

GPES Independent Advisory Group Minutes

Meeting date: Thursday 11 September 2014

Location: Park Crescent Conference Centre, Great Portland Street, London

Members in attendance:

Name	Title
Joanne Bailey	Chair
Christine Boyd	Lay Member and Vice Chair
Eve Sariyiannidou	Lay Member
MacDonald Mopho	Lay Member
Simon de Lusignan	Royal College of General Practitioners (RCGP) Nominee (left the meeting during agenda item 4)
Mary Hawking	British Computer Society (BCS) Primary Health Care Specialist Group GP Nominee
Ian Herbert	BCS Primary Health Care Specialist Group Non-clinical Nominee
James Wilson	Ethicist
Mary McCarthy	British Medical Association (BMA) Nominee

Also in attendance:

Name	Title
Frances Hancox	IAG Secretariat, Health and Social Care Information Centre (HSCIC)
Malcolm Oswald	IG Advisor, HSCIC
Amanda Wogan	Head of GPES, HSCIC
Matt King	GPES Customer Service Manager, HSCIC
Alan Hassey	Information Governance Clinical Lead, HSCIC (agenda item 3 only)

Apologies:

None.

Agenda items:

1.	Welcome and introductions
2.	Declaration of interests
3.	Future HSCIC information governance arrangements
3a.	Discussion of future HSCIC information governance arrangements
4.	Customer request: care.data updated addendum
5.	Any other business

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Welcome and introductions

The IAG Chair opened the meeting and welcomed Dr Alan Hassey, who was in attendance to provide an update on future HSCIC information governance arrangements.

Declaration of interests

No new interests were declared.

Future HSCIC information governance arrangements

The IAG received a presentation from Alan Hassey on current considerations and intentions for the HSCIC's future information governance arrangements. It was noted that these plans had not yet been finalised or confirmed and were subject to review. The IAG were also updated on recent developments such as the expanded independent membership of the Data Access Advisory Group (DAAG) and the increased frequency of its meetings.

There followed a discussion around a number of key topics including the HSCIC's plans to create a secure data facility, the role of other HSCIC committees, the importance of ensuring that the general practice patient doctor relationship would not be damaged by the sharing of data, the need to ensure a clear purpose for all data requests, and the practical considerations around the review of a large number of applications for data. The importance of ensuring continued independent external scrutiny of requests for data was emphasised.

Following this presentation and discussion, Alan Hassey left the meeting.

Discussion of future HSCIC information governance arrangements

The IAG discussed the role of the Standardisation Committee for Care Information in assessing data collection by the HSCIC. It was felt that the role of this committee was significantly different to the role of the GPES IAG, which considered the information governance concerns and public interest implications of data extracted by GPES, data processing, and then onwards data sharing from GPES to the data recipient (or recipients), rather than solely considering data extraction. The IAG agreed that it would be helpful if more information could be provided about the role of this committee to assist their understanding of its functions.

The IAG also discussed the volume of applications for data received by the HSCIC, and the likelihood that some potential applicants for data may be put off by the length of time that it took to process applications. It was suggested that if the HSCIC began to process applications more quickly, it was possible that the organisation would then begin to receive even more applications for data. There were concerns around the practicality of any single group reviewing this number of applications.

The importance of transparency was highlighted, and it was felt that it would be helpful if the HSCIC could publish further information regarding its intentions for the future independent review of requests for data.

The IAG discussed the proposal to hold a lessons learned workshop at a future IAG meeting, and it was agreed that a pre-workshop planning session would be helpful in order

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to agree the desired outputs of this work. Suggestions included considering learning outcomes for patient groups and the public, or producing a written report on the lessons learned since the GPES IAG was set up in early 2012. The IAG agreed the importance of determining who the audience for this work would be and how any suggestions made would be taken forwards.

Customer request: care.data updated addendum

Updated addendum to the customer requirement summary and benefits plan

The IAG received a presentation that summarised the customer request and how this had changed since version 2.1 of the care.data requirement (which had been considered at the 27 March 2013 IAG meeting and recommended to proceed to extraction), and since the care.data addendum considered on 12 September 2013. The presentation also outlined progress and key developments with care.data since September 2013, and how the HSCIC and NHS England had responded to the IAG's recommendation from the 12 September 2014 meeting.¹

It was noted that version 2.1 of the care.data requirement had specified that data would only be used for commissioning purposes. The updated addendum presented for consideration did not seek to amend the dataset that would be extracted, but proposed that data should be made available not just for commissioning purposes but also for use for two additional purposes: research and health intelligence (which would include public health and regulatory functions).

