

HSCTP 12/4/Mins**HEALTH AND SOCIAL CARE TRANSPARENCY PANEL**

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

Monday, 18, June, 2012

PRESENT		
Earl Howe		
David Haslam	Roger Taylor	Paul Robinson
Paul Najsarek	Julie Stansfield	Jeremy Taylor
Peter Lawrence	Charlotte Alldritt	Mark Davies (DH)
Tim Straughan	Paul Bate	Giles Wilmore
Peter Stephens		
APOLOGIES		
Nigel Shadbolt	Gill Lawrence	Bruce Keogh
Charlotte Alldritt	Katie Davis	Mark Davies (IC)
Ailsa Clare		
SECRETARIAT		
David Knight (DH)	Diana Paine (DH)	
Agenda		
1. Welcome and introductions		
2. Minutes of meeting 2 May 2012		HSTCP/12/ /Mins
3. US Summit - feedback		Verbal Giles Wilmore
4. US experience of open data and transparency		Todd Park, US CTO (via Skype)
5. The power of information – feedback on publication of information strategy 21 May		Verbal Giles Wilmore
6. Open government White Paper		Verbal Peter Lawrence
7. AOB		

1 Welcome and Introductions

Earl Howe welcomed Mark Davies (DH) as a new member of the panel in his role as the incoming Director with responsibility for the Information Strategy and Transparency policy in the Department. He thanked Giles Wilmore, who would be moving to a new role, for his contribution to the work of the panel.

2 Minutes of the meeting 2 May 2012 (HSCTP/12/3/mins)

2.1 Secretariat updated the panel on action points not covered elsewhere on the agenda:

- Details of the panel membership, terms of reference and minutes were in the process of being placed on the DH website [now available at <http://www.dh.gov.uk/health/about-us/public-bodies/advisory-bodies/hsctp/>]
- As agreed at the 2 May meeting a clinical audit sub group was being established with the aim of reporting back to the 17 October meeting
- Secretariat is following up with ICO about FOI criteria
- Panel members were reminded about the opportunity to suggest future agenda topics

2.2 Subject to correction of Tim Straughan's name the minutes for 2 May meeting were agreed for publication

Action

- Secretariat to arrange for 2 May minutes to be published on DH website [now available at: <http://transparency.dh.gov.uk/category/minutes-2/advisory-bodies/hsctp/>]

3 US summit – feedback (verbal update – Giles Wilmore)

3.1 Following an invitation from the US Government a delegation from DH, related bodies and outside organisations with an interest in open data, had visited the US to attend the health data initiative forum (HDI also known as the health datapalooza) and a one-day bilateral summit to discuss areas of mutual interest and agree a joint programme of work. Secretary of State attended the summit.

3.2 The HDI forum is focussed on innovation in the use of health data. It provided an opportunity to learn about open data initiatives and developments in the US and how the US Government has opened up access to, and use of Government held data and also enabled easier access for patients to their own health data eg Blue Button <http://www.va.gov/bluebutton/> , developed by the department of Veterans'

Affairs.

3.3 The summit was focussed around three themes:

- Clinical – data, technology and quality improvement: benchmarking and comparing clinical data internationally; development of registries. How to partner with industry to drive quality improvement
- Technical – data architecture and application development – interoperability and standards: collaboration to set standards, in particular for system interoperability, to support international developments
- this would help development of innovative solutions that could apply in the UK which otherwise is too small a market to attract developers, despite being a rich data source
- includes possible examination of scope to use blue button technology (see above) which supports patient access to their own data and the ability to share with 3rd parties
- Consumer and public engagement – including acting on feedback from service users

The UK and US teams are now in the process of finalising a joint programme of work to be developed over the next 3-6 months with current plans to invite a US delegation to the UK towards the end of 2012. Updates will be provided for the panel as the work goes forward.

3.4 Earl Howe thanked the secretariat and HSCIC colleagues, Hilary Scrase and Esther Webb, for their support in planning and organising the visit.

Action

- Secretariat to share briefing note from the US summit when finalised

4 **US experience of open data and transparency** (Todd Park, US Chief Technology Officer)

- 4.1 Earl Howe welcomed Todd Park and thanked him for agreeing to participate in the panel. He invited him to set out the US experience of opening up health data.
- 4.2 Todd set out the elements of the US approach. Early engagement with information intermediaries had been critical and the Health Data Initiative (HDI), championed by Kathleen Sebelius, Secretary of Health and Human Services, has been an important aspect of achieving this. The first event (in 2010) had brought together about 20 individuals and small companies who were set the challenge of using Government data to develop innovative and useful applications and tools, with the aim of then facilitating links with investors to develop these for the market. This has been very successful and this year's HDI forum had 1600 attendees with over 240 companies competing for 100 spots to showcase their ideas. This

approach has meant no additional cost to the taxpayer as the private sector develops and uses data that has already been paid for.

4.3 Panel members then asked a number of questions, summarised with Todd's responses below.

4.4 **How do you avoid confusion for patients and the public and ensure information is clear and objective?**

Government presentation of data was incomprehensible. US experience has been that entrepreneurs are doing a much better job of making relevant information available. Consumers 'vote with their feet' and quickly stop using poor quality information sources.

4.5 **How do you engage with the private sector?**

Engagement from the outset is critical – and then just see what happens. Throw the challenge out 'here is the data – see what you can do with it'. You also need to provide support to link developers with investors and also invite data owners and entrepreneurs not yet working with the data so they can see what is possible to encourage more data release and more developers. An event like the forum provides an opportunity to bring all these people together and to demonstrate what can be done.

