Health Research Authority

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01 July 2016

Mr Paul Williamson
User Voice Development Manager
Care Quality Commission
151 Buckingham Palace Road
London
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Dear Mr Williamson

Application title: **2016 Child Inpatient and Day Case Survey**
CAG reference: **15/CAG/0209**

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 originally considered at the CAG meeting held on 26 November 2015. This letter provides a final response and recommendation following applicant follow-up responses to the original provisional approval outcome

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 approved, subject to compliance with the standard and specific conditions of approval.

This letter confirms that support is now in effect from date of this letter.

Context

Purpose of application

This application from the Care Quality Commission (CQC) set out the purpose of this patient survey/survey evaluation in order to support development of a Children and

Young People's Health Outcomes Strategy. Support was sought to provide a legal basis to support the transfer of patient identifiable data from acute and specialist trusts to a specified 'approved survey contractor' for the purpose of mailing out questionnaires for the 2016 children's survey. The contractors specified are: Picker Institute Europe, Quality Health, Patient Perspective and CAPITA Surveys & Research (registered as Capita Business Services Ltd).

One of the principles of the Patient Survey Programme is that by ensuring organisations carry out patient surveys in a consistent and systematic way, using a standardised methodology and survey instrument, it is possible to build up a national picture of people's experience. With care it is then also possible to compare the performance of different organisations, monitor change over time, and identify variations between different patient groups. This will in turn lead to improvements in overall patient experience. These same principles will apply to the children's survey in exactly the same way as they do for adults.

The end product from this survey will be a set of aggregate statistical data that does not contain patient identifiable information. This statistical dataset is used for a wide variety of purposes to support ongoing improvement in patient experience.

A recommendation for class 5 and 6 support was requested to achieve the activity specified in the application.

Confidential patient information requested

Full details of the scope was set out in the letter dated 05 February 2016, in addition to the advice provided by the CAG on specific aspects. This letter should be read in conjunction with that provisional approval outcome. The remainder of this letter focuses on the responses provided in follow-up.

Confidentiality Advisory Group advice

Specific conditions of support

1. Confirmation of the final methodology detail once the results of the pilot are known to enable a recommendation of final approval to be made.

New approved contractor

The response confirmed that at the time of submission the approved contractor framework and the Co-ordination Centre contracts were being reviewed. The response confirmed that the contractors (Picker Institute Europe, Quality Health, Patient Perspective or CAPITA Surveys & Research) have all maintained their 'approved contractor' status. Members noted that they must all maintain a satisfactory (as assessed by the HSCIC) level of the Information Governance Toolkit for the duration of this support.

It was confirmed that an additional processor, Membership Engagement Services Ltd. (MES), had been engaged by the CQC as an 'approved contractor'. Members noted that they expected the newly appointed approved contractor to follow the same approach as dictated by the CQC, and must have a satisfactory IG Toolkit submission (as assessed by the HSCIC) for the duration of the approval; specific detail on the arrangements by MES in the response were not assessed by the members as they

clarified that they expected the arrangements to be consistent between all parties and subject to the requirements of the Information Governance toolkit. It was noted that MES had a parent company, however, for the purpose of this approval support applies only to MES.

2. Outstanding aspects pending the pilot (methodology, use of ICD-10 codes, cohort age (currently 0-15 only) to be presented back once known to CAG meeting as described in the application.

Pilot approach – stratified sampling

The response confirmed that in relation to the stratified sampling pilot there is a need to alter the sampling approach in order to potentially increase the proportion of responses received from those aged 8-15 years old. The intention is to assess the capability of trusts to draw a disproportionate stratified sample by conducting a pilot. All trusts that would be eligible to participate in the main survey would be required to participate in the pilot, as this would be the first time trusts have been asked to draw a sample in this way as part of the NHS Survey Programme. The response stated that it will benefit the implementation of this survey, but there is a need to test whether it can be conducted accurately and without too much burden on trusts before committing to use of a stratified methodology. It was confirmed that there are no guarantees that a stratified sample will ensure a larger number of trusts will be eligible to receive benchmark reports, due to the dependence on response rates. However every effort is being made by CQC and the Co-ordination Centre to address the factors identified as having the potential to negatively impact response rates.

For the purposes of the pilot, there is no requirement for: name, address or postcode. The data requested for the 'pilot transfer' will only include the following:

- Trustcode
- A standardised unique identifier code, to be constructed as survey identifier, trust code followed by a whole number
- Month of birth
- Year of birth
- Gender
- Date of admission
- Date of discharge
- Main speciality (of consultant) code on discharge

The variables required for the 'pilot transfer' represents a significantly reduced version of what was requested on page six of the initial application for the 'standard transfer for survey'. Only information essential for evaluating whether the pilot had been a success is being requested.

