HSCTP 12/3/Mins

HEALTH AND SOCIAL CARE TRANSPARENCY PANEL

MINUTES of meeting held at Department of Health, Richmond House, 79 Whitehall, London, SW1A 2NS

Wednesday, 2 May, 2012

PRESENT		
Earl Howe		
Nigel Shadbolt	Roger Taylor	Peter Stephens
Paul Bate	Gill Lawrence	Jeremy Taylor
Julie Stanfield	Charlotte Alldritt	Mark Davies
Bill McAvoy (substituting for Ailsa Claire)		Giles Wilmore
Bruce Keogh	David Haslam	
APOLOGIES		
Paul Najsarek	Katie Davis	Tim Straughan
Paul Robinson	Ailsa Claire	Peter Lawrence
SECRETARIAT		
David Knight (DH)	Diana Paine (DH)	
Attending on this occasion only:		
For item on clinical audit	Robin Burgess CEO HQIP Simon Bennett , clinical audit policy, DH Clare Callaghan, clinical audit policy, DH	
observer	Stephen Latham DEFRA	

Agenda

1.	Welcome and introductions	
2.	Minutes of meeting 22 March 2012	HSCTP/12/2/mins
3.	Clinical Audit data – getting the appropriate level of detail	HSCTP/12/3/1 HSCTP/12/3/1A,1B, 1C
4.	Identifying future data releases – criteria and process	HSCTP/12/3/2
5.	Information Strategy - update	verbal
6.	'Right to Data' White Paper - update	verbal
7.	UK/US summits - update	HSCTP/12/3/4
8.	AOB	

1 Welcome and introductions

1.1 Earl Howe, Chair, welcomed, Robin Burgess, CEO, HQIP and Simon Bennett and Claire Callaghan from the DH policy team for the item on clinical audit. He also welcomed Bill McAvoy, attending for Ailsa Claire and Stephen Latham, DEFRA, attending as an observer.

1.2 Apologies had been received from Ailsa Claire, Paul Najsarek, Katie Davis, Tim Straughan, Paul Robinson and Peter Lawrence.

2 Minutes of meeting 22 March 2012 (HSCTP/12/2/mins)

2.1 Minutes were agreed for publication.

Action

- Secretariat to publish 22 March minutes on DH website

3 Clinical Audit data – getting the appropriate level of detail

3.1 Robin Burgess, CEO, HQIP, presented the background to national audits that form part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). He highlighted the high participation rates (~85%) and the high quality of data produced on the effectiveness of care and outcomes. The audits are generally run by the relevant professional body and the level of data available is generally better than comparable data available anywhere else in the world. HQIP acts as the data controller for data sharing for the nationally funded audits. It is leading the work to make this data more transparent and accessible which is being taken forward in two phases.

3.2 Phase I of the clinical audit transparency project is making the audit data contained in current annual reports (at a defined level of granularity) available via data.gov. This is existing data that has been analysed in some way. A number of audits have already been made available and the remainder will follow in the coming few months. Three issues have arisen under Phase I:

- how much interpretation is required to make tables understandable?
- what is the appropriate level of detail (one size does not fit all)?
- concerns about the risk of identification for individual clinicians.

In general, it should be possible to address these and HQIP expect to publish all NCAPOP audits at the various levels of granularity currently used in each audit's Annual Report without difficulty.

3.3 Phase II, which could involve release of raw data, and publishing of data at greater levels of granularity, has already given rise to more serious concerns:

- professional bodies are concerned about loss of control over use of raw data once it is released and want to see suitable levels of data control that currently resides with HQIP
- less control could result in data being used by individuals/organisations who have conflicts of interest and/or may use the data to produce conflicting or misleading analysis without adequate explanation or context. This in turn could cause unfounded anxiety for patients.
- A consequence may be a reluctance by clinicians to participate in clinical audit in future, thus reducing the quality and utility of audit data and potentially undermining the future development of clinical audit in England.

3.4 The panel discussed the issues and raised a number of key points:

- agreement to the fundamental principle that this publicly funded data should be made available to benefit public and patients;
- that this data is currently under-used, including by the NHS;
- that it is critical that we take professions with us or we will lose the momentum gained and risk not only future further development but current progress – these are not routine data collections but rely on voluntary participation;
- that the key purpose of clinical audit is to improve care;
- the risks of ill-informed analysis are real and there is evidence from past experience with the cardiac surgery audit of the damage this can do;
- but, if interpretation is poor it is contestable – we need to encourage a greater understanding and more sophisticated approach to data;
- that different levels of data granularity may be appropriate for different audits – data at ‘clinical team’ level is appropriate where there is a clear link between the intervention and the outcome eg, orthopaedic surgery. But it will not be appropriate where the clinical pathway means that the specific intervention covered by the audit does not have such a direct link to outcome;
- that the term ‘clinical team’ means different things to different people, so there is a need to be clear what it means in aparticular context;
- the levels of data in Phase I are a start but they need to be more granular, more standardised, but also more supported;
- there is a need for a duty of publication within a set of rules;
- there was general acceptance of theneed for rules about data sharing with appropriate controls of data release to give

professionals confidence;

- decisions about how data is shared, and with whom, should be clearly independent from individual professional groups and bodies;
- clinical audit currently covers a relatively small proportion of care – need to recognise where we are and the longer term vision; and
- there is a need to balance risks and benefits and look at incentives to participation as well as recognising the importance of pace and timing.

