Department of Health

Minutes

Title of meeting	Health and Social Care Transparency Panel
Date	17 October 2012 **Time** 11.00-1.00
Venue	Richmond House
Chair	Dr Dan Poulter **Secretary** Diana Paine

Attendees

Dr Dan Poulter

Dr Mark Davies (HSCIC)

Roger Taylor

Paul Robinson

Paul Najsarek

Peter Stephens

Jeremy Taylor

Peter Lawrence

Bruce Keogh

Mark Davies (DH)

Julie Stanfield

Giles Wilmore

Attending for specific agenda items or as observers:

Robin Burgess HQI

Martin Dennys DHID/CfH

Steve Smith DHID/CfH

Glen Mason DH

Liz Tadd DfE (obs)

Secretariat

David Knight (DH)

Diana Paine (DH)

Apologies   Nigel Shadbolt

Gill Lawrence

David Haslam

Charlotte Alldritt

Tim Straughan

Tim Kelsey

Peter Lawrence

Tim Donohoe

Paul Bate

1 Welcome and introductions

The new chair, Dr Dan Poulter, Parliamentary Under Secretary of State – Health (PS(H)), welcomed members and asked everyone to introduce themselves and to explain their background and their interest in the transparency agenda. Although unable to attend this meeting he welcomed new members:

- Tim Donohoe, Director, NHS Informatics
- Tim Kelsey, Director, National Director Patients and Information, NHS Commissioning Board (NHSCB)

Attending for this meeting only:

- Giles Wilmore substituting for Tim Kelsey
- Robin Burgess, CE, HQIP for item on clinical audit
- Martin Dennys and Steve Smith DHID/CfH for item on NHS Spine
- Glen Mason, Social Care policy, DH, for item on social care
- Liz Tadd, Department for Education - observer

[Apologies are noted above.]

2 Minutes of meeting 18 June 2012 (HSCTP/12/4/Mins)

2.1   Panel asked for an addition to the minutes to note Todd Park's comment on the unwillingness of patients to pay for data, or tools and applications using data, in the context of business models in open data. Subject to this addition the panel approved the minutes for publication

Action

Secretariat to update and publish minutes

[in line with other Government departments DH has now moved to the Go.uk website - minutes are now available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/166387/18-June-2012.pdf   ]

3   Transparency in Clinical Audit (HSCTP/12/5/1)

3.1   At the May meeting the panel asked Dr Mark Davies to chair a sub group to make recommendations to the main panel on further implementation of the commitment to make clinical audit data more open.   The sub group's recommendations were set out in the above paper. (The sub group paper and notes of the sub group's meetings are now available on the Gov.uk website at https://www.gov.uk/government/policy-advisory-groups/health-and-social-care-transparency-panel#minutes)

3.2   The sub group had included audit suppliers and the recommendations were the result of detailed discussion and robust but constructive debate. As set out in the paper the key recommendations were:

- The definition of 'clinical team' should be agreed on an audit by audit basis by the data controller (currently HQIP), but within the framework of a set of consistent principles as set out in the paper
[note since the meeting HQIP have been awarded the new contract to continue to run NCAPOP from April 2013]

- Proposals to facilitate access for third party data intermediaries under a data sharing agreement should be tested in an early implementation phase

- Further work should consider the scope to make data from non-centrally funded national audits more accessible

- A meeting should be held with all NCAPOP audits to share the work of the group and the HSCTP recommendations
[*note:* this meeting was held on 11 December 2012]

3.3   The consensus of the meeting was that the recommendations provided a good basis for making clinical audit data more available. They struck a sensible and pragmatic balance between the sensitive issues identified by the clinical community and the benefits and opportunities presented by greater transparency. The importance of the continuing engagement of professionals was recognised. It was suggested that experience shows that many concerns can be allayed when the power and benefit of open data becomes clear, including when used by others to link with other data sources.

3.4   The ongoing development of clinical audit needed to place it as an integral part of practice, key to accountability and to the NHS developing as an organisation 'able to

learn'. A key aspect of the audit process would be feedback to NHS trusts to support service improvement. Every clinician should be able to explain what they do and how well they do it. This should be as part of a more open and supportive culture for staff. Increasingly a number of incentives and levers would require participation in relevant clinical audit:

- Financial incentives – best practice tariffs

- Clinical excellence awards

- Re-validation

- Specialised commissioning

3.5   There remained issues to be considered, reflecting variation between audits:

- maturity of audit and quality of data

- consent

The panel noted the recommendations arising from the second Caldicott review would be relevant here. It would also be helpful to ensure the ICO was aware of the further development of this work.

