Health Research Authority

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

June 2018

Present:

Name	*Capacity*	*Items*
Dr Martin Andrew	CAG Member	1.a., 1.b., 1.d.
Ms Sophie Brannan	CAG Lay Member	1.a., 1.b.
Dr. Tony Calland	Chair	1.d.
Professor Barry Evans	CAG Member	1.a., 1.b.
Dr Lorna Fraser	CAG Member	1.c.
Dr Harvey Marcovitch	CAG Member	1.c.
Ms Clare Sanderson	Alternate Vice-Chair	1.c.
Dr Murat Soncul	Alternate Vice-Chair	1.a., 1.b.
Ms Gillian Wells	CAG Lay Member	1.a., 1.b. 1.d.

Also in attendance:

Name	*Position (or reason for attending)*
Ms. Kathryn Murray	Confidentiality Advisor, HRA

1. NEW PRECEDENT SET REVIEW APPLICATIONS – NON RESEARCH

a) 18CAG0092 - Prostate brachytherapy survival outcomes supported by death certificate information from NHS Digital

Context

Purpose of Application

This application from the Royal Surrey County Hospital NHS Foundation Trust set out the purpose of audit which aims to follow-up patients who were treated with a pioneering low dose rate prostate brachytherapy from its introduction to 31/10/2014 who have subsequently died. For the purpose of

auditing prostate cancer specific survival outcomes, the applicants require information regarding the cause(s) of death to be provided by NHS Digital. Upon receipt of this information the pseudonymised Brachybase data registry will be updated.

A recommendation for class 4, 5 and 6 support was requested to cover activities as set out in the application.

Confidential Patient Information Requested

Cohort

- All patients who received the low dose rate prostate brachytherapy at the Royal Surrey County Hospital NHS Foundation Trust, prior to 31/10/2014, who are now deceased. The sample size is estimated at 250 patients.

The following items of confidential patient information will be disclosed to NHS Digital to facilitate linkage with the ONS mortality dataset, in order for cause of death to be supplied:

- Full name,
- Date of birth.

Confidentiality Advisory Group Advice

Public Interest

The CAG was assured that the application defined an appropriate medical purpose, which was the management of health and social care services via audit. Members agreed that there was a strong public interest in the activity proceeding as the audit may lead to improvements in the services for future prostate cancer patients within the Trust.

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

The Group recognised that, as all patients in the cohort were deceased, consent was not possible. No further issues were raised in this area.

- Use of anonymised/pseudonymised data

Confidential patient information was required to facilitate the linkage with mortality records by NHS Digital, which could not otherwise be achieved. No further issues were raised in this area.

Justification of Identifiers

Members agreed that the items of confidential patient information proposed were appropriate and proportionate to facilitate the required linkage. No further issues were raised in this area.

Exit Strategy

It is generally a principle that steps should be taken to move away from this potential support; such as through the seeking of consent or removing identifiable information once completed. The applicants advised that support under the Regulations was anticipated to be required for a period of six months in

order for NHS Digital to undertake the required linkage. It was confirmed that patient identifiers would be destroyed by NHS Digital upon completion of the linkage. No further issues were raised in this area.

Patient and Public Involvement and Engagement

Meaningful engagement with patients, service users and the public is considered to be an important factor for the CAG in terms of contributing to public interest considerations as to whether an unconsented activity should go ahead.

The applicants had provided a letter of support for the audit from the Chairman of a local charity, the Prostate Project. Members agreed that whilst the support of the charity strengthened the public interest in the activity proceeding, the views of an appropriate patient sample around the use of confidential patient information without consent for the audit purposes were still important. It was agreed that the applicants should seek the views of a small patient sample in relation to the project methodology and particularly the use of confidential patient information and provide feedback. It was suggested that the applicants may be able to facilitate this activity via the established links with the charity.

Patient Notification and Dissent

It is a general principle of the CAG, when recommending support, 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 known as patient notification. This is separate to the local obligation to comply with the principles of the Data Protection Act 1998.

