

Confidentiality Advisory Group

Minutes of the meeting of the Confidentiality Advisory Group held on 23 November 2023 via video conference.

Present:

Name	Capacity
Dr Tony Calland MBE	CAG Chair
Dr Patrick Coyle	CAG Vice Chair
Dr Martin Andrew	CAG Expert Member
Mr Anthony Kane	CAG Lay Member
Ms Rose Payne	CAG Lay Member
C. Marc Taylor	CAG Expert Member
Mr Thomas Bobby	CAG Expert Member
Dr Stephen Mullin	CAG Expert Member

Also in attendance:

Name	Position (or reason for attending)
Mr William Lyse	HRA Approvals Administrator
Ms Emma Marshall	HRA Confidentiality Specialist (Left during Application 6.b)
Dr Paul Mills	HRA Confidentiality Advise Service Manager (Left during Application 6.b)
Ms Caroline Watchurst	HRA Confidentiality Advisor

1. APOLOGIES FOR ABSENCE

Apologies for absence were received from: Professor Lorna Fraser (CAG Member) and Ms Clare Sanderson (Alternate Vice Chair).

Mr David Evans was conflicted with non-research applications and so did not attend this meeting.

2. DECLARATIONS OF INTEREST

2.1	23/CAG/0171 23/CAG/0172	NHS Lincolnshire ICB NHS Northamptonshire ICB
	Conflict:	CAG Member Ms Rose Payne declared an interest in both items – Rose is employed by a risk stratification tool provider to Integrated Care Boards but does not provide services to the two ICBs discussed in this meeting. The Committee agreed this did not constitute a conflict of interest and they could participate in the discussion.

3. SUPPORT DECISIONS

Secretary of State for Health & Social Care Decisions

The Department of Health & Social Care senior civil servant on behalf of the Secretary of State for Health & Social Care has agreed to the advice provided by the CAG in relation to the **26 October 2023** meeting applications.

Health Research Authority (HRA) Decisions

The Health Research Authority agreed with the advice provided by the CAG in relation to the **26 October 2023** meeting applications.

Minutes:

The minutes of the following meetings have been ratified and published on the website:

- **26 October full CAG meeting**
- **20 October Precedent Set meeting**

4. SUMMARY OF APPLICATIONS

This CAG meeting was convened to consider applications from Integrated Care Boards (ICBs) who wish to continue to undertake risk stratification for case finding. Both these applications were submitted after the 31 August 2023 risk

stratification meeting and therefore were considered separately. These applications will supersede the current risk stratification application managed by NHS England (CAG 7-04(a)/2013), which expired on 30 September 2023.

The applications discussed below each set out the non-research purpose of undertaking risk stratification case finding by Integrated Care Boards (ICBs). Risk stratification is a tool to identify patients that are at high risk of health deterioration and may require use of multiple services. This identification allows GPs to prioritise the management of their care to reduce and prevent poor outcomes. Risk stratification necessitates the use of large-scale national datasets combined with GP data.

Support is requested for the flow of confidential patient information from GP suppliers to the risk stratification supplier, and to link this information with national datasets through NHS number. Support is not being requested for the flow of national datasets as this is sent in a pseudonymised form, nor for the access by GPs to the linked dataset as this re-identification process is undertaken for direct care purposes.

Members noted that the applications used the same application format and requested the same scope of support of those ICBs considered at the 31 August 2023 CAG meeting. The CAG agreed that the generic points discussed at the 31 August 2023 meeting (as noted on pages 3-5 of the [minutes](#)) were equally applicable to the two applications being discussed today. As such, members confirmed that the specific conditions of support arising from those overarching discussions should be applied to these two applications.

5. NEW APPLICATIONS FOR CAG CONSIDERATION

5.1	23/CAG/0171	NHS Lincolnshire ICB - Disclosure of combined commissioning data sets and GP data for risk stratification purposes to Integrated Care Boards and Data Processors
	Contact:	Julie Ellis-Fenwick
	Data controller:	Matt Gaunt
	Application type:	Non-research
	Submission type:	New application

Confidential information requested

Cohort	All patients using services within the ICB, except those that have opted out
Data sources	<ol style="list-style-type: none"> 1. GP data 2. Secondary Use Service (SUS) dataset, including: <ol style="list-style-type: none"> a. Admitted Patients Care – Spells b. Admitted Patients Care – Episodes

	c. Outpatients d. Community Services e. Emergency Care f. Mental health Services Dataset g. Improving Access to Psychological Therapies dataset
Identifiers required for linkage purposes	1. NHS Number

Main issues considered, discussed and outcomes

The CAG noted that this activity fell within the definition of the management of health and social care services and was therefore assured that the application described an appropriate medical purpose within the remit of section 251 of the NHS Act 2006.

