

GPES Independent Advisory Group Minutes

Meeting date: Thursday 12 September 2013

Location: Ambassadors Bloomsbury, 12 Upper Woburn Place, London

Members in attendance:

Name	Title
Neil Serougi	Chair
Christine Boyd	Lay Member and Vice Chair
Eve Sariyiannidou	Lay Member
MacDonald Mopho	Lay Member
Mary Hawking	British Computer Society (BCS) Primary Health Care Specialist Group GP Nominee
Ian Herbert	BCS Primary Health Care Specialist Group Non-clinical Nominee
Joanne Bailey	British Medical Association (BMA) Nominee
Simon de Lusignan	Royal College of General Practitioners (RCGP) Nominee
James Wilson	Ethicist (from agenda item 3 onwards)

Also in attendance:

Name	Title
Frances Hancox	IAG Secretariat, Health and Social Care Information Centre (HSCIC)
Malcolm Oswald	IG Advisor, HSCIC
Amanda Wogan (via teleconference)	Head of GPES, HSCIC
Matt King	GPES Customer Service Manager, HSCIC
Mohammed Bassar	Higher Business Analyst, HSCIC

Apologies: None

Agenda items:

1.	Welcome and introductions
2.	Declaration of interests
3.	Actions and matters arising
4.	IAG management tasks
5.	Customer request: NHS England – Enhanced Service - Pneumococcal polysaccharide vaccination (PPV) programme 2013-14
6.	Customer request: NHS England – <i>care.data</i> addendum
7.	Any other business

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Welcome and introductions

The GPES Independent Advisory Group (IAG) Chair opened the meeting and welcomed the attendees. It was noted that Amanda Wogan, Head of GPES, was unable to attend in person and would be participating via teleconference.

Declaration of interests

It was noted that the IAG Chair's declaration of interests had been revised, and updated copies of the Register of Interests were provided.

Two IAG members provided additional updates to their declarations of interests, and it was agreed that a further updated Register of Interests would be circulated by email.

Actions and matters arising

The IAG Secretariat gave an update on ongoing actions:

- *09/05/13-03: GPES IG Advisor to draft updates to relevant GPES documents based on Caldicott Review Report recommendations and other key publications.* It was noted that the government's formal response to the Caldicott Review Report was expected to be published shortly, and that a further update on this action would be available by the 10 October 2013 IAG meeting.
- *13/06/13-01: GPES to update IG Assessment and other IAG pack documents based on IAG feedback and discussions.* The benefits plan template had been updated following IAG feedback, and it was agreed that this action would be closed.
- *11/04/13-01: Information Governance Explanatory Notes to be published following updates.* This action was pending the completion of action 09/05/13-03, and it was anticipated that an update would be available by the 10 October 2013 IAG meeting.
- *09/08/13-01: IAG Chair and Head of GPES to discuss the suggestion to focus IAG discussions and documents more on public interest and patient benefits.* It was noted that time would be allocated at the 10 October 2013 meeting to discuss public interest specifically, and it was agreed that a further update on this action would be provided at that meeting.

It was noted that the minutes of the 8 August and 9 August 2013 meetings had been agreed as accurate by email and had been published on the HSCIC website.

James Wilson joined the meeting at this point.

An IAG member had raised a query by email about how an objection code in a patient's record would affect the flow of patient identifiable data for the planned general practice to diabetic retinopathy service (GP2DRS) GPES customer requirement. It was explained that the "Dissent from secondary use of general practitioner patient identifiable data" code would prevent data being extracted for secondary purposes but would not prevent data being extracted for the purpose of direct patient care.

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Update 18 September 2013: The GPES team clarified following the meeting that this answer had addressed a different question to the one raised, and that a further update would be given at the 10 October 2013 meeting.

IAG management tasks

The IAG Secretariat gave an update on the calendar for upcoming meetings. A query was raised regarding the timings for the October meeting, and it was agreed that these would be confirmed as soon as possible.

Members were reminded of the timescales for reviewing draft minutes following IAG meetings and were asked to inform the IAG Secretariat if they would not be available within the specified dates.

Customer request: NHS England – Enhanced Service - Pneumococcal polysaccharide vaccination (PPV) programme 2013-14

Customer Requirement Summary

The IAG were given a brief overview of the customer requirement summary. Data had been requested to monitor the number of patients aged 65 or over who had received a pneumococcal polysaccharide vaccination (PPV). Data had been requested primarily in order to manage payments to general practices, and five additional data counts had been requested in order to support public health. It was noted that data on vaccinations had in previous years been submitted to the Health Protection Agency, and that while NHS England would be the customer for the proposed GPES extraction the data extracted would also be made available to Public Health England at clinical commissioning group (CCG) level. The IAG were informed that NHS England intended to publish data at national level, and that publishing data at local area team and CCG level was also under consideration.