3.6   **The panel endorsed the recommendations set out in the paper** and asked the sub group and HQIP to take forward implementation**.** The sub group would report back on progress at a subsequent meeting in 2013.

Action

- HQIP and subgroup to take forward recommendations

- Sub group chair to update ICO on progress

- Sub group to report back on progress in future meeting [expected to be 2nd meeting in 2013 – date tbc]

4   Review of potential to use data from the Spine (HSCTP/12/5/2)

4.1   The DH open data strategy included a commitment to examine the potential to make more effective use of the transactional data that passes through the NHS information Spine, both to support more efficient and effective care, and to provide more open data. The DH informatics directorate (DHID) had set up a group to undertake the review, and to report.

4.2   There had been earlier piecemeal work to look at the scope to intercept and capture data flowing through the Spine which had, for example, shown its value in identifying variation in practice. The review had highlighted the potential value of a more systematic approach, noting that while not always achieving total coverage, in many areas the data accounted for a very significant (and growing) proportion of NHS activity. The review had identified three main areas as having the greatest potential

for development in the short term (see table below summarising potential benefits):

- Electronic prescription service (EPS) - 75% of national data

- Referrals (choose and book) – 50% of national data

- Pathology results for test requested by GP practices (transmitted by the Data Transfer Service (DTS)) – all primary care pathology results

BENEFIT AREAS	Pathology	Prescribing & Dispensing	Choose & Book
Citizens hold Government to account	M – compliance with NICE or other guidelines	M – extent of equitable provision of drugs across England	M – achievement of waiting and other targets
Inform choice of public services	N/A	N/A	H – visibility of greatest choice, shortest waits, etc
Increase public service productivity	H - identify variances and inconsistencies in pathology services and GP service usage	H – identify variances and inconsistencies in prescribing	H – availability and utilisation of slots; incentives to improve performance
Improve public service outcomes	H – support analysis of care pathways; compliance with NICE or other guidelines; inform interventions and adjustments to service provision patterns	M - identify non-adherence of prescribers to guidelines, e.g. use of brands, or strengths or dosages	M - better resource allocation, incentives to improve performance
Support social growth	L – linking pathology data to other data relevant to health and social	H – visibility of 'postcode prescribing'	M – visibility of variable/inequitable provision
Support economic growth	M – support modernisation of pathology services	H – significant interest already exists in prescribing data, and Life Sciences are keen to have identifiable data available in anonymised linked form	L – identify areas of service shortfall for new entrants to provide

4.3   There was general agreement that this data had great value and should be used more effectively to support improvements in care. It was acknowledged that there were issues that would need to be addressed, in particular to engage the public and support informed citizen access to data:

- Information governance, patient consent (explicit and implied) and data protection – including any implications of the outcome of the second Caldicott review

- Public understanding of how the data will be used, for example:
  - for direct care,
  - for quality improvement,
  - for service planning,
  - for research; and,

- Public understanding of the different 'formats' the data might be used in:
  - anonymisation, pseudonymisation and the risks of jigsaw (mosaic) identification;
  - uses of identifiable data and the circumstances when it might be necessary to be able to re-identify data (for example adverse incidents, faulty devices or implants);
  - the importance of patient/event level data (not necessarily identifiable) to understand the impact of different interventions along a patient pathway

4.4   The panel supported maximising the use of Spine data. It was noted that the contracts for a number of the systems that form the Spine will be renewed in the next two to three years. This may mean for some areas it is more cost effective to wait for contract renewal to build in to future system specifications the facility to capture and store data flows. It was also noted that the NHS CB were now developing their plans for the collection and use of data, including a commitment to provide world class data for use by the NHS and the public with the development of the care.data programme. Decisions about funding and prioritisation of this work would need to be taken by the NHSCB and DH in consultation with other parts of the health and care system. The findings of the review would be shared with NHSCB colleagues to consider as part of that process.

Action

- Secretariat to ensure results of review made available to NHSCB colleagues working on care.data programme

4.5   During discussion it was also noted that there would be significant information issues associated with the transfer of responsibility of local delivery of public health to local government with 152 local authority organisations taking on new responsibilities. Need to consider the risk that there will be multiple and incompatible solutions and to ensure developments are underpinned by national standards of interoperability and

data definition. This would be a useful agenda item for a future meeting.