Having reviewed the application and considered the risks and benefits involved, the CAG was also assured that the proposed activity was in the public interest.

The CAG discussed that the current primary route for informing the population is via GDPR privacy noticed on practice and ICB websites. Members noted that the applicants stated a communication plan was to be drafted and as such requested for this plan to be provided within 3 months. (Condition 1)

Members agreed that the Privacy Notice was overcomplicated and too technical for the intended reader. The CAG requested for the Privacy Notice to be revised, and recommended review by the Patient and Public Involvement and Engagement Group. An updated privacy notice should be provided to CAG within 3 months. (Condition 2)

Together with the communication plan and privacy notice, the CAG also requested example patient notification materials. Members noted that GDPR notices should not be the sole avenue to informing the population and recognised a commitment for wider communication in the application. The CAG therefore asked the applicants to provide example notification materials. These materials could be used in a layered approach – that is providing summary information to population with signposting and QR codes attached to direct to further information. It is recommended that this revised notification material should be reviewed by the Patient and Public Involvement and Engagement Group. Example notification materials should be provided to CAG within 3 months. (Condition 3)

Members noted that a survey on risk stratification is currently live within the ICB area, which has so far had 6 responses, with most being supportive. The CAG discussed that the survey consists of a few basic questions followed by a number of demographic questions, many of which were quite personal. Members recommended that the applicants reconsider these questions to

maybe achieve a higher response rate. Nevertheless, the CAG agreed that a current sample size of 6 is not sufficient and requested for continued patient and public involvement to be undertaken. Members feedback to be provided CAG within the next 3 months on the continued patient and public involvement to be undertaken (Condition 4)

Confidentiality Advisory Group advice: Conditionally supported

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Secretary of State for Health and Social Care, subject to compliance with the specific and [standard conditions](#) of support as set out below.

Number	Condition	Response from the applicant
1.	Provide a communication plan, including a description of routes to use to inform patients based on local area and demographics within 3 months.	
2.	<p>Please update privacy notice in a lay language that is easily understood and provide to CAG within 3 months.</p> <p>It is recommended that the privacy notice is reviewed by a patient and public involvement group.</p>	
3.	Provide to CAG, within 3 months, example layered patient notification material, with a lay friendly summary, accessible towards the intended population, including signposting and QR codes to direct to further information. It is recommended that this notification material should be reviewed by the Patient and Public Involvement and Engagement Group.	
4.	<p>Provide a report of patient and public involvement undertaken to date within 3 months. The feedback should include:</p> <ul style="list-style-type: none"> a. What routes were used to involve patients (e.g., focus groups, surveys etc.) b. A broad summary of the demographics of the 	

	<p>attendees/respondents, and how many were involved.</p> <p>c. Summary of the topics discussed, which should include the use of confidential patient information without consent in relation to the linkages and purposes described in this application.</p> <p>d. A summary of the views of the groups, and whether you have updated anything to mitigate any concerns raised.</p> <p>e. A description of how you will continue to involve patients and the public on this area moving forwards.</p>	
5.	<p>Risk stratification is the process by which GP and secondary care confidential patient information are linked by 'approved organisations' and analysis is undertaken to identify individual patients that are at risk of an adverse event. General Practices, or groups of local General Practices who pool care resources, are able to reidentify those patients at risk to enable preventative care to be offered to avert future health problems. 'Section 251' Support is provided for this purpose.</p> <p>It does not extend to wider population health management, where there is no direct impact on individual care, and where the purpose of the processing is to commission, design or manage services for the benefit of the wider population and the NHS. Any use of Confidential Patient Information for these wider purposes will not have a common law legal basis under 'Section 251' support'.</p>	
6.	<p>ICBs should utilise caution if using a Type 1 opt out or broader Snomed code approach to a specific risk stratification opt out. Any ICB using this approach, particularly one where it may affect input into the shared care record, should in its patient notification highlight to patients that opting out may</p>	

	affect the care received.	
7.	Continue regular engagement with General Practices, as a minimum providing each practice with an information pack, detailing about risk stratification and the opt-out process.	
8.	<p>Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold. Confirmed:</p> <p>The NHS England 22/23 DSPT review for Prescribing Services was confirmed as 'Standards Met' on the NHS England DSPT Tracker.</p>	

The Group delegated authority to confirm its final opinion on the application to the Chair and reviewers.