3.5 The panel recognised this was a complex area and that there were issues of substance to be addressed in Phase II. It was agreed that a sub group should be formed to work with HQIP and clinical audit policy colleaguesto identify how best to take Phase II forward. In the meantime, it was expected that HQIP would continue to work with professional bodies to publish the data underpinning annual reports to deliver Phase I in the current year (2012-13).

Action

- Secretariat to set up sub group to look at Phase II transparency of clinical audit

4 Identifying future data releases – criteria and process (HSCTP/12/3/2)

4.1 An updated version of a paper setting out the criteria and process for the release of health and social care data under the open data strategy was presented. This would continue to be developed, for example we may want to amend in the light of lessons and experience from the US, following the bi-lateral summit planned for 7 June. Many of the more straightforward areas of data were now in the public domain and the Department now needed to consider how to identify and prioritise future data releases where more complex issues arise, such as the appropriate licensing arrangements and the cost implications and who should pay for any additional costs associated with making data transparent and accessible.

4.2 The flowchart provided a basis for a principle based approach. The panel could have a real role in supporting and advising DH and other parts of the health and care system in making clear and consistent decisions about future data releases. In many cases this more detailed consideration would best be done through sub groups and the clinical audit work (see para 3.5 above) would be a first opportunity to test out the approach.

4.3 The panel recognised that not all the expertise required may exist within the current membership and it might be necessary to co-opt experts onto the panel, or into sub groups, to cover issues such as the risks of jigsaw identification, or to understand data power in particular instances. It was noted that the new Cabinet Office open data White Paper, due to be published in June, was expected to require sector transparency boards to

add a privacy expert to their membership.

4.4 The criteria could usefully include reference to the criteria used by the Information Commissioner's Office.

4.5 When considering how best to make data accessible to the public need to anchor the data to a 'story' that reflects the patient/service user's experience.

Action

- Secretariat to check criteria with ICO and add to flowchart.

5 Information Strategy – update (verbal)

5.1 The strategy was expected to be published before the end of May.

Note: The power of information: Putting all of us in control of the health and care information we need, he Department of Health's information strategy for health and care, was published on 21 May 2012

http://informationstrategy.dh.gov.uk/

6 'Right to Data' White Paper – update (verbal)

6.1 The planned Cabinet Office White Paper on open data would focus on improved access to data:

- the Open Government Licence to cover use and re-use of data
- clear terms and conditions for data sharing
- emphasis on maximum access with minimum bureaucracy
- address privacy concerns

6.2 Development was being overseen by a cross government steering committee and a senior officials group. It was expected that it would be published in June alongside Departments' open data strategies setting out specific sector transparency commitments.

6.3 The panel welcomed the opportunity to learn from other Departments' work. It was noted that because of its work on the information strategy health had perhaps given more thought to some of the issues than other areas at this stage.

6.4 It would be important to make a clear distinction between how we should treat and use identifiable and non-identifiable data. This is a particularly sensitive issue for health and care and one where we would want to see the current work of the independent review of information governance led by Dame Fiona Caldicott (Caldicott II) acknowledged.

6.5 There would be an update on progress on the open data white paper at the next meeting.

7 UK/US summits – update (HSCTP/12/3/4)

7.1 Details for the planned meeting were now being agreed. There would be a one day bi-lateral meeting (7 June) to showcase successes and identify common challenges and problems that the US and UK could usefully develop solutions for through collaborative working. The UK delegation would also have an opportunity to attend the US two day health data initiative forum (5-6 June), a public-private collaboration that encourages innovators to utilize health data to develop applications to raise awareness of health and health system performance and spark community action to improve health.

7.2 Those attending would report back to the panel at the next meeting.

8 AOB

Members were invited to suggest future agenda items. There was no other business.

Action

- Members to send any suggestions for future agenda items to Diana Paine

Note date and time of next meeting:

Monday, 18 June, 9.30-11.30, Cathedral Room, Richmond House

	SUMMARY OF ACTION POINTS	ACTION BY
1	Publish 22 March minutes on DH website	Secretariat
2	Set up sub group to look at phase II transparency of clinical audit	Secretariat
3	Check criteria with ICO and add to flowchart.	Secretariat
4	Members to send any suggestions for future agenda items to Diana Paine	All members