



## Health Research Authority

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12 August 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 extend the duration of support to 31 May 2020, is fully supported, subject to compliance with the standard conditions of support.

## Amendment request

The applicant advised that the intended end date of the LeDeR programme had previously been 31 May 2019. The programme had since been extended to 31 May 2020, and the contract between HQIP and the University of Bristol for the delivery of the programme had been agreed.

The programme was funded by NHS England as part of a national suite of work aimed at reducing premature mortality and improving provision for people with learning disabilities. It was also part of the National Clinical Audit and Patient Outcome Programme, which Trusts are mandated to participate in as part of the standard NHS contract. As part of this, Trusts are required to review the deaths of people with learning disabilities in their care using the LeDer Methodology. The LeDeR programme was identified in the NHS Long Term plan, published in 2019, as being an initiative to reduce health inequalities for people with learning difficulties.

The applicants explained that there was a strong public interest in the Programme, as it was undertaken in the interests of improving patient care. Service improvements made as part of this programme were also likely to be relevant to other vulnerable groups. If continuing support was not given then a significant number of deaths already notified to the programme would not be reviewed, and the families of these patients would expect a review to be carried out. Further information about the service improvements required to reduce the premature mortality of those with learning disabilities was also needed, and would not be collected if the programme ended.

## Confidentiality Advisory Group advice

The amendment requested was considered by the Confidentiality Advisory Group. The CAG agreed that support under Section 251 and its Regulations should continue.

## 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 DSPT submission. **Confirmed for University of Bristol – School of Policy Studies on 10 July 2019.**

## Reviewed documents

<i>Document</i>	<i>Version</i>	<i>Date</i>
Amendment request form		14 May 2019
Ref: 402491 - University of Bristol - School of Policy Studies (Learning Disability Mortality Review Programme) (EE133799-SPS-LDMRP)		10 July 2019
HQIP letter of support to CAG		31 July 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

Ms Kathleen Cassidy  
Confidentiality Advisor

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

Email: [HRA.CAG@nhs.net](mailto:HRA.CAG@nhs.net)

Enclosures: Standard conditions of approval

### **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.