5.2	23/CAG/0172	NHS Northamptonshire ICB - Disclosure of combined commissioning data sets and GP data for risk stratification purposes to Integrated Care Boards and Data Processors
	Contact:	Efua Owusu-Antwi
	Data controller:	Sarah Stansfield
	Application type:	Non-research
	Submission type:	New application

Confidential information requested

Cohort	All patients using services within the ICB, except those that have opted out
Data sources	<ol style="list-style-type: none"> 1. GP data 2. Secondary Use Service (SUS) dataset, including: <ol style="list-style-type: none"> a. Admitted Patients Care – Spells b. Admitted Patients Care – Episodes c. Outpatients d. Community Services e. Emergency Care f. Mental health Services Dataset

	g. Improving Access to Psychological Therapies Dataset
Identifiers required for linkage purposes	1. NHS Number

Main issues considered, discussed and outcomes

The CAG noted that this activity fell within the definition of the management of health and social care services and was therefore assured that the application described an appropriate medical purpose within the remit of section 251 of the NHS Act 2006.

Having reviewed the application and considered the risks and benefits involved, the CAG was also assured that the proposed activity was in the public interest.

The CAG discussed that the current primary route for informing the population is via GDPR privacy notices the ICB website. Members noted that the application stated a communication plan is to be drafted and as such requested for this plan to be provided within 3 months. (Condition 1)

The CAG also requested example patient notification materials to be provided. Members noted that GDPR notices should not be the sole avenue to informing the population and recognised a commitment for wider communication within the application. The CAG therefore asked the applicants to provide example notification materials. These materials could be used in a layered approach – that is providing summary information to population with signposting and QR codes attached to direct to further information. It is recommended that this revised notification material should be reviewed by the Patient and Public Involvement and Engagement Group. Example notification materials should be provided to CAG within 3 months. (Condition 2)

The CAG noted that the ICB provided broad details for a plan to conduct a survey within their population. As such, members requested provide feedback on the outputs if the survey to be provided to CAG within the next 3 months. (Condition 3). This survey should include testing the acceptability of using confidential patient information without consent, for the purposes of risk stratification.

Confidentiality Advisory Group advice: Conditionally supported

The CAG agreed that the minimum criteria under the Regulations appeared to have been met, and therefore advised recommending support to the Secretary of State for Health and Social Care, subject to compliance with the specific and [standard conditions](#) of support as set out below.

Number	Condition	Response from the applicant
1.	Provide a communication plan, including a description of the routes to be used to inform patients based on local area and demographics, within 3 months.	
2.	Provide to CAG, within 3 months, example layered patient notification material, with a lay friendly summary, accessible towards the intended population, including signposting and QR codes to direct to further information. It is recommended that this notification material should be reviewed by the Patient and Public Involvement and Engagement Group.	
3.	<p>Please provide feedback on the outputs of the planned survey, within the next 3 months.</p> <p>This survey should include testing the acceptability of using confidential patient information without consent, for the purposes of risk stratification.</p>	
4.	<p>Risk stratification is the process by which GP and secondary care confidential patient information are linked by 'approved organisations' and analysis is undertaken to identify individual patients that are at risk of an adverse event. General Practices, or groups of local General Practices who pool care resources, are able to reidentify those patients at risk to enable preventative care to be offered to avert future health problems. 'Section 251' Support is provided for this purpose.</p> <p>It does not extend to wider population health management, where there is no direct impact on individual care, and where the purpose of the processing is to commission, design or manage services for the benefit of the wider population and the NHS. Any use of Confidential Patient Information for these wider purposes will not have a common law legal basis under 'Section 251' support.</p>	

5..	ICBs should utilise caution if using a Type 1 opt out or broader Snomed code approach to a specific risk stratification opt out. Any ICB using this approach, particularly one where it may affect input into the shared care record, should in its patient notification highlight to patients that opting out may affect the care received.	
6.	Continue regular engagement with General Practices, as a minimum providing each practice with an information pack, detailing about risk stratification and the opt-out Process.	
7.	<p>Confirmation provided from the DSPT Team at NHS England to the CAG that the relevant Data Security and Protection Toolkit (DSPT) submission(s) has achieved the 'Standards Met' threshold.</p> <p>Confirmed:</p> <p>The NHS England 22/23 DSPT review for Prescribing Services was confirmed as 'Standards Met' on the NHS England DSPT Tracker.</p>	

The Group delegated authority to confirm its final opinion on the application to the Chair and reviewers.

6. ANY OTHER BUSINESS

There was no other business for discussion

Dr Tony Calland MBE
Dr Patrick Coyle

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Signed – Chair

05/12/2023
04/12/2023

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Date

Willam Lyse

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Signed – Approvals Administrator

06/12/2023

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Date