The CAG recognised that as the patient cohort to be included within the audit was deceased, true patient notification was not possible; however, it was agreed that, in the interests of transparency, information about the audit should be included on the Trust's website. Confirmation would be required from the applicant that this would be progressed, together with sight of the text to be included.

It was also acknowledged that a project-specific objection mechanism could not be operated due to the deceased patient cohort; however, Members agreed that patient records should be checked for any evidence of historic dissent against the use of their data for purposes outside of direct care. It was also noted that NHS Digital would apply any previously registered Type 2 objections to the return dataset and the Group agreed that confirmation was required from the applicant that the data in relation to any individuals would also be removed from the data sample generated at Trust level.

Confidentiality Advisory Group Advice Conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, however, further information would be required and therefore advised recommending provisional support to the Secretary of State for Health and Social Care, subject to satisfactory responses to the request for clarification and compliance with the specific and standard conditions of support as set out below.

Request for Further Information

1. Provide confirmation that information around the audit will be placed on the Trust website, together with a copy of the text to be displayed.
2. Confirm that patient records will be checked for evidence of any historic dissent against the use of their data for purposes wider that direct care. If any evidence of historic dissent is found, the patient should be removed from the audit sample.
3. Confirm that, should NHS Digital remove any patients from the return sample due to the historic registration of a Type 2 objection, these individuals would be removed from the audit analysis sample.
4. The views of a small, but appropriate, patient sample should be sought around the project, with particular reference to the use of confidential patient information without consent to achieve the audit aims. An overview of the activity undertaken should be provided, together with feedback from

the patients. If the responses given are negative, the CAG will take this into account when considering whether support can be recommended, or whether further actions are necessary.

Specific Conditions of Support (Provisional)

1. Confirmation from the IGT Team at NHS Digital of suitable security arrangements via Information Governance Toolkit (IGT) submission (**Confirmed – NHS Digital undertaking data processing**).

b) 18CAG0098 - 2018 NHS Adult Inpatient Survey

Context

Purpose of Application

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 is produced which is 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 16th carried out to date. The methodology is well established and has been approved in principle by the CAG via Precedent Set Sub-Committee. The applicants confirmed that the survey methods are unchanged from the 2017 survey.

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

Picker Institute is 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 is not received by the Patient Survey Coordination Centre).

As part of the drive to improve response rates (RR) and possibly reduce response bias, and to explore a move to a mixed mode methodology using online methods within the NPSP, a pilot study is being proposed across 10 Trusts, which would each be asked to provide an additional 1,014 patient, and provide mobile telephone numbers for them, to test the effect of a three separate interventions in the 2018 NHS Inpatient Survey (IP18):

- Administering the questionnaire online (instead of a postal survey).
- Sending SMS reminders.
- Using a shorter questionnaire.

The control arm of the pilot will be the main sample. This pilot is aimed at testing the effects of three different methods of invitation which combine postal letters and text messages, and the use of an online questionnaire. Inclusion of mobile phone numbers was approved for last year's survey via full CAG review – as the proposed pilot does not require the disclosure of any additional items of confidential patient information, promotion to full CAG was not deemed appropriate at this stage. The interventions will be piloted as follows:

Intervention	**Mailing 1 (M1)**	**Mailing 2 (M2)**	**Mailing 3 (M3)**
Intervention 1	Postal letter with link to online questionnaire	Postal reminder with link to online questionnaire	Postal letter (no link) *and*

			hard copy of questionnaire
Intervention 2	Postal letter with link to online questionnaire, followed by SMS with link	Postal reminder with link to online questionnaire, followed by SMS with link	Postal letter (no link) *and* hard copy of questionnaire
Intervention 3	Same as main survey, with shorter questionnaire	Same as main survey	Same as main survey, with shorter questionnaire

It is noted that all pilot interventions will use the shorter version of the questionnaire.

A recommendation for class 5 and 6 support was requested to cover activities as described in the application.

Confidential Patient Information Requested

Cohort

- Inpatients aged 16 years old or over who were discharged from acute and specialist NHS hospitals in July 2018 (and earlier for smaller trusts), having had one overnight stay in hospital.

