieldwork, for all contractors.

The SCCEM will destroy the only identifier they retain (full postcode), approximately 6 months after the end of fieldwork, retaining it only for the purpose of checking for any errors that arise following publication.

The Sub-committee were content with this exit strategy.

Confidentiality Advisory Group advice conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, 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

1. Confirmation provided from the IG Delivery Team at NHS Digital 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 Digital **21/22** DSPT reviews for **Patient Perspective Ltd, Picker Institute Europe and Quality Health Ltd** were confirmed as 'Standards Met' on the NHS Digital DSPT Tracker (checked 27 July 2022)

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

Application maintenance

Annual review

Please note that this legal support is subject to submission of an annual review report, for the duration of support, to show that the minimal amount of patient information is being processed and support is still necessary, how you have met the conditions or report plans, any public benefits that have arisen and action towards meeting them. It is also your responsibility to submit this report every 12 months for the entire duration that confidential patient information is being processed without consent.

The next annual review should be provided no later than **02 August 2023** and preferably 4 weeks before this date. Reminders are not issued so please ensure this is provided annually to avoid jeopardising the status of the support. Submission of an annual review in line with this schedule remains necessary even where there has been a delay to the commencement of the supported activity, or a halt in data processing. Please ensure you review the HRA website to ensure you are completing the most up to date 'section 251' annual review form as these may change.

For an annual review to be valid, there must also be evidence that the relevant DSPT submission(s) for organisations processing confidential patient information without consent are in place and have been reviewed by NHS Digital. Please plan to contact NHS Digital in advance of the CAG annual review submission date to check they have reviewed the relevant DSPTs and have confirmed these are satisfactory.

Register of Approved Applications

All supported applications to process confidential patient information without consent are listed in the published 'Register of Approved Applications'. It is a statutory requirement for the Register to be published and it is available on the CAG section of the Health Research Authority website. It contains applicant contact details, a summary of the research and other pertinent points.

This Register is used by controllers to check whether support is in place.

Changes to the application

The application and relevant documents set out the scope of the support which is in place for the application activity and any relevant restrictions around this.

Any amendments which are made to the scope of this support, including but not limited to, purpose, data flows, data sources, items of confidential patient information and

processors, require submission of a formal amendment to the application. Changes to processors will require evidence of satisfactory DSPT submission. The amendment form can be found in the Confidentiality Advisory Group pages on the Health Research Authority website.

Support for any submitted amendment would not come into effect until a positive outcome letter has been issued.

Changes to the controller

Amendments which involve a change to the named controller for the application activity require the submission of a new and signed CAG application form and supporting documentation to support the application amendment. This is necessary to ensure that the application held on file appropriately reflects the organisation taking responsibility for the manner and purpose of data processing within the application, and that the legal support in place is related to the correct legal entity.

Applicants are advised to make contact with the Confidentiality Advice Team to discuss a change in controllership for an existing application in sufficient time ahead of the transfer of project responsibility to discuss the submission process timings.

Further information and relevant forms to amend the support is available on the HRA website.

Reviewed documents

The documents reviewed at the meeting are as follows.

Document	*Version*	*Date*
CAG application from (signed/authorised)		28 June 2022
Letter from statistician [UEC22_Draft Sampling instructions_V1.0_PROTECT]	1.0	
Other [UEC20_ 2020 Type 1 Main Questionnaire_V1.0_PROTECT]	1.0	
Other [UEC20_ 2020 Type 3 Main Questionnaire_V1.0_PROTECT]	1.0	
Other [UEC22 Sampling flowchart V1 PROTECT]	1.0	
Other [UEC22_Data flow diagram - post codes_V1_PROTECT]	1.0	
Other [UEC22_Dissent_V1.0_PROTECT]	1.0	
Other [UEC22_Draft Survey handbook_V1.0_PROTECT]	1.0	
Other [UEC22_GDPR Model service contract_V1_PROTECT]	1	
Other [UEC22_Multilanguage sheet_V1_PROTECT]	1	
Patient Information Materials [UEC22_Dissent poster English Type 1_V1_PROTECT]	1.0	
Patient Information Materials [UEC22_Dissent poster English Type 3_V1_PROTECT]	1.0	

Membership of the Committee

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

Mr David Evans, CAG member declared a conflict of interest, as he is employed by NHS England and NHS Improvement. He did not participate in the development of the recommendation provided by the CAG.

Please do not hesitate to contact me if you have any queries following this letter. I would be grateful if you could quote the above reference number in all future correspondence.

With the Group's best wishes for the success of this project.

Yours sincerely

Caroline Watchurst
Confidentiality Advisor

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

Email: cag@hra.nhs.uk

Included: List of members who considered application
Standard conditions of support

Confidentiality Advisory Group precedent-set meeting attendance
07 July 2022

Members present:

Name	
Dr Martin Andrew	CAG member
Dr Malcolm Booth	CAG member
Ms Clare Sanderson	CAG alternative vice-chair

Also in attendance:

Name	*Position (or reason for attending)*
Ms Caroline Watchurst	HRA Confidentiality Advisor

Health Research Authority

Standard conditions of support

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

The applicant and those processing the information under the terms of the support 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 and are acting in compliance with the application detail.

6. Activities must be compliant with the General Data Protection Regulation and relevant 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.