The IAG were informed that although it was proposed that the potential uses of data should be expanded, data would not be made available for solely commercial purposes and no data that identify individuals were proposed to be made available.

The potential benefits that could be derived from the use of these data for research and health intelligence were outlined.

A query was raised regarding why this requirement had been presented as an updated addendum rather than a full new customer requirement summary. It was explained that this was due to the fact that the key characteristics of the data extraction (such as the data to be extracted, the frequency of extraction, and the processing to be carried out by GPES) would not be changing from what had been set out in the care.data customer requirement summary v2.1, which the IAG had considered at the 27 March 2013 meeting.

The IAG discussed the definitions of 'research' and 'health intelligence'. It was felt that these had been very loosely defined in the documents provided, and that this could create potential ambiguities about what uses of data would and would not be permitted. It was noted that research would usually require approval from a Research Ethics Committee, but that some areas of work did not always require this approval.

Some concerns were raised around how useful the linked dataset as currently specified would be for research purposes, and therefore whether the requirement would be able to realise all of the stated benefits. It was noted that NHS England proposed to hold a

¹ The full text of the recommendation made by the GPES IAG for the September 2013 care.data addendum is published on the HSCIC website: <http://www.hscic.gov.uk/gpes/caredata>

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consultation on potentially expanding the requested dataset scope at a later date.

There was a discussion around the progress made against the IAG's recommendations made in September 2013 on the earlier care.data addendum, and it was acknowledged that while the fifth recommendation (publication of two privacy impact assessments and the updated template data sharing agreement) had been completed and steps had been taken towards meeting the other four recommendations, this work was not yet complete. The IAG agreed that these recommendations remained relevant and that the HSCIC and NHS England should continue to work towards meeting them.

The IAG discussed the benefits plan, and agreed that this had significantly improved since the previous care.data addendum was discussed in September 2013. However the need to include specific, measurable outcomes was emphasised and it was hoped that the use of data during the pathfinder stage would allow more specific benefits to be demonstrated.

It was suggested that given public concerns about the provision of data to pharmaceutical companies, the potential use of data by pharmaceutical companies should have been set out more clearly in the documents provided. The IAG reiterated the fact that the potential use of data by organisations such as these ought to be made clear to the general public through the ongoing care.data communications work.

Simon de Lusignan left the meeting at this point.

The IAG considered the timing of this request and whether it might have been more logical to expand access to data for additional purposes following the pathfinder stage, when more information would be available to evaluate the potential benefits of sharing data more widely. It was suggested that considering whether to share data for a wider range of purposes in advance of the pathfinder stage beginning would mean that the communications to individuals registered at the pathfinder practices could be updated to include these other potential uses of data. It was also noted that the leaflet previously sent out to households had mentioned the potential use of data for research purposes, although the IAG expressed their concerns about the quality of the leaflet that had been issued and how informative individuals would have found it.

The importance of evaluating the pathfinder stage was discussed, and it was noted that the care.data programme intended to involve the care.data advisory group and the Independent Information Governance Oversight Panel (IIGOP) in the evaluation process. The IAG recognised the references in the updated addendum document to assessing the burden on general practice staff, and it was hoped that this would be included in the evaluation process.

The IAG suggested that given the level of detail included, the linked dataset could be considered to be potentially identifying if it were made available outside of the HSCIC secure data facility. They emphasised the importance of a rigorous independent approval process for access to these data as well as the importance of making the general public aware in order to ensure fair processing under the Data Protection Act 1998. It was noted that data that would identify a person would not be released, meaning that only data that would be anonymised in the environment into which it would be released could be made available at this stage.

Concerns were expressed that although the HSCIC had committed that data would only be made available within a secure data facility during the pathfinder stage, no commitments appeared to have been made on how data would be made available following this stage.

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Information governance assessment

The IAG received a brief presentation on the information governance assessment for this requirement. This highlighted changes in HSCIC information governance since the previous care.data addendum was considered in September 2013, such as the HSCIC's commitment to publish details of all data disclosures and the increased independent review of applications to the HSCIC for data. The IAG were informed that that this assessment did not assess whether the data would be identifying, as this would be dependent on the environments into which data would be released.

It was noted that individuals who did not wish for identifying data from their general practice records to be extracted for secondary purposes could make an objection, and data from their general practice records would then not be extracted for care.data. The importance of raising patient awareness of this was emphasised, in order to ensure that individuals were aware of the opportunity to make an objection. It was noted that the information governance assessment referred to a survey published by the Joseph Rowntree Reform Trust that suggested that slightly under half the population had heard of care.data, which was a higher level of public awareness than had been achieved by the Summary Care Record campaign. It was suggested that this was at least partly due to the mainstream media coverage of care.data.

