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08 February 2018

Dr Pauline Heslop
LeDeR Programme Manager
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Bristol
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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 and Social Care Approval 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:

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 requests support for the following two changes:

1. Redacted, rather than pseudonymised, information to be sent to Steering Groups – which would involve the sharing the initials and NHS number of the patient where necessary, plus the name of relevant professionals, agencies, organisations and care providers sufficient to enable recommendations to be addressed.
2. The Learning Disability Mortality Review team to be able to store the data in this redacted form for the 10 year period.

Confidentiality Advisory Group Advice

Public Interest

The CAG acknowledged there was a strong public interest in the application activity; however, it was noted that learning points from the case reviews which had been undertaken were not currently being implemented as staff at the sites were unable to target the learning points due to the receipt of data in an anonymised format.

Whilst it was acknowledged that there was potentially an increased risk of re-identification of the deceased patient from the redacted data set, Members were assured that this risk was outweighed by the potential future benefit for patients with learning disabilities from the implementation of learning points from the care reviews.

Justification of Identifiers

Applicants should justify the necessity of each identifiable data item in the context of how each is essential to achieve the aims, and as part of this justification consider whether less identifiable variants of each item would be sufficient e.g. month and year instead of full date of birth.

The Group discussed the proposed redaction process which would be applied to the data included within the case review information which is shared with local steering group. The CAG was assured that the inclusion of information around the clinics and departments involved, together with the patient's NHS Number was justified; it was not satisfied that patient initials needed to be included in this information. Members discussed this point further and it was commented that whilst NHS Number was a direct patient identifier, this was not directly identifiable outside of an NHS environment. It was noted that the patient's initials were potentially identifiable to a wider audience outside of the NHS environment due to the specialist patient cohort.

The CAG would provide a recommendation of support to the inclusion of information in relation to relevant professionals, agencies, organisations and care providers involved in the case, together with patient NHS Number within the redacted care review information which is shared with steering groups and retained by the programme team for the 10 year period. Support was not extended to the inclusion of patient initials.

Duty of Confidentiality

The CAG considered the terms of reference for the local steering groups which had been shared as part of the amendment application. Within the document, one the stated purpose/roles of the group was to ensure agreed protocols are in place for information sharing, accessing case records and keeping content confidential and secure. At a later section within the document, it was stated that the governance of the group was to be advised in line with the area governance arrangements. Members acknowledged that the redacted data that would be shared as part of the case review would not contain any confidential patient information; however, due to the increased risk of the redacted data set, it was recommended that these roles be revisited to ensure that the data is appropriately handled to ensure security and confidentiality.

Confidentiality Advisory Group Conclusion

In line with the considerations above, the Confidentiality Advice Group 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 and Social Care.

Specific Conditions of Support

1. Support is extended to the transfer of redacted information to be sent to Steering Groups – this would include the NHS number of the patient where necessary, plus the name of relevant professionals, agencies, organisations and care providers to enable the case review recommendations to be implemented.
2. Support is extended to allow the Learning Disability Mortality Review team to retain data in this redacted form for the 10 year period.
3. Confirmation of suitable security arrangements via IG Toolkit submission - **(Confirmed - Version 14, 2016-17, reported a reviewed satisfactory score at 92%)**.

Recommendation:

1. It was recommended that the terms of reference for the local steering groups be revisited to ensure appropriate protocols are in place to ensure the confidentiality of the data.

Reviewed Documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
CAG application from (signed/authorised) [Amendment Request]		10 November 2017
Covering letter on headed paper [Cover Letter]		
Other [HQIP Letter of Support]		04 January 2018

Other [Response to CAG Queries]		05 January 2018
Other [Steering Group]		
Other [16/CAG/0056 Provisional Outcome Letter]		05 May 2016
Other [16/CAG/0056 Final Outcome Letter]		13 June 2016
Patient Information Materials [Public Information Material]		17 November 2017

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

Confidentiality Advisory Group Meeting 25 January 2018

Group Members:

<i>Name</i>	<i>Present</i>	<i>Notes</i>
Dr Malcolm Booth	Yes	
Ms Sophie Brannan	Yes	Lay
Dr Tony Calland	Yes	Chair
Dr Patrick Coyle	Yes	Vice Chair
Mr Anthony Kane	Yes	Lay
Dr Rachel Knowles	No	Apologies received
Professor Jennifer Kurinczuk	Yes	
Mr Andrew Melville	Yes	Lay
Dr Murat Soncul	Yes	Alternate Vice Chair

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Ms Natasha Dunkley	Head of the Confidentiality Advice Service
Miss Kathryn Murray	Senior Confidentiality Advisor
Mr Dave Murphy	Observer – HRA Communications Manager

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.