Exclusions:
- deceased patients
- children or young persons aged under 16 years at the time of sampling
- obstetrics/maternity service users, including spontaneous miscarriages
- patients admitted for planned termination of pregnancy
- psychiatry patients
- day cases
- private patients (non-NHS)
- any patients who are known to be current inpatients patients without a UK postal address
- any patient known to have requested their details are not used for any purpose other than their clinical care, including those responding to posters displayed on hospital wards referring to the survey (the survey instructions request that all responses to posters are logged and used for this purpose).

The mailing file sent to contractors contains the following information:

- A standardised unique identifier code (see application for full details of how this is constructed)
- Title (Mr, Mrs, Ms, etc.)
- First name
- Surname
- Address Fields
- Postcode (where available)
- Mobile telephone number for those patients included in the pilot, from a total of up to 10 Trusts**.**

The sample data file (used to link demographic data to the survey responses, to aid analysis and to enable checks to be carried out for any errors in how the sample was drawn contains:

- The unique identifier code,
- Admission/discharge dates,
- Length of stay (this is calculated from the admission and discharge dates),
- Whether admission from Treatment Centre,
- Route of admission,

- NHS Site code on admission and discharge,
- Ethnicity,
- Gender,
- Year of birth,
- CCG Code: to enable analysis at this level by stakeholders for the production of relevant indicators,
- ICD10 code.

The sample file is also shared with the Coordination Centre to enable centralised checks on the appropriateness of samples drawn. For clarity, please note that the Coordination Centre do **not** receive any names or addresses.

Confidentiality Advisory Group Advice

Public Interest

The CAG was assured that the application defined an appropriate medical purpose, through the management of health and social care services. Members were clear that there was an ongoing public interest in inpatient survey, as it gathered important information around patient experience and the performance of individual Trusts.

It was acknowledged that the methodology for the 2018 survey proposed piloting three interventions in an attempt to improve response rates. The pilot interventions proposed involved including a link to an online questionnaire, sending SMS messages with a link to the online questionnaire and the use of a shorter questionnaire. The Group acknowledged that the survey had achieved a reasonable response rate in 2017, which had piloted the use of an SMS prompt to complete the survey (rather than a link to an online survey), which led to a marginal increase in response rates. The value of the work undertaken to improve response rates was recognised and it was not surprising that there was a move towards online and SMS usage in the methodology. Members raised concerns around the potential privacy impact of the proposed intervention methodology as it was not clear from the documentation whether the potential for too much intrusion had been considered due to the multiple approaches to the potential respondent. Further assurance was required from the applicant around this point and it was noted that it would be helpful to understand if this had been discussed with the public involvement group.

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

Members acknowledged that, due to the large scale of the survey, it would be impracticable for direct care teams to seek consent from individual patients, prior to the survey circulation. It was recognised that support was requested to facilitate survey distribution and patients could choose whether or not to respond. The survey methodology was supported by the CAG in principle and no further issues were raised in this area in connection with this particular submission.

- Use of anonymised/pseudonymised data

Confidential patient information was required to facilitate distribution of the survey, which could not otherwise be achieved. No further issues were raised in this area.

Justification of Identifiers

The Group was satisfied that the items of confidential patient information requested were appropriate and proportionate to the facilitation of the survey.

Members considered the paradata items which would be collected in relation to the pilot intervention for the online completion of the survey. Whilst it was acknowledged that this did not contain any items of confidential patient information, the CAG requested confirmation from the applicants that they had tested that the rich combination of data gathered here could not lead to the inadvertent identification of individuals, as it was noted that this would be linked with the survey response. Reassurance was also requested from the applicants that as assessment had been made that this dataset would not include any markers which could be considered identifiable in the context of the General Data Protection Regulation (GDPR) or the Data Protection Act 2018.

Patient and Public Involvement and Engagement

Meaningful engagement with patients, service users and the public is considered to be an important factor for the CAG in terms of contributing to public interest considerations as to whether an unconsented activity should go ahead. The applicants had confirmed that the Inpatient Survey Advisory Group had been consulted about this year's programme and provided support to the pilot interventions at a meeting held in February 2018. Members acknowledged the work which had been undertaken but agreed it would be helpful to understand the demographics and number of individuals involved in this group.