The IAG noted that the HSCIC had published a new template data sharing agreement, and suggested that it might be beneficial for this to include sanctions that would apply to organisations who were responsible for data breaches. It was also suggested that stating that any organisation responsible for data breaches would not be eligible to receive data in future could also encourage the responsible handling of data.

A query was raised regarding whether organisations that receive data from the HSCIC would be considered data processors, and therefore whether the HSCIC would be held responsible for any data breaches that took place at the recipient organisation. It was explained that data recipients would not be considered data processors as they would be making decisions about how to process the data received in order to achieve their intended purpose. The IAG noted that the HSCIC and NHS England would be considered joint data controllers for care.data, and considered the impact that this could have on decisions regarding the release of data.

Consideration of recommendation

The possibility was raised of recommending that data extracted during the pathfinder stage could be used for the specified additional purposes, but that at the end of the pathfinder stage this should be subject to further consideration. It was noted that by the end of the pathfinder stage additional information should be available about the benefits realised and the effectiveness of public communications, in addition to details of what information governance controls will be in place following the pathfinder stage. The IAG also emphasised that a more tightly defined definition of health intelligence and research purposes should be established prior to the end of the pathfinder stage, as the definition provided was felt to be too broad.

The IAG discussed the fact that data would not be made available for purely commercial purposes, but that the data could potentially be made available for purposes that would support healthcare while also having a commercial element. It was suggested that it would

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be important to ensure that the general public were made aware of this, and the importance of ensuring that individuals could not be re-identified from the data provided was again emphasised.

A query was raised regarding the involvement of CCGs in care.data, and it was noted that the care.data programme had approached a number of CCGs to seek expressions of interest in involvement in the pathfinder stage. A further query was raised regarding whether a business case for care.data had been published and it was noted that this was in development. The IAG also queried whether the care.data directions issued by NHS England to the HSCIC supported the proposed additional purposes, and it was anticipated that these directions would be updated in future.

The IAG reiterated the importance of the recommendations they had made for the previous care.data addendum in September 2013. It was acknowledged that the HSCIC had made significant progress and it was agreed that where these had not already been completed NHS England and the HSCIC should continue to work to ensure their completion.

Some concerns were raised around the lack of publicly available information about the care.data programme board, and the fact that papers provided to the care.data advisory group and referred to in that group's minutes had not been published. It was felt that increased transparency for both groups would help increase public confidence.

The IAG discussed the fact that during the pathfinder stage, data would only be made available in the HSCIC secure data facility. It was suggested that the pathfinder evaluation might consider what proportion of applications for data met their requirements by using the secure data facility, and what proportion would have needed the disclosure of data by the HSCIC. There was also a suggestion that following the pathfinder stage the HSCIC could consider allowing access to data from within a number of similar secure data facilities across the country, for example hosted by universities or accredited safe havens, in order to expand access to the data while maintaining appropriate safeguards.

It was suggested that the evaluative framework used to assess the pathfinder stage should include considering whether the data extracted met the anticipated benefits and also considering the data quality of the linked dataset produced. The IAG noted that IIGOP would be involved in the evaluation process and would provide advice to the care.data programme, and it was hoped that IIGOP would consider these points in addition to considering whether the communications activity had resulted in satisfactory understanding with the pathfinder practices' population and therefore fulfilled the fair processing requirements under the Data Protection Act 1998.

It was noted that there were some minor typographical errors in the documents provided, and that these would be corrected prior to publication.

Recommendation

The GPES IAG made the recommendation by majority vote that this requirement should proceed subject to changes and/or further approvals.

The following changes were recommended:

1. The current lack of clarity about the data disclosure controls that will be in place following the care.data pathfinder stage was a significant cause of concern, and more information would be welcomed about commitments beyond the pathfinder

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stage. Only data from the pathfinder practices should be made available for the additional two purposes set out in the updated addendum. Expansion to purposes beyond commissioning should receive further consideration at the end of the pathfinder stage.

2. As part of their advice on whether data extraction from pathfinder practices is ready to commence, the Independent Information Governance Oversight Panel should be asked to consider whether they are satisfied that the pathfinder communications and fair processing activities have resulted in satisfactory understanding within the pathfinder practice populations.
3. The HSCIC and NHS England should ensure that all the IAG's recommendations for the previous care.data addendum made on 12 September 2013 are met in full.
4. Clearer definitions of 'research' and 'health intelligence' should be proposed by the care.data programme.
5. The IAG also suggested independent evaluation of how far the data collected has met the examples given of benefits envisaged.

No further approvals were thought to be required.