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

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13 June 2016

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

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 non-research 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 (SofS) for Health on whether an application should be approved, and if so, any relevant conditions. This application was considered at the CAG meeting held on 21 April 2016.

Secretary of State approval decision

The Secretary of State for Health, having considered the recommendation from the Confidentiality Advisory Group as set out below, has determined the following:

1. The application is approved, subject to compliance with the standard and specific conditions of approval.

This letter should be read in conjunction with the outcome letter dated 5 May 2016.

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.

This application was a re-submission of 16/CAG/0005 previously reviewed at the 14th January 2016 CAG meeting.

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.

Confidential patient information requested

Access was requested to information:

- Relating to people with learning disabilities: name of deceased person, date of birth, date of death, gender, NHS number, first 2 digits of postcode, ethnicity, gender, information about the circumstances leading to the death of the individual, including the person's medical history, details of diagnoses and treatments, contacts with services, the care and support that they have received prior to death, and their cause of death.
- Relating to the person's next of kin/family: name of relative/next of kin, address, and relationship to the deceased.

Confidentiality Advisory Group advice conclusion

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 support to the Secretary of State, subject to compliance with the specific and standard conditions of support as set out below.

Request for further information

1. Clarification about what minimising use of data means. **Received 26/05/2016**
2. Clarification about when data will be pseudonymised. **Received 26/05/2016**
3. Clarification about the approach to families when reporting about the Review. **Received 26/05/2016**

Specific conditions of support

1. Receipt of revised patient information. **Clarification received 26/05/2016 and reviewed by the Chair**
2. Confirmation from the IGT Team at the Health and Social Care Information Centre of suitable security arrangements via Information Governance Toolkit (IGT) submission. Please see security review requirement section of the HRA website: http://www.hra.nhs.uk/resources/confidentiality-advisory-group/confidentiality-advisory-group-cag-application-advice/ and contact Exeter.helpdesk@nhs.net with any queries. **Confirmed**

As the above conditions have been accepted and/or met, this letter provides confirmation of final approval. I will arrange for the register of approved applications on the HRA website to be updated with this information.

Annual review

Please note that your approval is subject to submission of an annual review report to show how you have met the conditions or report plans, and action towards meeting them. It is also your responsibility to submit this report on the anniversary of your final approval and to report any changes such as to the purpose or design of the proposed activity, or to security and confidentiality arrangements. An annual review should be provided no later than 13 June 2017 and preferably 4 weeks before this date. If at any stage you no longer require support under the Regulations as you will cease processing confidential patient information without consent you should inform the Confidentiality Advice Team of this in writing as soon as possible.

Reviewed documents

The documents reviewed at the meeting were:

Document	*Version*	*Date*
GP/consultant information sheets or letters [11. Appendix 11 LeDeR Programme leaflet for professionals]	v2	01 January 2016
GP/consultant information sheets or letters [Appendix 12 LeDeR Programme leaflet for families v2]	v2	01 January 2016
[resubmission cover paper v1]		
[section-251 form non-research]		
[Email - LeDeR Programme (our ref 2521) HRA decision]		12 April 2016
[Appendix 1 Data flow and process chart]	v1.0	
[CAT assessment form]		
[Email - LeDeR Programme (our ref 2521) HRA covering email]		12 April 2016
Patient Information Materials [Appendix 2 Involving families in the		

review process guidance for local reviewers]		
Patient Information Materials [Appendix 9 Information sheet]	v2	01 January 2016
Patient Information Materials [Appendix 10 Easy read information sheet]	v2	01 January 2016
Patient Information Materials [Appendix 13 LeDeR Programme leaflet easy read]	v2	01 January 2016
REC favourable opinion letter and all correspondence [Appendix 15 16CAG0005 s251 no recommendation]		

Membership of the Committee

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

None

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

Yours sincerely

Diane Pryce
On behalf of the Secretary of State for Health
Email: HRA.CAG@nhs.net

Enclosures: *List of members who considered application*
Standard conditions of approval

Confidentiality Advisory Group meeting 21 April 2016

Group Members:

Name	*Profession*	*Present*	*Notes*
Dr William Bernal		Yes	
Dr Kambiz Boomla		Yes	
Ms Hannah Chambers		Yes	
Dr Patrick Coyle		Yes	
Professor Barry Evans		Yes	
Ms Kim Kingan		Yes	
Prof Jennifer J Kurinczuk		Yes	
Mr David Smallacombe		Yes	
Dr Mark Taylor		Yes	
Mr Marc Taylor		Yes	

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.