

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

November 2017

Reviewers:

Name	Capacity
Ms Rachel Heron	Confidentiality Advisor

Application title: **General health and hospital admissions in children born after ART; a population based linkage study**

CAG reference: **ECC 4-03 (g)/2012**

Context

This application set out details of a study to identify whether children born from assisted reproductive technologies are at greater risk of health problems and an increased risk of hospital admissions. Support was requested to enable linking of HFEA records to ONS birth records, and to enable the Health and Social Care Information Centre (now NHS Digital) to link to MRIS and HES records.

Amendment Request

The amendment request was for an extension to Section 251 support to cover delays in the receipt of data, which were extensively described in the application. Delays had been encountered in receipt of data from NHS Digital and from HFEA due to unforeseen duplications and problems.

Confidentiality Advice Team Advice

The amendment requested was considered by the Confidentiality Advice Team who noted that there would be no changes to any aspect of the application other than the timescale, and that there would not be an increase in the time taken for data processing overall.

Confidentiality Advice Team Conclusion

In line with the considerations above, the Confidentiality Advice Team agreed that the minimum criteria under the Regulations appeared to have been met for this amendment, and therefore advised recommending support to the Health Research Authority.

Specific Conditions of Support

1. Confirmation of suitable security arrangements via IG Toolkit submission. **Confirmed.**

2. Confirmation of a favourable opinion from a Research Ethics Committee. **REC approval is in place – amendment not required by the REC for extension to timeline.**

Reviewers:

Name	Capacity
Ms Rachel Heron	Confidentiality Advisor

Application title: **Tracking the Impact of Gestational Age on health, educational and economic outcomes: a longitudinal Record linkage study (TIGAR)**

CAG reference: **15/CAG/0196**

Context

Purpose of Application

This application from University of Oxford set out the purpose of the overall aim of the study to investigate the effect of gestational age at birth on health, educational and economic outcomes up to age 11 years.

TIGAR will use information about all children born in England during 2005/2006 (about one million). Information on the children will be obtained from: birth records; records of hospital admissions or outpatient visits up to age 10 years and primary school records (e.g. SATs results, special educational needs). The information from these sources will be linked together by independent organisations, which will make the data completely anonymous before sending it to the TIGAR team for analysis.

Support is requested to allow the disclosure of confidential patient information from;

- The HSCIC to the Office for National Statistics (ONS)
- The ONS to the Education Data Division
- The TIGAR team to access patient confidential information within the ONS VML – this is for validation purposes

A recommendation for class 1, 2, 4 and 6 support was requested.

Confidential Patient Information Requested

Access was requested to child name, sex, date of birth and most recent postcode for the linking process.

A later amendment was requested (and supported) to include date of death for analysis.

Amendment Request

The original application requested transfers of data from ONS to the research team for validation on two occasions.

This request was for a third data transfer to enable another check to be carried out. The reason for this additional phase of checking was that the research team who undertook the initial linkage from which the TIGAR data was extracted, did not have time to check the matching of the children's data before their research funds ran out. Full details and a data flow diagram were provided.

Confidentiality Advice Team Advice

The amendment requested was considered by the Chair, who reviewed the track changed Protocol and was content that this amendment should be supported. Although it required additional access to data within the ONS VML the applicant had explained why this was required and demonstrated that it was necessary for the project to continue.

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 Health Research Authority.

Specific Conditions of Support

1. Confirmation of suitable security arrangements via IG Toolkit submission. **NPEU, University of Oxford – v14 confirmed published and reviewed.**
2. Confirmation of a favourable opinion from a Research Ethics Committee. **Confirmed.**

Reviewers:

Name	Capacity
Dr Tony Calland	Vice Chair
Miss Kathryn Murray	Senior Confidentiality Advisor

ContextPurpose of Application

This service evaluation application from Nuffield Department of Orthopaedics Rheumatology and Musculoskeletal Sciences (NDORMS) at the University of Oxford aimed to investigate the causes of death in patients with hip fracture. The mortality rate was unusually high (up to 30% in the 12 months following hip fracture). In 2013 61,000 patients experienced hip fracture in England, Wales and Northern Ireland therefore a considerable number of patients were affected. The published findings would enable better follow-up care by enabling clinicians to identify patients more likely to die in the 12 months following hip fracture. Potential correlations could be made between demographic trends and causes of death, increasing awareness within the medical community of the likely risks to patients, and facilitating future research on effective follow up and preventative strategies.