4.6 **Is there a typical business model for how companies sell these products to people and other businesses?**

No – there are a lot of different models and it is still early days. It may lead to different business models in how US health providers operate as better information provides the means to move from a fee per service model – which doesn't necessarily incentivise the most effective care, to a model which rewards keeping people well or providing services in a different way. The availability of better data provides the information to make the business case for improving services and delivering them in differently.

This in turn is creating new markets for data intermediaries eg care co-ordination or population health management, which providers will buy; tools to help employers, who fund much of health insurance, to manage costs; and applications that support patients to manage their own care and engage more effectively with their clinicians. One area that has not developed is a market where patients are willing to pay for data, or services based on data.

4.7 **What type of Government involvement has really made a difference? What would you have done differently?**

Just opening up the data is not enough. The hard work is to engage properly with entrepreneurs: getting feedback on what has been released, making people aware of what is available, finding out what other data they would like to be made available. Showcasing developments allows information intermediaries to learn from each other. Key message: active engagement and provide opportunities for data intermediaries to connect

with data suppliers.

4.8 Have there been any problems with identifiable data becoming public or other adverse incidents?

You must be very rigorous about the risks of releasing identifiable data as a result of mosaic/jigsaw identification (and remember that this is not just about the risk of linking existing data but also future data, not yet available, or possibly not yet even collected). We make a clear distinction between aggregated, anonymised data eg smoking rates by county, which can be made completely open as there are no privacy issues and other, potentially identifiable, data where we use a controlled access approach modelled on how data for research is managed. Data in the latter category is released under data sharing agreements with clear terms and conditions and significant penalties for misuse.

4.9 How do we make UK attractive for US developers? Eg do we use open standards or support pilot work with developers?

Open standards will help but you might need to work with organisations within or closely supported by Government to begin with to demonstrate potential.

4.10 How would you summarise the role of Government?

Get incentives right – move away from fee for service.

Liberate underlying data.

Encourage meaningful use – eg bonuses for providers who use electronic records to support data sharing

4.11 Earl Howe drew the discussion to a close and thanked Todd Park for his participation.

5 The power of information (Giles Wilmore)

5.1 The document had been well received with good coverage and a generally positive response. It was acknowledged that it set out a compelling vision but it was not an action plan. The challenge would be to deliver in a system where the centre no longer dictated how services should be delivered and with devolution of decision making. What are the incentives to make it happen? Cultural change would be needed and how Government communicated the key messages to persuade and incentivise the system would be critical. It needed to be clear about the role of Government, which will be to stimulate the right conditions for change but not to deliver or drive from the centre. The role of providers and the incentives and rewards for that sector would be important in delivering the necessary change.

5.2 Some members felt the document was less clear on the potential role of the private sector. More generally Government needed to develop a

supporting eco-system for better use of data and information and to develop the market. Cabinet Office led developments such as the Open Data user group and the Open Data Institute would work with entrepreneurs and developers to support this.

6 Open Data White Paper (verbal update - Peter Lawrence)

- 6.1 The Cabinet Office produced Open Data White Paper was in the process of getting cross Government clearance (through the Public Expenditure (Efficiency and Reform) Cabinet sub-committee (PEX(ER)) and publication was expected towards the end of the month.

[note: *Open Data White Paper – Unleashing the Potential* was launched 28 June: <http://www.cabinetoffice.gov.uk/resource-library/open-data-white-paper-unleashing-potential>].

- 6.2 The White Paper will set out how Government will make it easier to access public data; encourage data publishers to release data in standardised, open formats; and establish a 'presumption to publish' unless there are reasons, such as privacy, why this is not appropriate. The importance of building public trust was recognised and the document would clearly distinguish between use of personal and non-personal data. A number of proposals would be aimed at developing an eco-system to support the growth of a data intermediary market.
- 6.3 The document would set out the scope to make smarter use of data, particularly in sharing data within Government and across departments, within the existing legislative framework. There would be a comprehensive review of the use and re-use of data and if required legislative change might be introduced in the future to enable better use of data. A social mobility sector panel, chaired by the DPM, would also look at the potential of linking and sharing data. Large companies would be encouraged to be more open and transparent, and to release data to support this, as part of social responsibility deals.
- 6.4 The cross Government website data.gov would be refreshed to make it easier to use. A new code of practice for Freedom of Information was also being developed.
- 6.5 The panel asked whether there were examples from other Government Departments of consideration of the balance of benefits and risks in sharing identifiable data as is being covered by the Caldicott II review in health. It was confirmed that similar issues had had to be considered by the Ministry of Justice when releasing court sentencing data and by the Department for Education with the national children's database. The White Paper was expected to set out plans to have a privacy expert on the cross Government Public Sector Transparency Board and to ensure that these issues could also be adequately covered by individual sector boards.

7 AOB

Panel members asked for an update at the next meeting on suggestions for open data and other issues, such as access to ONS data, made at the HSCTP workshop in January and at the February and March meetings. There was no other business.

Action

- Secretariat to provide update on open data releases and issues at next meeting

Note date and time of next meeting:

Wednesday, 17 October, 11.00-13.00, Board Room, Richmond House

	SUMMARY OF ACTION POINTS	ACTION BY
1	2 May minutes to be published on DH website	Secretariat
2	share briefing note from the US summit	Secretariat
3	update on open data releases and issues at next meeting	Secretariat