This in turn means that the following variables will only be required for the 'standard transfer for survey':

- Ethnic group
- Length of stay
- Referring CCG
- Treatment Centre Admission
- Route of admission
- NHS site code of admission
- NHS site code of discharge
- GPPC code
- Treatment function code

The response confirmed that no mailings will take place as part of the pilot; the focus is on assessing how capable trusts are at constructing a stratified sample correctly. This means that unlike other pilots recently conducted as part of the NHS Patient Survey Programme (e.g. CAG 10-02(b)/2015) there will be no requirement for pilot sample data to be transferred to a mailing house.

Age of cohort

It was confirmed that for the 2014 Children's Survey, those aged 16 and 17 will not be included within the sample population. It was confirmed that those aged 0-14 days old will now be excluded from the sample population, this would represent the only change to the cohort age from that which was used within the 2014 iteration of the survey. The reason for this decision is having conducted an evaluation of the 2014 Children's Survey, it was evident that some trusts had difficulties identifying 'well-babies' and removing them from the sample. For example, some trusts included newborns treated for jaundice as a well-baby whilst others did not. CQC will therefore continue to use three different versions of the questionnaire, each of which is bespoke to the needs of the sub-groups: 14 days-7 years old, 8-11 years old and 12-15 years old.

ICD-10 codes

It was confirmed that for the 2016 Children's Survey, ICD-10 codes will not be requested.

Sample period

In an attempt to further boost the number of responses received from those aged 8-15 the sampling period in 2016 will primarily be November and December, with some trusts possibly also sampling back into October. The rationale for this shift in sample period is based on analysis of HES data, as these months were revealed to have the highest number of inpatient and day-case discharges amongst those aged 8-15 years old.

Addition: Community trusts

The response also requested approval for the transfer of patient identifiable data from a maximum of three community trusts, as opposed to the acute trusts. It was confirmed that in 2014 no community trusts had participated. There are three community trusts which have a high number of children and young people admissions. As such, in order to fulfil the CQC's regulatory role, gathering information on patient experiences at these trusts is recommended for 2016, provided that they are able to draw a minimum size sample of 300. The same security arrangements information required of acute and specialist trusts for transferring patient identifiable will be applied to community trusts.

3. All letters to parent/guardian to be provided on Trust letter headed paper

Confirmed.

4. Confirmation that previously expressed objections will be upheld

Confirmed.

5. Confirmation from the IGT Team at the Health and Social Care Information Centre of suitable security arrangements for each contractor via Information Governance Toolkit (IGT) submission. **A copy of an email dated 27/08/15**

from Mr John Hodson was included as part of the submission that confirmed satisfactory security arrangements.

A reminder was given that while the response was comprehensive, future documentation should be reviewed for relevance and conciseness to avoid ensure only relevant information is presented.

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and noted that the applicant had advised that a number of aspects were undergoing a pilot before final methodology could be confirmed. This information would be submitted to a full CAG meeting before any final approval could be issued and come into effect

The CAG therefore advised recommending provisional support to the Secretary of State for Health, subject to satisfactory resolution of and compliance with the specific and standard conditions of support as set out below.

Reviewed documents

The documents reviewed at the meeting were:

Document	*Version*	*Date*
CAG application from (signed/authorised)		03 November 2015
Other [20151026 CIP16 Sampling flow chart]	1	26 October 2015
Other [20151026 Error report for 2014 survey V1]	1	26 October 2015
Other [20151103 CYP14_0_to_7_adults_questionnaire_v1]	1	03 November 2015
Other [20151103 CYP16 How dissent is managed V1]	1	03 November 2015
Other [Stakeholder consultation for development of 2014 survey V1]	1	26 October 2015
Other [20151026 Stakeholder consultation for evaluation of 2014 survey V1]	1	26 October 2015
Other [CYP service contract briefing V1]	1	03 November 2015
Other [CYP service contract V1]	1	03 November 2015
Other [CAG 1-05(a) 2014 final approval]		
Other [CAG 1-05(a) 2014 Amendment Outcome Letter]		25 February 2015
Patient Information Materials [20151103 CYP14_Questionnaire_8-11yrs_v1]	1	03 November 2015
Patient Information Materials [20151103 CYP14_Questionnaire_12-15yrs_v1]	1	03 November 2015
Patient Information Materials [CYP16 DRAFT sample declaration form V1]	1	03 November 2015

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.

Dr Miranda Wolpert declared a potential competing interest and did not participate in the discussion.

Yours sincerely

Natasha Dunkley
Confidentiality Advice Manager

On behalf of the Secretary of State for Health

Email: HRA.CAG@nhs.net

Enclosures: *List of members who considered application*

Confidentiality Advisory Group meeting 26 November 2015

Member present	
Dr Tony Calland (CAG vice-Chair)	Chair
Dr Kambiz Boomla	
Ms Clare Sanderson	
Dr Murat Soncul	
Mr Anthony Kane	Lay
Professor Jennifer Kurinczuk	
Ms Gillian Wells	Lay
Dr Miranda Wolpert	

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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.