Minutes

Title of meeting	Health and Social Care Transparency Panel	
Date	23 April 2013	**Time** 14:45-16:45
Venue	Richmond House	
Chair	Dr Dan Poulter	**Secretary** Diana Paine
Attendees	See below	
Apologies	See below	

PRESENT		
Dr Dan Poulter		
Dr Mark Davies (HSCIC)	Roger Taylor (dialled in)	Paul Robinson
Paul Najsarek	Peter Stephens	Jeremy Taylor
David Haslam	Bruce Keogh	Mark Davies (DH)
Nigel Shadbolt	Jem Rashbass	Geraint Lewis

APOLOGIES		
Tim Kelsey	Alan Perkins	John Newton
Julie Stanfield		

Attending for specific agenda items or as observers:		
Geraint Lewis	Eve Roodhouse	Charlotte Urwin (obs)
John Oppenheim (obs)		

SECRETARIAT		
Diana Paine (DH)	Amina Aladin (DH)	

1   Welcome and introductions

Dr Dan Poulter, Parliamentary Under Secretary of State – Health (PS(H)), welcomed members.

Attending for this meeting only:

- Geraint Lewis for item on the development of care.data
- Eve Roodhouse for item on data linkage service

[Apologies are noted above.]

2   Minutes of meeting 17 October 2012 (HSCTP/12/5/Mins)

2.1   Panel approved minutes for publication without amendment.

Action

Secretariat to publish minutes

in line with other Government departments DH has now moved to the Gov.uk website

3   NHS England - the development of care.data

(presentation Geraint Lewis, Chief Data Officer, NHS England)

3.1   Presentation set out the key features of care.data:

- Supply timely, accurate information to citizens, clinicians and commissioners
- Build on success of data collection such as Hospital Episode Statistics (HES) but move to wider patient pathway: care episode statistics (CES)
- Bring together inpatient, A&E, outpatient and GP data
- 3 main types of output for different purposes (slide 10):
  - identifiable data - to use for patient access to records (through portal) and under s.251
  - potentially identifiable data (pseudonymised, event level) – for use for eg commissioning, research
  - aggregate data – publicly available
- Enable better analysis of patient journey and to track history of health interventions over a prolonged period – (eg theographs – slides 8 & 9)

There is a phased approach to developing the service and it will take time for all of these features to become available (slide 13)

3.2   GP data will be brought into system through the GP extraction service (GPES) from May 2013 [**DN check with NHSE – has date moved?]**. Identifiable patient data is protected by a quintuple lock and data is held in the Health and Social Care Information Centre (safe haven for health and care data). In time expect to provide patient access to their own data in machine readable, downloadable, format.

3.3   Members welcomed these developments and the vision for more effective use of data to drive improved care. Questions and issues raised inlcuded:

- How does this relate to summary care record?
  - while there is some overlap in the information that both may hold data care.data will not capture free text
- What scope is there to share social care and health data?
   - major difficulty is that the coding language doesn't currently exist in social care. Adoption of the NHS number as a common unique identifier would be an important first step.

It was suggested that how to support adoption of the NHS number as a unique identifier across health and social care might be an area the panel could look at in the future.

4   HSCIC - Data Linkage Service

(Presentation by Eve Roodhouse, programme lead, Data Linkage Service, HSCIC)

4.1   Presentation covered the new data linkage, the value and benefits of linked data, the current service and plans for the next two years. Service provides:

- Extracts of pseudonymised datasets created by linking data held by HSCIC and by linking data held by HSCIC and customer data
- Extracts of linked data in identifiable form where appropriate information governance arrangements are in place
- Cohort flagging
- NHS number tracing and list cleaning

4.2   Increasingly will provide routine linked products:

- Patient Reported Outcome Measures (PROMS) linked to HES
- Mortality data linked to HES
- Mental Health Minimum Data Set (MHMDS) to HES (from 29 April 2013)
- Plans for further routine linkages over next 2 years

Also provides data service for commissioning on behalf of NHS England

4.3   Members noted key importance and potential of linked data. However a major issue is ensuring data quality. Work undertaken by National Quality Board, Quality Information Committee has highlighted the poor quality of much data. This point was acknowledged; HSCIC check data quality and use algorithms to test quality of data linkage and matching. In some cases it is appropriate to test quality by making it available so it can be challenged. NHS England has a key role in driving data quality through publication of information standards and setting minimum

reporting requirements in standard contracts.

