



Health Research Authority

Minutes of the meeting of the Sub Committee of the Confidentiality Advisory Group 29 July 2016

Present:

Name	Capacity	Items
Dr Tony Calland	Chair	1a
Dr Malcolm Booth		1a
Dr Harvey Marcovitch		1a

Also in attendance:

Name	Position (or reason for attending)
Rachel Heron	Confidentiality Advisor, HRA

1. NEW PRECEDENT SET REVIEW APPLICATIONS – NON RESEARCH

a) Post surgical predictors of chronic pain after total knee replacement 16/CAG/0105

This application from Big Health Data Group, Oxford University set out the purpose of linking data from the National Joint Registry with data from HES and linked PROMs data in order to study patients who have undergone knee replacement surgery, to identify post-operative factors associated with the development and persistence of pain. For the 20% of patients who experience long-term pain after surgery, this will inform future interventions that can either reduce the incidence of this kind of pain or that will provide more effective management for pain.

Identifiable data will be sent from NJR to HSCIC, for linkage and subsequent pseudonymisation. This data is held by the NJR with express written consent from the patient, recorded as 'Yes', 'No' or 'Not recorded'. NJR also has support to collect patient data where consent is indicated as 'Not Recorded'.

All identifiers will be removed to produce a pseudonymised linked extract of HES/PROMS records, with each record having an associated unique NJR pseudonymised patient identifier. This information will be sent to Oxford University for analysis.

A recommendation for class 1, 4 and 6 support was requested to achieve the purposes set out in the application. .

Confidential patient information requested

Access was requested to NHS number, date of birth, gender and postcode, provided by NJR.

Confidentiality Advisory Group advice

Public interest

The Committee agreed that the medical purpose of the application was clear, and a strong public interest had been demonstrated. The application was deemed a worthwhile part of the larger project.

Practicable alternatives

Members considered whether a practicable alternative to the disclosure of patient identifiable data without consent existed, taking into account the cost and technology available in line with Section 251 (4) of the NHS Act 2006.

- Feasibility of consent

It was agreed that consent was not feasible given the size of the sample.

- Use of anonymised/pseudonymised data

The Committee noted that only pseudonymised data would be used for analysis, following linkage by the HSCIC.

Justification of identifiers

The Committee discussed the use of NHS number, date of birth, postcode and gender. In a reply to a query from the Confidentiality Advice Team the applicant had stated that the minimum information required was the NHS number, postcode and date of birth.

It was noted that the identifiers requested were the same as approved for previous similar studies. The Committee was happy to recommend support but would ask for clarification on this point.

Additional points

Patient notifications: - the Committee agreed that the approach to patient notification was not adequate. Study specific materials should be disseminated through clinics, patient support groups and/or the website. The Committee agreed that a study specific patient information leaflet was necessary for this purpose.

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.

Specific conditions of support

1. Study specific patient information leaflets to be produced and placed in a publicly accessible place.

Appendix 1. CAG Sub Group Minutes

2. Confirmation of which identifiers are to be used should be provided, along with clarification on how the identifiers will be used – are they for linkage only or is postcode, for example, to be analysed for deprivation score?
3. Confirmation from the IGT Team at the Health and Social Care Information Centre of suitable security arrangements via Information Governance Toolkit (IGT) submission.

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Signed – Officers of CAG

Date

_____	_____
_____	_____
_____	_____

Signed – Confidentiality Advice Team

Date