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

15 September 2016

Reviewers:

Name	Capacity	Items
Dr Martin Andrew	Sub-Committee member	1
Dr Kambiz Boomla	Sub-Committee member	1
Dr Malcolm Booth	Sub-Committee member	1
Dr Tony Calland	Chair	1
Dr Harvey Marcovitch	Sub-Committee member	1
Dr Patrick Coyle	Sub-Committee member	1
Mrs Diana Robbins	Sub-Committee member	1
Rachel Heron	Confidentiality Advisor	1

1. Re-submission: 16/CAG/0097 Pathways of Care for young people in secure institutions (national service evaluation)

The applicant discussed the application in teleconference with members of the CAG, to clarify the conditions set by CAG and to assist in preparing the resubmission. It was agreed that the resubmission could be reviewed by virtual Sub-Committee of members rather than full meeting, to enable the applicant to remain within her timescale of funding.

Context

Purpose of application

This application from Central and North West London NHS Foundation Trust set out the overarching purpose of undertaking a NHS England funded service evaluation linked to CAMHS Transformation.

The aim was to scope the secure institutions which currently make up the secure estate for young people, to clarify how many young people are currently detained in secure institutions in England and to identify the level of need, characteristics and pathways of care for these young people. This indicated to be important in beginning to address the gap in knowledge in this area where service provision has grown organically without prior service evaluation, to inform commissioning needs for the Clinical Reference Group and Commissioners, consider the implications of service delivery in terms of the different legislative and funding bodies and enable discussion about whether pathways into the different secure institutions are

appropriate for the young people. This service evaluation of the pathways into and needs of young people within the entire secure estate is intended to enable the overall secure service providers to consider what intervention package would be appropriate into the different secure institutions.

A recommendation for class 1, 5 and 6 support was requested to achieve the purposes set out in the application.

Confidential patient information requested

Support was requested to cover data collection in relation to all young people in secure institutions (hospitals, secure children's homes, secure training centres, young offender institutes) on a specific date (*date tbc*). Support was requested to allow the disclosure of confidential patient information from any prison (young offender institution or secure training centre), secure children's homes, or secure mental health wards with insufficient resource to complete the service evaluation to Central and North West London NHS Foundation Trust. Access was intended to be carried out onsite, with the relevant person to extract de-identified information. In accessing the notes, the study team would have access to any identifiers stored there.

The data items were listed in section (m) of the application form.

Confidentiality Advisory Group advice

Public interest

Members noted that the principal aim of the study was to identify the needs of those in secure care to identify whether the current secure estate is able to meet their needs and whether they are detained in the appropriate institution under the most beneficial legislative framework, and to help assess whether the services provided are meeting needs. The public interest was indicated to be served through assessing whether the secure estate is able to meet the needs of the young people in their care, and whether specialisation of the various institutions may improve the service provision for these young people. This will enable the English secure estate to ensure that they fulfil the Children's Rights to receive appropriate therapeutic or psychosocial input to reduce their risks to themselves and/ or the public when in secure settings.

Members agreed that there was likely to be a high public interest in this evaluation.

Scope

Members raised a number of queries regarding scope that are set out below.

The response in the advice form indicated the following "*there are some Trusts which may not be able to provide the personnel to collect this data and they have asked if our assistant psychologist can be provided an honorary contract from their Trust and collect the information from their notes and immediately place it pseudonymised into the overall database. This Trust is asking for CAG approval for this. We are not asking for any support but for confirmation of your approval for this process*". A later response then indicated "*in some cases, identifiable data will be processed*

outside the care team by the project team's assistant psychologist. As outlined above, this is not likely to be for many sites, just those with large numbers of young people, and availability for staff within the direct care team to collect data. These are the cases for which we are asking for CAG support".

Members agreed that the language appeared to raise some inconsistencies and misunderstandings as to the remit of the CAG and the purpose of applying for support under Regulation 5 of the Health Service (Control of Patient Information) Regulations 2002. In essence, if support is provided by the Secretary of State for Health, following advice from the CAG, this provides a legal basis to enable disclosure of relevant information to specified individuals to prevent a breach of confidence by those disclosing the information.

Noting this applicant considered this activity to be a service evaluation, Members highlighted that provision of an honorary research contract does not provide a legal basis, in its own right, to enable access to identifiable patient information. Applicants apply via the CAG as part of the process to obtain a legal basis to prevent the breach of confidentiality that would otherwise take place in providing access to those who would not already have legitimate access to the information during the course of normal patient care. For someone to access patient identifiable information without consent there should be a clear legal basis e.g. consent or support under Regulation 5.

In light of the position regarding honorary research contracts and for the purposes of the application under consideration, the CAG was of the understanding that support was being sought to enable the assistant psychologist to access patient identifiable information where data would not be extracted by a member of the care team. This however raised questions for CAG as to whom support would apply to as a later response made mention of a research assistant. Members advised that this should be clarified so that scope was clear.

Members also queried the method of extraction that would be undertaken, and requested greater clarity as to the process that would be followed and by whom. The application indicated that the "'*sitting in method' relates to this process that as the service evaluation is across many sites the assistant psychologist / research assistant, is employed by the Trust/ University which is coordinating the overall service evaluation and not in the direct care team for most of the sites*". However, members were not entirely clear on the precise process and requested that the methodology of extraction should be specified.

Members requested clarification on which sites would not be able to undertake the data extraction, so as to be clear as to the precise scope for which support would be applicable. The application indicated there would be limited sites but members requested greater specificity.