The IAG queried why the customer had requested a catch-up data collection for 1 August to 31 August 2013, but not for 1 April to 31 July 2013, as it was not clear whether any alternative data collections were in place for those months. The IAG agreed that they would support a further catch-up collection of data from 1 April 2013, and requested that this be suggested to the customer.

A reference in the Customer Requirement Summary to the proportion of patients 'vaccinated against PPV' was noted, and it was explained that this was factually incorrect as PPV was itself the vaccine. It was agreed that this would be corrected prior to the publication of the Customer Requirement Summary on the HSCIC website. The IAG were also informed that the data count titles in the Customer Requirement Summary had been updated slightly to reflect the specific wording used elsewhere by the customer. In addition to this, the document had been updated to state that NHS England would consider publishing data at local area team and CCG level as well as national level.

The IAG queried whether historical data would be considered, as it was unlikely that vaccine contraindication would be re-entered in a patient's record each year, and it was confirmed that contraindication recorded in previous years would be taken into account.

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There was some uncertainty regarding the sixth proposed data count, which would collect the number of patients 'who did not receive a pneumococcal vaccination and have no recorded reason for not receiving a pneumococcal vaccination'. It was not thought that general practices commonly recorded the offer of a vaccination unless a patient had been given the vaccine or had declined the offer or the vaccine, and so it was suggested data count 6 would be unlikely to return any useful data when compared to data count 5 (the number of patients 'who have not consented to a pneumococcal vaccination within the reporting period'). The IAG suggested that the customer should be asked to consider this.

A query was raised regarding whether the data published by NHS England would include the total proportion of the population who had been vaccinated, as calculated using historical data. It was thought that this could be determined by combining the year on year data already available with the data published for 2013-14.

Benefits Plan

The IAG agreed that the benefits plan effectively described the potential benefits to patients, general practices and the customer, and it was noted that the data could be very useful for public health purposes.

The potential benefits of extracting data weekly rather than monthly were discussed, and it was noted that weekly data could assist in managing any outbreaks of pneumococcal infections.

Information Governance Assessment

The IAG were informed that NHS England would be the data controller for the data received from GPES, but that it was planned that CCG level data would also be shared with Public Health England. The suggestion that data could be published at CCG and local area team level as well as national level was discussed, and it was suggested that the data would be more useful for the healthcare profession if it were provided at CCG level.

A point of accuracy was raised regarding paragraph 4 of the assessment, which could be interpreted as stating that the data extracted were not non-identifying; it was agreed that this sentence should be re-worded to state clearly that the data were non-identifying.

It was noted that the data extracted would be held within the Calculating Quality Reporting Service (CQRS) and that access to the data would be subject to role based access controls.

The IAG discussed whether extracting data weekly rather than monthly could be considered excessive, as it was noted that some concerns had been raised when the IAG discussed the proposed weekly extractions for other Enhanced Services. It was noted that weekly data for this particular requirement would assist management of any outbreaks of infection, but it was suggested that any future Enhanced Services requirements should request monthly rather than weekly unless there was a specific justification for requesting weekly data. There was a suggestion that general practices who logged into CQRS to monitor their performance would find it helpful to know that all data would be updated weekly, but the IAG noted that extracting data weekly rather than monthly when there was no specific justification for doing so could be considered excessive.

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A query was raised regarding whether any comparative information would be made available to general practices when logging into CQRS to access data about their own practice. It was suggested that it would be useful for practices to be able to compare their performance to their CCG as a whole.

The data requested would be aggregated, and the assessment concluded that it would be non-identifying. The risk of any individuals being identified was assessed as negligible if the data were published at national, CCG or local area team level; it was suggested that this risk could be higher if the data were ever published at general practice level, but it was noted that the customer did not propose to publish data at that level.

The IAG reiterated that they would support a catch-up collection of data from 1 April 2013 to 31 August 2013 (rather than just 1 - 30 August) to allow for any vaccinations given before August, and asked for this to be suggested to the customer.

Recommendation

The GPES IAG made the unanimous recommendation that the NHS England – Enhanced Service - Pneumococcal polysaccharide vaccination (PPV) programme 2013-14 requirement should proceed to extraction.

