

Minutes of the meeting of the Sub Committee of the Confidentiality Advisory Group

Amendments September 2015

Reviewers:

Name	Capacity	Items
Dr Mark Taylor	Chair	1a, b, 2a
Professor Barry Evans		1a
Mr Anthony Kane		1a

1. AMENDMENTS –RESEARCH

a) BRIGHTLIGHT: Do specialist cancer services for teenagers and young adults (TYA) add value?- ECC 8 -05(d)/2011

This application from University College London detailed a cohort study to determine whether specialist Teenage and Young Adult (TYA) specialist care affects outcomes. All patients aged 13-24 diagnosed with cancer in England would be invited to participate.

A recommendation for class 2, 3 and 6 support was requested to allow National Cancer Research Network (NCRN) nurses to access data from the North West Cancer Intelligence Service (NWCIS) in order to identify patients and request their consent for entry into the study.

Confidential patient information requested

Access to identifiers including name, NHS number, Hospital ID no, date of birth, hospital and diagnosis was requested to allow a link research nurse to identify and delegate consent duties to the most appropriate researcher within their network.

Amendment request

An amendment request was received which outlined two changes for member's consideration:

1. To rescind the closure of the application which had been closed on the basis that recruitment had been completed and that support was no longer required.
2. To extend the approval to allow access to individual Hospital Episode Statistics (HES) activity records for those young people who had consented to BRIGHTLIGHT (class 4 support). Data required by the Health and Social Care Information Centre (HSCIC) to make the data link (NHS number, name, date of birth) would be transferred from University College London Hospitals NHS

Foundation Trust (UCLH). This request was made after the Health and Social Care information Centre (HSCIC) had determined that the consent provided would not be sufficient to allow access to HES data and had therefore advised that the applicant write out to individuals to re-consent them. The applicant specified that they considered this to be impracticable due to the potential for non-response and that it was an additional burden on a cohort who had already provided consent.

Confidentiality Advisory Group advice

The amendment requested was forwarded to a sub-committee of members who noted the reasons specified for not contacting individuals again and agreed that it was likely that issues of non-response would make re-consenting impracticable. It was considered that the purpose and processes were sufficiently consistent with the reasonable expectations of the patients in the consented cohort that it would be appropriate to support the amendment without insisting on an additional patient information process.

Members agreed that the support had been ended prematurely given these unforeseen additional circumstances and recommended that the closure was rescinded and that the amendment to allow the transfer of HES data without re-consenting the cohort should be supported.

b) Millennium Cohort Study-14/CAG/1006

This application from the University of London set out the purpose of carrying out tracing via the Health and Social Care Information Centre for the Millennium Cohort Study (MCS; a continuing, multi-disciplinary, longitudinal study of some 19,000 subjects born in 2000/2001).

A recommendation for class 2, 3, 4 and 6 support was requested to cover access to mortality and address information from the HSCIC.

Confidential Patient Information Requested

Access was requested to NHS number, name, date of birth, full address and postcode.

Amendment request

The applicant submitted an amendment request to confirm change in Data Controller. The applicant confirmed that as of the 2nd December 2014, the Institute of Education (IOE) joined University College London (UCL) as a single faculty school, to be known as the UCL Institute of Education.

Confidentiality Advice Team advice

The amendment requested was reviewed by the Confidentiality Advice Team who had noted that the data controller for the Millennium Cohort Study had changed from the University of London to University College London.

Confidentiality Advice Team conclusion

In line with the considerations above, support for this amendment was recommended to the Health Research Authority.

2. AMENDMENTS NON-RESEARCH

a) Understanding failure in Unicompartmental Knee Replacement - ECC 8-02 (FT3)/2013

This service evaluation application from the University of Oxford detailed the linkage of HES and PROMS data to NJR data using the Health and Social Care Information Centre. Data would be linked using NHS number, date of birth and postcode. Patient identifiable data would be removed from the dataset prior to disclosure to the applicant and the identifiable data will be destroyed as soon as linkage is complete.

A recommendation for class 1, 4 and 6 support was requested to allow access to an authorised user for the purpose of extracting and anonymising confidential patient information and to link patient confidential patient information obtained from one or more source.

Confidential patient information requested

Access was requested to NHS number, date of birth and postcode to link HES data to NJR data.

Amendment request

An amendment was requested for an extension to the end date with no additional data required. The Confidentiality Advice Team noted that the project had been extended for five years from the date of the initial permission in order to allow the completion of the current research. The applicant confirmed that the original project end date was 28th February 2015 but that this would now be extended until 28th February 2018.

Confidentiality Advice Team advice

The amendment requested was forwarded to the CAT who agreed that the project end date could be extended until 28th February 2018.

Confidentiality Advice Team 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.