Action

- Secretariat to arrange future agenda item on PH information needs and local government - to be picked up in the second half of 2013

5   Update on current commitments and suggestions from the panel (HSCTP/12/5/3)

5.1   Secretariat provided a short update on delivery of open data commitments and progress on other issues to support transparency agenda that have been identified by panel members in earlier meetings:

- There is now a government wide facility to ask for data to be made available through data.gov - <u>Suggest a dataset | data.gov.uk</u>

- More choose and book data is now available for public use - <u>Choose and Book reports —</u>

- Children and Maternity datasets – it will be mandatory to collect data in the Maternity and Children's dataset from April 2013 for those organisations that have electronic systems. It is expected that the first reports based on this data will become available in April 2014. Intend to have an update on progress in developing the collection on the agenda Autumn 2013.

- Research data – it is not currently possible to provide more detailed NIHR clinical research data on adopted industry studies as there are not the IT systems in place to support collection.

- SHAPE (Strategic Health Asset Planning and Evaluation) tool – currently covered by an MOU that limits who may access and use the data

5.2   The other key area that had previously been raised was access to ONS births and deaths data so that it can be linked to other health data. The value and utility of this data is recognised but access is governed by the provisions in the Statistics and Registrations Act 2007. Legal interpretations of what the Act allows vary and further work will be undertaken with Cabinet Office (sponsor department for ONS and the applicable legislation) and other colleagues with a view to reporting back at the next panel meeting.

Action

- Secretariat to follow up on ONS issues and report back to next HSCTP meeting

6   Transparency and Social Care (HSCTP/12/5/4)

6.1 An update on developments in adult social care relevant to the transparency agenda highlighted the key differences between the largely nationally set agenda in the NHS and the more local and plural nature of social care. 152 local authorities may take different approaches and there is a very significant role for voluntary organisations and the private sector in both public and private funded service provision.

6.2 There is considerable experience and expertise in the areas of information, advice and advocacy and increasing empowerment of clients through the use of personal budgets for eligible individuals. The current zero based review (ZBR) is reviewing data collections to ensure national data collections are useful and meet future information needs. LAs were encouraged to produce published 'local accounts' and most now did this. Quality and scope was variable but the best areas actively engaged with users to develop the information that would be published.

6.3 A lack of consistency in presentation of information between LAs, and the regulator's move away from star ratings for providers, has meant that it is difficult for the public to use information to compare providers. The White Paper and recently published draft bill emphasised the importance of information and transparency. The key challenge will be how information can help drive better integration of health and social care, particularly in the context of significantly constrained resources. Individuals want a seamless service that meets their health and care needs. For benchmarking and comparative purposes there would also be a need to integrate the national and local pictures.

6.4 Future developments might drive a 'micro industry' providing technical user interfaces eg catalogues of care, user experience, ways to pay for care on-line, encouraging local small businesses to provide services. The panel highlighted a number of important areas where further work was needed:

- Information to allow users to compare providers and services – need a minimum common dataset covering key indicators based on outcomes not activity. With the proposals to close the Audit Commission this source of data would be gone but in certain areas VOs were producing reports that could challenge and support LA accountability eg Mencap and Age UK

- Capturing user feedback and experience - although generally better developed than in NHS this was a critical area as so much service provision is outsourced making evaluation and comparison more challenging. There are national user (annual) and carer (bi-annual) surveys which are useful at a more local level.

6.5 The panel would revisit this topic at a future meeting

7   **AOB**

Some members suggested the panel should have a twitter account.

Action

- Secretariat to investigate establishing HSCTP twitter account

Note changed date and time for next meeting:

Tuesday, 22 January 2013, 10.00 – 12.00

	SUMMARY OF ACTION POINTS	ACTION BY
1	update and publish minutes 18 June meeting [minutes now available at Health and Social Care Transparency Panel meeting: June 2012	Transparency]	Secretariat
2	HQIP and subgroup to take forward clinical audit recommendations	HQIP Clinical Audit sub group
3	update ICO on progress on transparency in clinical audit	Chair Clinical Audit sub group
4	Report back on progress in future meeting [expected to be 2nd meeting in 2013 – date tbc]	Clinical Audit sub group
5	Ensure report of review to evaluate to make more effective use of NHS spine data made available to NHSCB colleagues working on care.data programme	Secretariat
6	Follow up on ONS issues and report back to next HSCTP meeting	Secretariat
7	investigate establishing HSCTP twitter account	Secretariat