Patient Notification and Dissent

It is a general principle of the CAG, when recommending support, 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 known as patient notification. This is separate to the local obligation to comply with the principles of the Data Protection Act 1998. The applicants had provided copies of posters and flyers which had been produced by the CQC to promote the survey and would be provided for display in participating Trusts. It was recognised that Trusts would be requested to include a contact telephone number on the document to facilitate dissent; however, Members agreed that it would also be helpful to include a supplementary communication means, i.e. email address, on the document.

Security Assurance

It is the policy position of the Department of Health that all approved applications seeking support under these Regulations must evidence satisfactory Information Governance toolkit compliance. Assurance is currently assessed against Version 14.1 (2017/18) of the IG Toolkit submission. It was noted that self-assessed scores for Capita Business Services Ltd. and Membership Engagement Services had been published in respect of version 14.1 (2017/18) of the toolkit; however, these self-assessments had not yet been reviewed by NHS Digital. It was also noted that Patient Perspective did not yet appear to have submitted V14.1 of the IG Toolkit. In order to complete this element, the CAG must receive confirmation of satisfactory security arrangements directly from NHS Digital, or via population of the 'reviewed grade' field on the IGT website. This would need to be addressed by the applicant.

Additional Points

As a supplementary point, the Group noted that private patients were excluded from the survey. It was recognised that the CQC also had a responsibility for private hospitals and it was raised, as a general query, whether there were plans to include this cohort in future surveys.

Confidentiality Advisory Group Advice Conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, however, further information would be required and therefore advised recommending provisional support to the Secretary of State for Health and Social Care, subject to satisfactory responses to the request for clarification and compliance with the specific and standard conditions of support as set out below.

Request for Further Information

1. Confirm whether an assessment was undertaken in relation to the number of contacts proposed for the pilot interventions and the potential for this to have a negative privacy impact on potential respondents. Clarify whether this potential risk was discussed with the Inpatient Survey Advisory Group.
2. Confirm whether the number of paradata items which will be collected have been tested to ensure that, in conjunction with survey responses, to ensure there is no potential that a patient could be inadvertently identified from the information. Clarify whether the paradata sample has been assessed to ensure that this does not contain any markers which may be considered identifiable in relation to the GDPR or the DPA 2018.
3. Provide details of the demographics and number of patients included within the Inpatient Survey Advisory Group.
4. Clarify that Trusts would be advised in include both a telephone number and email address on the notification posters to facilitate opt-out.
5. Clarify whether there are any plans to include private patients within any future Inpatient Surveys.

Specific Conditions of Support (Provisional)

1. Confirmation from the IGT Team at NHS Digital of suitable security arrangements via Information Governance Toolkit (IGT) submission (**Pending – NHS Digital review of Version 14.1, 2017/18, of the IG Toolkit submission remains outstanding for Capita Business Services Ltd., Membership Engagement Services and Patient Perspectives**).

c) 18CAG0107 - National Cancer Patient Experience Survey 2018 (CPES)

Context

Purpose of Application

This application from NHS England set out the purpose of administering patient surveys to evaluate services provided to cancer patients in 2018. This would enable comparisons between Trusts, for commissioners, providers and patients (all of whom could access the published results), would allow for monitoring of improvements in services, drive further improvements, and provide NHS England with an up to date overview of cancer patient experience across England.

The survey methodology and data transfer arrangements remain unchanged since 2011. Quality Health would request a list of eligible patients from participating Trusts, and would mail out surveys to patients after removing duplicates and checking to ensure no surveys were sent to the addresses of deceased patients. Quality Health would then anonymise the data.

A recommendation for class 1, 4, 5 and 6 support was requested to cover activities as described in the application.

Confidential Patient Information Requested

Cohort

- All adult patients (aged 16 and over), with a primary diagnosis of cancer, who have been admitted to hospital as inpatients for cancer related treatment, or who were seen as day case patients for cancer related treatment, and have been discharged between 1st April 2018 and 30th June 2018 will be invited to participate in the survey.