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

Although support is sought to collect data in a limited number of sites, noting that these sites had not been specified, the application indicated that it is not practicable to seek consent in these sites. This was asserted to be because the large numbers of young people detained at these sites (e.g. 300+ on one site) would mean that seeking consent from each of these young people during the short project timeframe would be impracticable. Members agreed that consent was not likely to be practicable.

- Use of anonymised/pseudonymised data

It was noted that the proposed methodology involved researcher access to identifiable case records on-site; this was indicated to be where there was no staff capacity to undertake themselves. This approach would mean that as a consequence this would involve physical access to identifiable information.

Patient and public involvement

The applicant indicated that there is a parent representative on the steering committee who had provided input into the questionnaires used and will inform the interpretation of the analyses.

Data Protection responses

While the CAG is not responsible for assessing compliance with the Data Protection Act (DPA) 1998, it must be assured that the activity is not inconsistent with the principles of the DPA. It appeared to members that the response to the first principle was annotated and not final and this should be completed with the correct information.

Patient notification and objection

It is a general principle of the CAG, when recommending support under Regulation 5, for reasonable measures to be taken to inform the relevant population of the activity and to provide a right and mechanism to respect objection, where appropriate. This is separate to the local obligation to comply with the principles of the Data Protection Act 1998.

The response confirmed that the data will be collected by the direct care team in the majority of cases, and the project team's assistant psychologist will be involved in this process in a very small number of services. For these few services, the applicant will ask if they would like to place information sheets about the project on notice boards / visible spaces. This will also provide details of how to opt out, should any young person wish to do so.

While supportive in principle, members advised that further information should be provided on the mechanism for respecting patient objection. For example, what information will be provided and how will the objection be processed and managed. This should be specified. Members advised that a more detailed response should be provided or alternatively, if the applicant is of the view that a mechanism for patient objection should not be put in place then a strong case should be put forward.

Clarification request

The clarifications should be read in the context of the CAG advice above. The following clarifications were provided during a teleconference between Professor Bartlett and a sub-committee of members, and in a summary letter from the applicant dated 26 August 2016.

1. Members were unclear as to the precise scope of support that was requested and requested clarification on the following:
    a. It was indicated that a small number of sites may not be able to provide resource; please clarify which sites are not able to provide resource.
    It was clarified that 2 out of 54 sites had so far stated they would require the research assistant to assist with data collection. Others could follow, but the applicant indicated that this would be a minority.

    Further correspondence dated 06 September detailed that Werrington YOI and potentially Ardenleigh secure unit had also asked that relevant data be collected from their sites.

    b. How many researchers are seeking support, for example, is support requested for the assistant psychologist only, or a research assistant?
    It was explained that the terms assistance psychologist and research assistant had been used interchangeably, and referred to only one person.

    c. Clarification as to the methodology of the data extraction
    The applicant stated that the research assistant would have login details for SystmOne at Cookham Wood, and this would be extended to work on other sites via an honorary contract at the relevant sites.

2. Clarification as to the relevant population; it was noted that there may be young people in a secure unit due to criminal activity with no mental health issues, therefore members questioned whether the cohort would be confined solely to those with mental health issues only, or whether it would be broader. At present, members were supportive of extracting medical information relevant to mental health only.
    It was explained that there were 3 questions in the census relating to physical health conditions, which were to capture complexity in the young people in these secure environments. They would only collect data relevant to the main focus of the project, which would be any diagnosis of a physical disability, long-term health condition, or neurodevelopmental disorder diagnosis. This was to look at the contribution of these conditions to co-morbidity and could be relevant to the decision about what constituted a suitable placement.

3. Further robust information on the information to be provided and the mechanism that could be put in place to manage objection, or alternatively to provide a robust view as to why a mechanism for patient objection should not be implemented.

    The opt-out arrangements were discussed in the teleconference. It was agreed that a poster would be displayed in public areas to advertise the study and enable young people to opt out. This approach was preferred to

approaching each individual to ask if they wished to opt out. It was felt that this population could opt out due to a dislike of authority rather than the nature of the study. Due to high levels of illiteracy in the population, ascertaining whether participants did wish to opt out could also involve substantial resources which the study team did not have.

The CAG accepted the rationale given for not approaching each participant to ask if they wished to opt out. Although the applicant had raised the question as to whether providing a mechanism was appropriate, no strong rationale had been provided for doing this therefore members agreed that a poster, providing a right of opt-out, would be acceptable in this context.

It was agreed that the opt-out system proposed constituted an adequate method for managing objection. Staff at each site would be informed of the posters and the study and could assist with explaining the poster and passing on any objection.

Members advised that a copy of the poster providing the right of opt-out should be provided to confirm this was in place

4. Confirm the schedule two and three condition applicable under the Data Protection Act 1998 in relation to the first principle.

   Members noted this had not been provided, and advised that compliance with the data Protection Act 1998 was a mandatory local requirement, and those involved in processing the information under this support must remain compliant as a specific and standard condition of support.

Confidentiality Advisory Group advice conclusion

The CAG agreed that they were supportive in principle of access to identify physical and mental health issues and the responses provided, and therefore advised recommending support to the Health Research Authority, subject to compliance with the specific and standard conditions of support as set out below.

Specific conditions of support

1. Provision of a sample poster to be placed in the participating sites that includes a mechanism for managing patient objection. **Confirmed 12 September 2016.**

2. Confirmation from the IGT Team at NHS Digital of suitable security arrangements via Information Governance Toolkit (IGT) submission. **Confirmed 26 August 2016.**

Signed – Officers of CAG

Date

Signed – Confidentiality Advice Team

Date