

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

4 May 2016

Reviewers:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Patrick Coyle		Yes	
Clare Sanderson		Yes	
Jenny Kurinczuk		Yes	

Amendment

CAG8-03(PR9)/2013 National Prostate Cancer Audit

Purpose of application

This application refers to a collaborative prostate cancer audit which is part of the Healthcare Quality Improvement Partnership programme looking at treatment and outcomes for all patients. The application detailed the linkage of the HES dataset already held by the Royal College of Surgeons (PIAG 2-07(i)/2004 Audit of outcomes after surgical procedures using linked HES data and ONS mortality data) to cancer registry data held by Public Health England using the Health and Social Care Information Centre’s data linkage service.

Amendment request

This amendment request was for the data flow, data items and duration.

1. Data flow; the data flows have changed in response to the continued evolution of the NCRS, the NPCA data collection partner, and creation of the Office for Data Release (ODR), part of PHE.
2. PHE’s ODR are to supply a pseudonymised data set directly to the CEU containing records of all the men diagnosed from 1st April 2016 onwards (for the duration of the NPCA) linked at patient level to corresponding HES records and date of death from the Office for National Statistics (ONS). CEU will not at any point receive patient identifiers.
3. Data items; the NPCA Prospective Audit minimal dataset includes 49 data items in total. The majority of these data items are routinely collected as part of the monthly flow of Cancer Outcomes Services Data (COSD) to the NCRS. A limited number of additional data items were created for the NPCA, primarily planned radiotherapy data items, which are currently unavailable within COSD. These data items are collected and submitted by Trusts alongside their routine monthly COSD submissions.

4. Duration amendment; the timeframe for the patient cohort was extended to include a diagnosis date of 31st December 2013. In this amendment the applicant was requesting to extend the patient cohort to include patients diagnosed for the duration of the NPCA, currently planned to 31st March 2018.

Confidentiality Advisory Group advice

In line with the Standard Operating Procedures (SOPs) 10.8, this amendment request was considered by a sub-committee of the CAG via correspondence.

Members sought further information from the applicant on what progress had been made towards moving to a consent model for the prospective collection of information for this audit.

The applicant responded to confirm they were relying on an opt out process and not directly seeking consent, more specifically, the NCRAS system used for all cancer registration patients: "Every cancer department in the NHS is sent a patient leaflet explaining what cancer registration is, what data is collected and how, should an individual wish, they can opt out. They are asked to share the leaflets with their patients and to make them aware of the work of the registry."

Members were in agreement that consent would be problematic as the applicant was distanced from the actual point of data collection and that patient consent cannot be relied upon and instead the applicants are informing patients and allowing them to opt out. However, members were unsure how effective this approach will be and requested further information was provided by the applicant about this at the annual review.

Confidentiality Advisory Group conclusion

In line with the considerations above, the sub-committee 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.