Health Research Authority

Skipton House
80 London Road
London
SE1 6LH

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

Dr Pauline Heslop
LeDeR Programme Manager
Norah Fry Research Centre
School for Policy Studies
University of Bristol
8 Priory Road
Bristol
BS8 1TZ

03 January 2017

Dear Dr Heslop

Application title: **Learning Disabilities Mortality Review Programme**
CAG reference: **16/CAG/0056 (re-submission of 16/CAG/0005)**

Thank you for your amendment request to the above audit 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.

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 amendment is conditionally 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.

Context

Purpose of application

This application from University of Bristol set out the purpose of the Learning Disability Mortality Review (LeDeR) Programme as a service improvement initiative. It was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England.

The aim of the programme was to drive improvement in the quality of service delivery for people with learning disabilities (LD) and help to reduce premature mortality and health inequalities in this population. The remit of the LeDeR Programme was primarily to support local agencies to review deaths of people with learning disabilities and to use the learning gained to make improvements in the delivery of care. The LeDeR programme will develop and roll out a standardised process for reviews to support this local delivery, and provide strategic support for its implementation. In doing so, it will be building on the well-established practice in health and social care of conducting mortality reviews as a means of improving patient care.

The anonymised mortality case reviews will be collated and evaluated by the programme team to ensure that learning is being embedded in practice. This will be reported on annually. Reports on the findings of this work will be disseminated to regulators, policy makers, commissioners, service providers, practitioners and patient and family groups with the aim of supporting changes that improve the quality and safety of care for people with learning disabilities.

A recommendation for class 1, 4, 5 and 6 support was requested to allow the disclosure of confidential patient information from:

- The reporting of personal details about people with learning disabilities who have died from 1st April 2015 to 31 May 2018 to the LeDeR Programme
- Collection of detailed case information and review of health or social care case notes in order for a local reviewer to conduct a review of the death
- To share NHS numbers (or other key identifiers) with the Office for National Statistics to obtain the ICD10 codes for each person's causes of death.

Amendment Request

The amendment requested the following two changes to the existing supported project:

1. Change to Data Flow – previously the applicants had shared NHS Numbers with the Office of National Statistics (ONS) in order to obtain the ICD-10 code for each person's death. However, due to changes in ONS data flows, the applicants are now required to share data with NHS Digital in order to obtain the coding of death causes.
2. Extension of Data Items and Retention – the current application provided support for the applicants to collect the first two digits of a deceased person's postcode in order to identify any service improvements related to area based population. However, since undertaking the pilot stage of the programme, the applicants had found that the full postcode was required in order to use UK Data Service GeoConvert programme. The applicants indicated that once postcodes had been used to identify the area-based deprivation indices, the postcode would only be retained at district level, which the amendment was also requested to support.

Confidentiality Advisory Group Advice

The amendment request was forwarded to the Chair for consideration and confirmation was received that the change to the data flow described in the amendment request did not constitute an amended data flow on behalf of the applicants. This was an administrative change only due to revision in the data collected/released by NHS Digital and support was recommended.

The Chair considered the requested extension to data collection to include the full postcode and retention following deprivation-score calculation of the postcode at district level. The Chair acknowledged that the applicants required this extent of data to enable assessment of any relationships between area deprivation scores and unequal health outcomes to enable identification of any unexpected local clusters of deaths related to inadequacies in the local system. However, it was noted that support was recommended on the provision that the applicants explored the potential for the required deprivation score to be provided by NHS

Digital with the data download, preventing the requirement for full postcode to be processed again by the applicants. An update on progress with this condition was required as part of the next annual review submission.

Confidentiality Advisory Group Conclusion

In line with the considerations above, the Chair agreed that the minimum criteria under the Regulations appeared to have been met for this amendment, and therefore advised recommending support to the Secretary of State for Health.

Specific conditions of support

1. Explore the potential for deprivation scoring to be undertaken by NHS Digital on the applicant's behalf and the relevant information provided as part of the data download. Provide an update at the next annual review around the progress which has been made with this condition.
2. Confirmation of suitable security arrangements via IG Toolkit submission - **(Confirmed - Version 13 (2015-16) reported a reviewed satisfactory score at 91%).**

Reviewed documents

Document	*Version*	*Date*
Amendment Request Form – Signed by Professor Pauline Heslop		06 December 2016

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.

Yours sincerely

Ms Kathryn Murray
Senior Confidentiality Advisor
On behalf of the Secretary of State for Health

Email: HRA.CAG@nhs.net

Enclosures: Standard Conditions of Approval

NHS
Health Research Authority

Standard conditions of approval

The approval provided by the Secretary of State 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.