Customer request: NHS England – *care.data* addendum

Addendum

The IAG were given a short overview of the addendum to the *care.data* Customer Requirement Summary v2.1, which had been discussed by the IAG at the 27 March 2013 meeting, and had received a recommendation to proceed. It was noted that no changes had been made to the data requested, but that the customer would like to make the data from the linked Care Episode Service (CES) data set available to a wider audience for a wider range of potential purposes. Five possible broad purposes for the disclosure of data were listed, and it was noted that if a customer requested data for any other purpose then the HSCIC would need to consider this in consultation with stakeholders. Potential users of the data could include universities, commercial companies, healthcare charities and information intermediaries. It was noted that only non-identifying data would be made available, and that individuals or organisations would have to apply for data for a specific purpose and sign a data sharing agreement before receiving any data.

The planned process for disclosing CES data to customers was discussed. It was noted that customers could apply to the HSCIC Data Linkage and Extract Service for data currently held by the HSCIC and that these requests were considered by the relevant HSCIC information asset owner, with support from information governance staff from the HSCIC information assurance directorate, and that any requests for identifying data would need to include a valid legal basis such as patient consent. Where the HSCIC received requests for data that were considered to be sensitive, the request was considered by the Data Access Advisory Group (DAAG).

The IAG were informed that the HSCIC intended to publish a register of disclosures of CES data, and it was noted that although details of DAAG decisions were available on the HSCIC website, there were currently no published details of other data disclosures. A query was raised regarding what level of detail would be published regarding applications for CES data, as it was noted that the HSCIC had previously not published details of some data

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disclosures as the details were considered to be commercial in confidence. The IAG emphasised that publishing details of all organisations receiving CES data, and the specific purposes for which the data would be used, would be important to maintain public trust.

A query was raised regarding whether applications for CES data should be considered by the GPES IAG. This was not included as part of the IAG's role under the group's Terms of Reference, but it was noted that at the time when the IAG Terms of Reference had been drafted this type of customer requirement had not been anticipated.

There were concerns raised that if the IAG recommended that this addendum proceeded then the HSCIC would make decisions about applications for access to CES data without the IAG having the opportunity to consider them, and without assurance that applications would be considered by a similarly independent group. While it was acknowledged that independent scrutiny was not a legal requirement, it was considered to be good practice and important to build and maintain the trust of the general public and the healthcare profession.

Concerns were raised regarding the patient information leaflets produced by NHS England for *care.data*, as these currently did not mention the broad range of potential purposes and potential data recipients (e.g. commercial companies) proposed by the *care.data* addendum. The Group also had major concerns about the process for making most patients aware of the contents of the leaflets before data extraction for *care.data* commenced

The risk of deidentified data being reidentified by the customer was discussed, and it was stated that customers would be required to sign a data sharing contract that would include a statement that they would not attempt to reidentify individuals.

The European Commission's Horizon 2020 programme was briefly discussed, but there were not thought to be any immediate implications for this customer request.

Benefits Plan

The customer had provided a number of potential benefits that could arise from the use of CES data for health intelligence, health improvement, audit, healthcare research, and service planning, management and improvement.

The IAG agreed that there could potentially be significant benefits from using CES data, but there were concerns regarding whether the examples provided were sufficiently robust to balance the potential risks of sharing data more widely with the governance structures described.

It was suggested that the customer might find it beneficial to run a small number of pilot projects that would use CES data for a specific purpose, in order to more effectively demonstrate the benefits that could be realised from the use of this data for purposes other than commissioning.

Information Governance Assessment

It was noted that the Information Governance Assessment provided for this customer request did not follow the standard template used for previous GPES customer requests, as the data requested had not changed from the *care.data* Customer Requirement Summary v2.1. The IAG were informed that while the assessment for v2.1 had classified the data

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requested as identifying, this assessment did not assess whether the data would be considered identifying due to the broad range of possible data recipients and purposes, although it was noted that NHS England and the HSCIC had committed that only non-identifying data would be released. The reference in the Customer Requirement Summary to 'potentially identifiable' data was queried, and it was stated that this data would be considered non-identifying within the controlled environment it would be released into.

The IAG were informed that the Information Commissioner's Office had advised that the HSCIC should be considered the data controller for *care.data*.