The following items of confidential patient information are required:

- Name – survey distribution,

- Address – survey distribution,
- Postcode – survey distribution and analysis (translated to index of multiple deprivation,
- Treating site – survey distribution,
- NHS number – sample validation,
- Date of birth – sample validation and analysis
- Sex – analysis,
- Ethnicity – analysis.

Confidentiality Advisory Group Advice

Public Interest

The CAG was assured that the application described an appropriate medical purpose, through the management of health and social care services. It was agreed there was continued public interest in ongoing work to improve the experience of cancer patients.

Suitability for Precedent Set Review

It was acknowledged that this application was similar to proposals submitted by Picker Institute Europe under precedent set criteria 11; however, no specific criterion existed for Quality Health applications to administer the cancer patient surveys.

The 2016 and 2017 Cancer Inpatient Experience Surveys were both considered and given a recommendation of support following precedent set review. The 2017 survey was considered via this review pathway as a precedent had been set in the previous year's submission. The Sub-Committee at that time agreed that Quality Health operated a very similar methodology to the Picker Institute Europe surveys and were content to review via the precedent set review pathway. It was further noted that Quality Health was an approved contractor used by the Picker Institute Europe to facilitate the provision of the survey activity.

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

The Group acknowledged that support was required to facilitate the mail out of the surveys to patients, the return of which would constitute implied consent. It was recognised that this was a well-established method for the administration of surveys, and the applicant argued that the high response rates and the high number of patients (around 83% response rate recorded in the 2010 survey) who indicated they would be willing to take part in future surveys demonstrated that proceeding with this methodology was within the public interest. It was further argued that if consent to be sought in face to face contact with health professionals, this could lead to selection bias. Members were satisfied with the rationale put forward by the applicant and agreed that consent was not feasible for the purposes of survey mailing.

- Use of anonymised/pseudonymised data

Access to confidential patient information was required to facilitate the distribution of the survey which could not be otherwise achieved.

Justification of Identifiers

The CAG was content that the items of confidential patient information requested were appropriate and proportionate to the proposed activity. No further issues were raised in this area.

Patient and Public Involvement and Engagement

Meaningful engagement with patients, service users and the public is considered to be an important factor for the CAG in terms of contributing to public interest considerations as to whether an unconsented activity should go ahead.

The applicants explained that NHS England had commissioned a review of the Cancer Patient Experience Survey to be undertaken by the Picker Institute Europe, which included the provision of two focus groups held in London and Manchester. The applicants explained that the findings of the activity were due in July 2018 and may lead to changes in the CPES methodology.

Ongoing patient and public involvement and engagement activity had been added as a condition of support to the 2017 survey and as the applicants had explained, the findings of the work which had been undertaken to satisfy this condition were due imminently. Members were unclear why the application submission had been made when there was potential for the project methodology to require revision following the engagement activity which had been undertaken. The Group agreed that it would be preferable to consider findings of the focus groups, in case anything significant is reported, before any final recommendation is given for the proposal. The applicants would be asked to provide feedback at such time as it was available, or provide a strong justification to support why this delay would be detrimental to the overall survey process.

Patient Notification and Dissent

It is a general principle of the CAG, when recommending support, 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 known as patient notification. This is separate to the local obligation to comply with the principles of the Data Protection Act 1998.

The applicants provided copies of posters and leaflets which would be provided to participating Trusts for display to promote the forthcoming survey and to enable patients to raise any objections ahead of the patient sample being drawn. It was acknowledged that this was a change from the 2017 survey, as previously the participating Trusts, as data controllers for the information which would be disclosed to Quality Health to facilitate the survey distribution, were responsible for displaying their own notification/fair processing materials. Patients could raise an objection to the use of their data direct with their local site. Information was also included within the covering letters which would be sent with the survey to explain how a patient could raise an objection and request removal of their data. The Group reviewed the documentation and no issues were raised in this area.

Confidentiality Advisory Group Advice Conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, however, further information would be required and therefore advised recommending provisional support to the Secretary of State for Health and Social Care, subject to satisfactory responses to the request for clarification and compliance with the specific and standard conditions of support as set out below.