The applicant requested linked data from the National Hip Fracture Database (NHFD) and ONS data held by NHS Digital. Identifiable data would be provided from NHFD to NHS Digital in order to facilitate the linkage and provide pseudonymised data to NDORMS.

A recommendation for class 4 and 6 support was requested to link patient identifiable information from more than one source, to allow access to an authorised user for this purpose.

Confidential Patient Information Requested

Access was requested to data from NHFD in relation to patients over 60 years of age undergoing hip fracture surgery.

NHS number, date of birth, gender, postcode and unique NHFD identifier to be provided from NHFD to NHS Digital

Date of death and cause of death would be returned to Oxford University for analysis, along with age, gender and clinical data.

Amendment Request

The amendment requested additional support to enable NHS Digital to also undertake linkage with the HES dataset. The purpose of this additional linkage is to enable the case ascertainment quality of the NHFD to be determined by searching HES for a number of IC10 and OPCS4 codes which pertain to hip fracture. This will provide the applicants with a representative sample of the hip fracture population. The amendment would also result in limited linkage of those patients registered with the NHFD to both ONS and HES data.

Confidentiality Advisory Group Advice

The amendment was forwarded to the Vice Chair for consideration. It was noted that the proposed additional activity maintained a medical purpose and was within the public interest, to ensure a fully representative sample of the hip fracture population could be

achieved to support the wider project work. The Vice Chair acknowledged that the additional processing of confidential patient information to facilitate the amendment would be undertaken by NHS Digital; however, there were no additional items of confidential patient information required to facilitate this. The Vice Chair was assured by the rationale provided by the applicants and recommended support for the additional amendment activity.

Confidentiality Advisory Group 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.

Specific Conditions of Support

1. Confirmation of suitable security arrangements via IG Toolkit submission.
(Confirmed – NDORMS, Big Health Data Group – V14 2016/17, 100% satisfactory, NHS Digital – V14 2016/17, 92% satisfactory).

Reviewers:

Name	Capacity
Dr Kambiz Boomla	Member
Dr Malcolm Booth	Member
Dr Patrick Coyle	Vice Chair
Ms Rachel Heron	Confidentiality Advisor

Context

This non-research application from Picker Institute Europe, CQC and NHS England set out the purpose of carrying out the 2017 NHS Adult Inpatient Survey, using standardised methodology to build up a national picture of patient experiences. A set of aggregated statistical data was produced which was shared with individual Trusts, CQC, NHS England and the Department of Health and used to monitor and compare the performance of trusts, and to drive improvements.

This survey would be the 15th carried out to date. The methodology was well established and had been approved by the CAG via Precedent Set Sub-Committee.

Participating trusts identified the sample in line with the inclusion/exclusion criteria, and disclosed names and addresses to approved contractors for the purpose of mailing out the surveys (this data was held in a mailing file along with the unique identifying code which is printed on the survey itself). Demographic information for each potential participant was collected in a separate sample file, linked by the identifying code.

Picker Institute was commissioned to manage and coordinate the surveys under the title of the Patient Survey Coordination Centre, carrying out checks across the samples submitted by trusts and disseminating aggregated results (identifiable information was not received by the Patient Survey Coordination Centre).

This application was escalated from the Precedent Set review to the CAG meeting due to the addition of a new approach to be piloted with up to 10 of the Trusts: sending SMS reminders to potential participants after the 1st and 3rd mailing of the survey (where the patient had not responded to the survey). As this was a new element where precedent advice had not been set, the advice of the CAG was sought.

If the pilot were successful, the applicant intended to request support for a roll-out of this approach as standard across the survey programme, citing reduced costs as the main benefit of text messages as opposed to postal reminders

Amendment Request

The applicant had decided to use a different provider from the one originally commissioned to undertake the sending of SMS reminders (from Firetext to Healthcare Communications).

Healthcare Communications proposed to retain the patients' mobile telephone numbers for original application for 72 hours rather than the 24 hours proposed by Firetext. This was to enable the system to continue to try to send the text if it was not delivered the first time (due to connection problems or the phone being switched off, for example

The request, therefore, was for the period of retention of mobile telephone numbers by the provider to be increased to 72 hours.

Confidentiality Advisory Group Advice

The request was considered by a Sub-Committee of members who had been present at the discussion of the original application. Members agreed that this amendment was justified and were reassured that the text message would only be received once by the patient, after which time the number would be deleted.

Confidentiality Advisory Group 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.

Specific Conditions of Support

1. Confirmation of suitable security arrangements via IG Toolkit submission. **Healthcare Communications, v14 confirmed reviewed and published on NHS Digital website.**