The types of organisations who could potentially apply for data were discussed. It was suggested that insurance organisations would not be eligible to receive data, but it was pointed out that some organisations might provide healthcare services as well as insurance and that it could be difficult to manage this overlap. The potential purposes for which data could be used were also discussed, and it was noted that while five main purposes had been listed by the customer it had also been stated that applications to use the data for other purposes would also be considered by the HSCIC, in consultation with stakeholders. There were concerns around the difficulty of assessing the potential risk of disclosing data to such a broad range of organisations for such an expansive list of potential purposes. It was noted that there would also be some difficulty in assessing the potential benefits from releasing data for such a wide range of purposes without further details, making it highly problematic for the IAG to compare the potential risks with potential benefits. It was suggested that the public interest of each data disclosure would need to be considered on a case by case basis.

The IAG noted that the assessment stated requests for data would be classified as either identifying or non-identifying, and said that it needed to know how this classification would be determined before being in a position to make a recommendation to proceed.

The IAG asked whether all disclosures of identifiable data by the HSCIC needed prior approval by the Health Research Authority's Confidentiality Advisory Group (HRA CAG). It was reiterated that this addendum did not seek the disclosure of identifiable data. More widely, it was noted that a legal basis for disclosure of identifiable data was always required and one appropriate legal basis could be approval by the HRA CAG under Section 251 of the NHS Act 2006.

Current HSCIC governance arrangements for data disclosures were discussed, and concerns were raised regarding the potential lack of independent scrutiny when considering applications for data. It was suggested that groups such as the HSCIC DAAG, which currently considered applications for sensitive data, would benefit from including more external members. In particular there were concerns that the HSCIC DAAG's current membership of four individuals (two of whom were employees of the HSCIC) did not reflect an appropriately broad range of perspectives. In addition, it was noted that applications for data that were not considered sensitive would normally be signed off by the relevant HSCIC information asset owner rather than being considered by an independent group, and that as the general practice extract for *care.data* would not include Read codes categorised as sensitive it could follow this process. It was suggested that it would be appropriate for applications for CES data to be subject to a similar process to the current GPES governance arrangements, including independent scrutiny to determine whether data disclosure would be in the public interest. There were concerns that it could be perceived as a conflict of interest for HSCIC staff to determine whether or not a customer should receive data without any external input, and the importance of maintaining the trust of both the general public and the healthcare profession was emphasised.

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It was noted that NHS England's privacy impact assessment and the HSCIC's privacy impact assessment had not yet been published, and nor had the updated template data sharing agreement between the HSCIC and data recipients. It was indicated that these would have been useful to help inform the IAG's discussions.

A query was raised regarding whether general practices could be given the option to opt into a *care.data* extraction for commissioning purposes only, but it was thought that this would be very technically complex.

It was suggested that additional narrative should be provided with the IAG's recommendation based on the group's discussions, and it was agreed that the exact wording would be approved by email.

Following the group's recommendation, some additional points of context were raised for additional information. It was noted that the role of DAAG had previously been carried out by a subgroup of the National Information Governance Board (NIGB), and that the HSCIC and NIGB had agreed that it would be appropriate for the process to be managed by the HSCIC. It was also noted that discussions were ongoing within the HSCIC executive team regarding the role of advisory groups such as the GPES IAG, and that it had been recognised that similar independent scrutiny was not necessarily provided in other areas of the HSCIC's work. The IAG were informed that the creation of a wider advisory group to consider other areas of the HSCIC's work had previously been considered, but that the plans had not progressed to completion. The IAG reiterated that although there was no legal requirement for data disclosures to be considered by an independent group, this could play an important role in maintaining the trust of the healthcare profession and the general public.

Recommendation

Following consideration of the NHS England – *care.data* addendum requirement, the GPES IAG made a recommendation by majority vote of further consideration or significant changes.

In particular the GPES IAG suggested that:

- *Applications to the HSCIC for disclosure of data from the Care Episode Service should be subject to appropriate governance controls, including independent external scrutiny that would consider whether data disclosure would be in the public interest.*
- *Details should be published about those governance controls and about the data disclosure decisions made.*
- *Additional information should be provided about which types of organisations would be eligible to receive data.*
- *The information materials produced should sufficiently describe the intended wider audience for Care Episode Service data. They should be updated to make patients and the public aware that data could be shared with other organisations outside the NHS.*
- *The two Privacy Impact Assessments referred to in the Information Governance Assessment should be completed and published, as should the updated template*

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data sharing agreement for use between the HSCIC and data recipients.

Any other business

A suggestion was made that the IAG would find it helpful in future if additional details could be provided regarding the views of other bodies on matters the IAG were asked to consider; such as the position of the Information Commissioner's Office with regard to *care.data*.

It was noted that GPES had appointed a Technical Author who would lead the production of documents for consideration by the IAG.