Request for Further Information (Summary)

1. Feedback from the Picker Institute Europe review of the Cancer Patient Experience Survey should be provided for review before a final recommendation for the application would be issued. If the delay pending the report of these outcomes would be detrimental to the facilitation of the survey, a strong rationale should be provided to explain how and why this would impact the programme for consideration by the Group.

Specific Conditions of Support (Provisional)

1. Confirmation from the IGT Team at NHS Digital of suitable security arrangements via Information Governance Toolkit (IGT) submission (**Confirmed – Quality Health show a reviewed satisfactory grade on Version 14.1, 2017/18**).

d) 18CAG0110 - 2018 Urgent and Emergency Care Survey

Context

Purpose of application

This application from the Picker Institute Europe set out the purpose of carrying out the 2018 Urgent and Emergency Care Survey, sponsored by the Care Quality Commission. The findings of the survey are used by NHS Trusts and CCGs to facilitate local improvement, by the CQC as part of its regulatory activities and to support other relevant functions and will be shared in a non-identifiable format with NHS England, the Department for Health and Social Care and wider NHS Organisation to gain understanding of patients' experiences of NHS services and to drive improvements to them.

The 2018 survey will be the seventh carried out to date. The title of the survey has been revised for this year's proposed survey (from the previously titled 2016 Emergency Department Survey) to reflect changes in terminology and increased focus on urgent care as well as emergency care. All emergency department surveys prior to 2016 included patients attending Type 1 services only. The sampling approach was changed in 2016 to include Type 3 services. Broadly, these services are defined as:

- Type 1 - A major, consultant-led A&E department with full resuscitation facilities operating 24 hours a day, seven days a week.
- Type 3 - Other A&E / minor injuries unit / urgent care centre treating minor injuries and illnesses. Can be doctor or nurse-led and accessed without an appointment.

Participating Trusts will be asked to begin preparations for the patient sample to be drawn in September 2018. Confidential patient information will be shared with the approved contractors facilitating the survey to enable the standardised to be followed across the full programme of activities.

Some minor changes to the study methodology are proposed for the 2018 survey as follows:

- A separate survey questionnaire is under development for patients who attended a Type 3 Department (Urgent Care Department),
- The sample size for patients attending a Type 3 Department has been increased from 300 to 420 to enable benchmarking across Trusts. This is in addition to the 950 patient sample for Type 1 Department attendances (Emergency Department), as per the 2016 survey. For Trusts without a Type 3 Department, the sample size for Type 1 Department attendances will remain at 1250, as per the 2016 survey.

A recommendation for class 5 and 6 support was requested to cover activities as described in the application.

Confidential Patient Information Requested

Cohort

- People aged 16 and over who attended a Type 1 emergency department in September 2018 or a Type 3 urgent care department in September 2018. Trusts will be instructed to contact the Survey Coordination Centre if they are unable to draw the required sample size from their Type 3 department in which case they will be instructed to also sample back to August 2018.

The Sampling Instructions will ask Trusts to exclude:
deceased patients,

- children or young persons aged under 16 years at the date of their attendance at the emergency department,
- any patients who are known to be current inpatients ,
- planned attendances at outpatient clinics which are run within the Emergency Department (such as fracture clinics),
- patients without a UK postal address,
- patients attending primarily to obtain contraception (e.g. the morning after pill), patients who suffered a miscarriage or another form of abortive pregnancy outcome whilst at the hospital, and patients with a concealed pregnancy*,
- any patient known to have requested their details are not used for any purpose other than their clinical care,
- any patients who were admitted to hospital via Medical or Surgical Admissions Units and therefore have not visited the emergency department,
- For the type 3 sample, any services which are mainly or entirely appointment-based.

*As per 2016, Trusts will be advised to check ICD-10 codes, or obstetric or gynaecology codes. If the use of these codes will not enable identification of women who should be excluded, the Trust would then be required to check notes on their records to ascertain reason for attendance.

Administration of the 2018 Urgent and Emergency Care Survey requires NHS trusts to share two distinct sets of information with their approved contractor:

The **mailing file** is used to address questionnaires to the appropriate person. It contains:

- A standardised unique identifier code,
- Title (Mr, Mrs, Ms, etc.),
- First name,
- Surname,
- Address Fields,
- Postcode.