[A copy of the QIC report can be found at the link below – it was also sent to members on 3 May

http://www.england.nhs.uk/wp-content/uploads/2013/04/1ndqr-exec-sum.pdf]

4.4   The panel queried how much of this data would be open. This may be possible in some cases in the future but in general users will need to demonstrate that there are appropriate information governance arrangements in place and at present there is also a charge for access to the service (although this is set at a nominal £1 for data requested for research purposes).

5   Access to ONS data

5.1   The issues of finding a legitimate basis for sharing ONS death data with information intermediaries for commercial purposes had been a long running problem. A number of possible approaches had been considered but advice from the relevant Government legal teams was that there did not appear to be a statutory basis for doing so. The panel identified this as a significant barrier to developing a vibrant market of information intermediaries (IIs). It also limited the ability of IIs to support NHS organisations with business intelligence to evaluate and benchmark the quality of their services.

5.2   It was agreed that this issue needed to be resolved, and if necessary changes to the relevant legislation should be considered. The panel asked for this to be raised formally with Cabinet Office (as lead Department on open data and transparency and as sponsor Department for the legislation governing the operation of UK Statistics Authority and ONS)

Action

- Secretariat to write to Paul Maltby, Director, Open Data and Transparency, Cabinet Office
  [copy of letter circulated with papers for 9 July 2013 meeting]

6   Clinical Audit data

6.1   A short update item. HQIP were working with information intermediaries to pilot the new approach to data sharing as agreed through the work undertaken by this panel's Clinical Audit sub group. It was also noted that NHS England has announced plans for publication of consultant level data for 10 surgical specialties in the summer.

[**Note:** first data was published 28 June – information for 7 specialties to be published by 5 July with remaining three to follow in Autumn:

http://www.england.nhs.uk/2013/06/28/mjr-brkthgh-nhs-transp-cons/]

7   New data requests submitted through data.gov

7.1   Government had made a new facility available through data.gov where anyone could 'suggest a dataset' that they believe is collected by Government and that they would like to be able to access by completing a short on-line form. These requests are then referred to the relevant Government department for consideration. Cabinet Office had recommended that sector transparency boards should have a role in considering these requests, in particular where the decision of the relevant department was that it was not appropriate to release the data

7.2   DH had received 16 requests to date, as summarised in the annex to the paper. Officials were currently working through the requests and would bring them back to the next meeting for members' consideration.

7.3   The topics generated a broader discussion on the role of HSCTP. A number of members felt there was a need to revisit this in more detail at a future meeting to consider the proper role of the panel and how best to use meetings to drive the open data and transparency agenda

Action:

- **Role of HSCTP to be a substantive topic for discussion for a future meeting** (on the agenda for next meeting on 9 July)

8   Twitter account for HSCTP

8.1   A number of members had suggested at the last meeting that the HSCTP should have a twitter account to tweet news about the panel's work. A short paper set out some of the issues to be considered:

- Should the account be in the name of the panel or in the name of the individual running the secretariat?
- Would members be willing to clear minutes by e-mail with a couple of weeks of the meeting, rather than at the next meeting?
- Should we move to a policy of publishing all papers and presentations discussed at panel meetings?

8.2   Members were generally supportive of having a twitter account, which should be in the name of the panel. They were also content to clear minutes by e-mail and to have papers and presentations published alongside the minutes of meetings. It was suggested the account should be used for:

- Highlighting topics discussed and availability of minutes and papers
- Re-tweeting relevant factual tweets about open data and transparency
- Sign posting announcements and developments about open data and transparency

However some members felt the panel needed to consider how they would want to use the account as part of the broader discussion of its role before starting an account.

9   Possible workshop and working with panel

9.1   Possible items for future discussion or more detailed work by eg a sub group were discussed:

- Quality of data
- Promotion of unique identifier to support integration
- Exploitation of richness of data

It was agreed that this item touched on the same issue of the role of the HSCTP and should be revisited as part of that discussion.

10   WMS on Open Data

10.1   A copy of the most recent DH contribution to the Minister for Cabinet Office's quarterly written ministerial statement was shared with members on 15 February. Members had no comments on the content.

11   AOB

There was no other business.

	SUMMARY OF ACTION POINTS	ACTION BY
	write to Paul Maltby, Director, Open Data and Transparency, Cabinet Office on behalf of panel	Secretariat
	Role of HSCTP to be a substantive topic for discussion for a future meeting	Secretariat