



Health Research Authority
Confidentiality Advisory Group
On behalf of the Secretary of State for Health

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03 July 2014

Dear Ms Halt

Study title: 2014 Child Inpatient and Day Case Survey
CAG reference: CAG 1-05(a)/2013

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 for Health on whether an application should be approved, and if so, any relevant conditions. This application was considered on 10 April 2014.

Secretary of State for Health approval decision

The Secretary of State for Health, 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.

This letter should be read in conjunction with the outcome letter dated 30 April 2014.

Context

Purpose of application

This application from the Care Quality Commission detailed the first iteration of a national children's survey conducted as part of the national NHS patient survey programme. The survey was developed to incorporate the views of children and young people into existing national patient surveys.

A recommendation for class 5 and 6 support was requested to cover access to contact details of patients (children aged 0-17) who had been admitted as an inpatient or received treatment as a day case patient in June 2014.

Confidential patient information requested

Access was requested to name and address of patient and the patient's parent/carer.

Background

This application was considered by the Confidentiality Advisory Group on the 10 April 2014, CAG advised that the application was conditionally approved. The applicant subsequently replied to the conditions of approval on 23 May 2014 and the responses are summarised in the table below.

Conditions	Responses
1. Confirmation of suitable security arrangements via IG Toolkit submission, please provide information in relation to any improvement plans submitted.	Improvement plans for Capita and Picker were submitted.
2. Support is provided to access contact details for parents/carers of patients aged 0-12 and for patients aged 13-17.	<p>The applicant specifies that they would be unable to proceed with this condition in place and raises the following issues:</p> <ul style="list-style-type: none"> • From discussion with a sample of trusts (a random selection of 17 trusts based on size), CQC have learnt that parent name is not recorded as default by all trusts, although it is recorded by some. • Some trusts record next of kin as a default for parent, and the applicant asserts that this is likely to be problematic for 'looked after children', or where parents are separated and a child is taken to hospital by the parent who was not named as 'next of kin'. • Some trusts record more than one person as next of kin, which the applicant asserts would be problematic for deciding which contact to mail the questionnaire to, or for which next of kin, the trust holds address information. • The applicant also asserts additional concerns about the quality and accuracy of the information recorded. <p>The applicant proposed that they address surveys to patients under the age of 16 to 'the parent/carer of x' for this age group as per the guidelines issued by the Market Research Society.</p>
3. Support is provided for a period of 12 months and the representativeness checking process using anonymised data outlined above should be utilised with those Trusts undertaking the dissemination of surveys themselves to determine whether this did present a feasible alternative. Strong evidence would be	The applicant confirmed that a report would be provided for CAG following completion of the survey.

required that there was no practicable alternative if a further application for a future survey was submitted.	
4. Please provide further information in relation to the disclosure of data to the Department of Health and NHS England, in particular the requirement for respondent level data.	Essential sample variables would be provided to NHS England within the respondent level dataset (year of birth, gender, ethnicity, CCG code, route of admission and site code). Access within NHS England would be restricted. The Department of Health would not require a respondent level dataset.
5. Please submit the patient information materials in relation to the survey.	A draft version of a patient/ parent/ carer leaflet for trusts was provided.
6. Please confirm that patient objections can be processed both at Trust level and by the survey contractor and that there will be a consistent approach to managing objections by survey contractors and details of this approach.	It was confirmed that PALS would manage patient objection at a local level. The applicant will write to all contractors setting out the standards expected of them in order to promote a consistent approach to managing objections.

Confidentiality Advisory Group Advice

Members considered the further information provided by the applicant and noted that the applicant had considered the potential of accessing parent/carer, rather than child, data in detail and that evidence had been provided that this would not be feasible. Members agreed that this would not be feasible and agreed to withdraw this condition of approval.

Members advised that the suggestion that mail outs would include initial and surname of child only on envelopes was a positive step and should be adopted where possible.

In general members commented that the CQC may wish to ensure that their code of practice specifically addresses circumstances where the data relates to a child.

CAG advice conclusion

In line with the considerations above, 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 *conditional* support to the Secretary of State for Health, subject to compliance with the specific and standard conditions of support as set out below.

Specific conditions of support (revised)

1. Confirmation of suitable security arrangements via IG Toolkit submission, please see security review requirement section here; <http://www.hra.nhs.uk/resources/confidentiality-advisory-group/confidentiality-advisory-group-cag-application-advice/> and contact exeter.helpdesk@nhs.net with any queries.
2. Support is provided for a period of 12 months and the representativeness checking process using anonymised data outlined above should be utilised with those Trusts undertaking the dissemination of surveys themselves to determine whether this did present a feasible alternative. Strong evidence would be required that there was no practicable alternative if a further application for a future survey was submitted.

Further actions

Please respond back to the conditions of support. Once provided, the response will be reviewed and if satisfactory, the SofS will confirm final approval. Support only comes into effect once this final approval letter has been received.

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.

Reviewed documents

The documents reviewed at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Response letter from CQC		23/05/2014
Managing dissent paper		May 2014
Response to subsequent queries from CAG		16/06/2014
Patient information leaflet	4	

Membership of the Group

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

Dr Miranda Wolpert declared a competing interest in the application as a member of the Children and Young People's Health Outcomes Forum, the recommendations of the Forum had led to this application. The interest was declared to the applicant and Dr Wolpert did not take part in the discussion in relation to the outcome of this application.

Yours sincerely

Claire Edgeworth
Deputy Confidentiality Advice Manager

Email: HRA.CAG@nhs.net

*Enclosures: List of members who were present at the meeting
and those who submitted written comments*

Standard conditions of approval

**Confidentiality Advisory Group
Attendance at meeting on 19 June 2014**

In attendance

Name	Position (or reason for attending)
Ms Natasha Dunkley	Confidentiality Advice Manager, HRA
Ms Claire Edgeworth	Deputy Confidentiality Advice Manager, HRA

Group members

Name	Capacity
Dr Mark Taylor (Chair)	Lay
Dr Kambiz Boomla	
Dr Tony Calland	
Professor Julia Hippisley-Cox	
Dr Patrick Coyle	
Mr Anthony Kane	Lay
Professor Jennifer Kurinczuk	
Ms Clare Sanderson	
Dr Murat Soncul	
Mr C. Marc Taylor	
Ms Gillian Wells	Lay
Dr Miranda Wolpert	
Professor Ann Jacoby	
Mr Barry Evans	
Ms Hannah Chambers	Lay

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.