The **sample file** is used to link demographic data to the survey responses, to aid analysis and to enable checks to be carried out for any errors in how the sample was drawn. This file contains:

- The unique identifier code (as above),
- Date and time of attendance,
- NHS Site code,
- Department type (Type 1 or Type 3),
- Ethnicity,
- Gender,
- Year of birth,
- CCG code.

The two sets of information listed above will be submitted by participating Trusts to approved contractors as one file. Approved contractors will split the data out and only the sample data will be provided to the Survey Coordination Centre to enable centralised checks on the appropriateness of samples drawn. The Survey Coordination Centre does **not** receive any names or full addresses.

Confidentiality Advisory Group Advice

<u>Public Interest</u>

The CAG was assured that the application defined an appropriate medical purpose through the management of health and social care services. It was recognised that there was an ongoing public interest in collating patient views in order to evaluate the services provided in order to improve care moving forwards.

Revisions to the Survey Scope

The Group noted that the scope of survey had been revised in order to account for users of more ambulatory settings in urgent care and minor injury units (Type 3 units). It was noted that the title of the survey had also been revised to reflect this change. Members were supportive of the proposed increased sample sizes for the survey, to ensure that survey produced robust results.

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

The Group recognised that the proposed application would operate via the standardised methodology for surveys facilitated by the Picker Institute Europe; which had been supported in principle by the CAG. The applicants had also explained that a pre-invitation contact had been considered; however, it was determined that there was no value in this additional contact. Members considered the rationale and acknowledged that patients would have the choice around whether to respond to the survey request when received. It was agreed that consent was not feasible for the proposed activity and no further issues were raised in this activity.

- Use of anonymised/pseudonymised data

Confidential patient information is required to facilitate the distribution of the surveys which could not be otherwise achieved. No issues were raised in this area.

Justification of Identifiers

Members were assured that the items of confidential patient information requested were appropriate and proportionate to the proposed activity and no issues were raised in this area.

Patient Notification and Dissent

It is a general principle of the CAG, when recommending support, 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 known as patient notification. This is separate to the local obligation to comply with the principles of current data protection legislation.

Copies of the dissenting poster and flyer which had been developed to support the 2016 survey were included in the submission for information purposes. The applicants had clarified in response to queries that Trusts which were participating in the survey would be informed that a contact telephone number and email address should be included on the documentation to offer differing means of contact to patients. It was recommended that Trusts were also advised to include a postal address to facilitate

objection where possible. Members agreed that submission of the final documentation to be used for the 2018 survey was required prior to any final recommendation of support coming into effect. It was also acknowledged that the wider patient-facing materials, including the invitation and questionnaire documents were also being finalised – the Group agreed that sight of any wider revised documentation was also required.

Security Assurance

It is the policy position of the Department of Health that all approved applications seeking support under these Regulations must evidence satisfactory Information Governance toolkit compliance. It was noted that a self-assessed score for Patient Perspective Ltd. had been published in respect of version 14.1 (2017/18) of the toolkit; however, this self-assessment had not yet been reviewed by NHS Digital. In order to complete this element, the CAG must receive confirmation of satisfactory security arrangement directly from NHS Digital, or via population of the 'reviewed grade' field on the IGT website. This would need to be addressed by the applicant.

Confidentiality Advisory Group Advice Conclusion

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, however, further information would be required and therefore advised recommending provisional support to the Secretary of State for Health and Social Care, subject to satisfactory responses to the request for clarification and compliance with the specific and standard conditions of support as set out below.

Request for Further Information

1. Provide copies of the finalised poster and flyer, together with any wider patient-facing documentation which has been revised, which will be used within the 2018 survey programme for consideration.
2. Trusts should be advised to include a postal address to facilitate patient objection where possible – confirm that this guidance has been disseminated to participating Trusts.

Specific Conditions of Support (Provisional)

1. Confirmation from the IGT Team at NHSD Digital of suitable security arrangements via Information Governance Toolkit (IGT) submission (**Pending – Patient Perspective remains outstanding**)