



Health Research Authority

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11 October 2019

Dr Pauline Heslop
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8 Priory Road
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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 non-research application, submitted for support under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002 to process confidential patient information without consent. Supported 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 and Social Care on whether an application should be supported, and if so, any relevant conditions.

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:

1. The amendment, to include the North East Commissioning Support Unit (NECSU) as a data processor and to amend the data flows to include NECSU, is fully supported, subject to compliance with the standard conditions of support.

Amendment request

This amendment outlined a request for support for a change to the data flow and the inclusion of an additional processor within the scope of support. NHS England have contracted the North East Commissioning Support Unit (NECSU) to provide targeted support for the completion of reviews of deaths of people with learning difficulties that were notified to the LeDeR programme on or before 31 December 2018 and which remain unfinished or unallocated to a reviewer. This requires that NECSU is added as an additional data processor and that the data flows are changed.

NECSU will use the web-based review system used by the LeDeR programme staff at the University of Bristol to review unallocated or unfinished cases. NECSU will access the data held on the review system to monitor the progress and the reviews allocated to them and develop statistical tables and outputs on the progress of the reviews. NECSU will also adopt the role of a Local Area Contact, helping the review to access information that will contribute to an understanding of the circumstances leading to the patient's death and to support the completion of mortality reviews and carrying out quality assurance on the completed reviews. NECSU will also extract learning and recommendations from completed NECSU reviews in order to feed this information back to the relevant Clinical Commissioning Groups. A previous amendment submitted to the CAG in February 2018 had requested support for the LeDeR programme to send redacted information to the Steering Groups, and in this amendment the applicants were seeking support to enable the NECSU to send information on the same basis.

Confidentiality Advisory Group advice

The amendment requested was considered by the Confidentiality Advisory Group. The Group raised no queries about the amendment and agreed that the described changes were reasonable.

Confidentiality Advisory Group conclusion

In line with the considerations above, the CAG 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. Confirmation of suitable security arrangements via DSP Toolkit submission. **Confirmed: University of Bristol, School of Policy Studies, Learning Disability Mortality Review Programme (by NHS Digital e-mail dated 10 July 2019) and The North of England Commissioning Support Unit (by DSPT tracker checked 02 October 2019) has a confirmed 'Standards Met' grade on DSPT submission 2018/19.**

Reviewed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
Amendment request form		10 September 2019
Attachment 1 LeDeR data flow map	7	05 September 2019
Attachment 2 LeDeR Process Flowchart	5	10 September 2019
Appendix 3 HQIP letter of support to CAG		09 September 2019
Attachment 4 Role and Responsibilities of CSU		Undated
Attachment 5 LeDeR programme privacy notice	2	05 September 2019

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

Miss Katy Cassidy
Confidentiality Advisor

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

Email: HRA.CAG@nhs.net

Enclosures: Standard conditions of support



Health Research Authority

Standard conditions of support

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

The applicant and those processing the information 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.
6. Activities remain consistent with the General Data Protection Regulation and 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.