HEALTH AND SOCIAL CARE TRANSPARENCY PANEL
CLINICAL AUDIT SUB-GROUP

NOTE of meeting held at Department of Health, Wellington House
133-155 Waterloo Road, London, SE1 8UG

Thursday, 12 July 2012

PRESENT		
Mark Davies (Chair) (MD)	Giles Wilmore (GW)	Robin Burgess (RB)
Jane Ingham (JI)	Paul Robinson (PR)	James Roxburgh (JR)
Roger Taylor (RT)	Michael Chapman (MC)	
(by phone)	Mick Peake (MP)	Julie Henderson (JH)
APOLOGIES		
Peter Stephens	Gill Lawrence	Simon Bennett
SECRETARIAT		
Karen Noakes (KN)	Diana Paine (DP)	

1 Context and background, benefits of open data

1.1 MD and GW set out the background and context for the commitment to make clinical audit data more widely available, covering the wider cross Government transparency and open data agenda and the specific commitments set out in the DH information strategy, The power of information, and earlier transparency commitments. GW emphasised the importance of more open data to drive improvements in care through better information for both patients and clinicians, and the scope to add value to data to make it more useful.

1.2 The aim of the sub group was to provide advice to the HSCTP on how best to implement the commitment in a way that balances appropriately the potential benefits of more open and granular data with the risks of, for example, misuse or misinterpretation. It was noted that the audit community supports more open data but that it was concerned that the risks should be properly recognised and taken into account in deciding how to meet the commitment.

2 Risks, issues and challenges

2.1 Phase II of the programme to make clinical audit data available for use by outside groups and individuals aims to release more granular data – both at

a more detailed level and in a more raw (less analysed) form.

2.2 This raised concerns about a number of risks and other issues:

- Re-use and analysis of data by third parties – concerns about potential for poor quality of analysis and interpretation based on an inadequate understanding (eg of casemix, confidence intervals) leading to misinterpretation, over simplification and accidental or deliberate misrepresentation
- Setting the level of granularity and understanding what is the lowest (most granular) level of data that is appropriate. This will vary between audits.
- Clarity about what is meant by 'raw' data – the term is used to mean different things. Completely 'raw' data, i.e. unanalysed, not risk adjusted, would not be appropriate for release
- More granular data might identify individual clinicians and it would be important to ensure clinicians were aware of this
- Poor quality interpretation can provide misleading information for the public and patients, causing unnecessary anxiety, undermining confidence in clinicians and failing to provide the right information to empower patients to hold services to account and to make informed choices
- Importance of opportunity to validate and check data with clinicians before publication (both to ensure data is robust and to retain clinicians' confidence in the process)
- Loss of clinicians' confidence in process may lead to reduced engagement which will undermine value and power of audits, including future development of more detailed audit and audit in new clinical areas – goodwill of clinical community is critical to success and has driven huge quality improvement as a result of clinical audit in recent years
- Importance for clinicians that they get something in return for participation – eg opportunity to publish papers based on data

2.3 Other considerations included:

- the governance arrangements in place,
- whether for complex datasets there are multiple data controllers, and
- any requirements for s251 approvals for use of personal data.

2.4 It was also noted that the availability of more data might also lead to more complex FOI requests.

2.5 Overall the potential benefits of greater transparency were recognised by audit suppliers and the clinical community but their remained significant concerns about the risks. **The key role of the group was to develop a way of effectively delivering the transparency commitments for clinical audit data while taking into account these issues.**

3 Possible solutions

3.1 Some key principles were suggested:

- Data release should be underpinned by robust, widely understood rules about use
- Data control and decisions about data release should sit clearly outside the bodies that supply data so demonstrably independent and objective eg resting with DH or HQIP
- Data should not be released before clinicians have had an opportunity to check it
- We should define what is sufficient quality for purposes of data release
- Given sensitivities about data and its use open release may only be appropriate at present at a less granular level. **We need to consider the appropriate use of data sharing agreements that allow organisations and individuals to use more granular data within clearly defined parameters covering analytical methodology and purpose**

3.2 Other elements that would reassure the clinical community would be a period of protected time for them to use data before it was more widely available. It was noted that audit suppliers lack the resource to make more use of the data they collect and it would be helpful if more support was available to enable them to do more with the data, both for their own use, and for release for use by others.

3.3 For information intermediaries there were significant limitations in what could be done with the type of data currently available:

- Insufficient detail to allow more complex analysis of real interest and utility
- Frequency - the annual snapshot offered by many audits is not very useful – more frequent data would be of more interest. It was noted however that some audits are making more frequent data available eg stroke audit.

3.4 The options that might be considered to deliver the commitment to deliver more open clinical audit data were:

- **Development of core principles to govern the criteria that should apply to decisions to give controlled access to data**
- **Release of more granular data within a data sharing framework**. Options could include:
  - data sharing agreements that set out criteria for how data could be used and for what purpose – this might apply to any body wishing to use the data (ie this dataset can be used by any body under the following T&Cs) or be on a case by case basis (where individual agreements for use are set, potentially with differing T&Cs)
  - 'licensing' or accreditation of a body ie recognising it as a reputable and responsible body, using appropriate analytical approaches and

using data for appropriate purposes – which would then have relatively more freedom to use datasets rather than needing to apply for each use

- An agreement that the commercial, third sector or other external body should share the analysis with the audit supplier before publication and that any publication would be subject to approval by the professional body. Exploring the potential offered by collaboration between audit suppliers and commercial or other external bodies.
- The possibility of some 'protected' time for the clinical community to use the data before wider release – eg 3-6 months

3.5 Any proposals needed to take account of legal and information governance requirements.

4 Next steps and work plan

4.1 The concerns and sensitivities in clinical audit were recognised by the whole group. It was important to develop a programme that would retain the confidence of the clinical community while supporting and driving forward greater transparency to benefit patients and the public and drive service improvement.

4.2 It was agreed that we needed to develop some principles and criteria to support the future release of clinical audit data. It was suggested we take a small number of real life examples of data and its use by third parties to help develop these principles and to identify any practical challenges or barriers, taking up RT & PR's offers to work with the audit community. Work should be progressed over the summer to identify potential principles and criteria and to work with some of the audits to develop them.

4.3 It would also be helpful to bring all leads of NCAPOP audits together for a workshop to work through issues with the sub group.

4.4 Two further meetings of the sub group should be set for September and October to enable a report back to the Health and Social Care Transparency Panel meeting on 17 October.

5 AOB

5.1 None.

Note date and time of further meetings:

Wednesday 12 September 2.00-4.00 pm
Thursday 4 October 2,00-4.00 pm
(may be subject to change)