

Royal College of Psychiatrists

Consultation Response



DATE: 20 October 2011

RESPONSE OF: THE ROYAL COLLEGE OF PSYCHIATRISTS

RESPONSE TO: Making open data real: A Public Consultation

The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and is the professional and educational organisation for doctors specialising in psychiatry.

We are pleased to respond to this consultation. This consultation was prepared by the Special Committee for Professional Practice and Ethics, the Academic faculty and the College lead for Informatics, Dr Jonathan Richardson.

This consultation was approved by: Dr Ola Junaid-Associate Registrar

Making Open Data Real

The Royal College of Psychiatrists welcomes the opportunity to respond to this consultation document.

It is made very clear in this document that nothing in this proposal *undermines privacy of personal data holdings* i.e as currently managed under DPA provisions. The underlying argument in favour of sharing data is one that the College should support provided personal data is protected and individuals cannot be identified (and that is what the document itself says) although there might be occasions when this is difficult eg in very specialist areas.

Mental health services have an important role protecting personal information from prying eyes of varying sorts and stigmatic loss of identity: so we are reassured by the assertion (at 6.13) that *the proposals do not apply to personal data*, and the reference to the benefits of the model of the Caldicott guardian (8.12) with the suggestion that this model could be applied elsewhere

There are two areas we wish to highlight:

1. There is the issue of health services research and the use of anonymised data for such work. They make a good case for the benefits to health care services of access to anonymous information; and as a medical college, we support better and richer quality research: which means challenging the absurd restrictions that exist. This is an opportunity to join with other medical colleges perhaps to push for this. There are some associated problems with research into small services where service users are identifiable (forensic, eating disorders etc) where anonymisation may not be sufficient protection: but this would presumably be under the control of a research Caldicott guardian; not the Data Protection Act. Publishing numbers of cases of rare conditions in each area together with clinicians involved in care could provide

comprehensive patient registries with the potential to transform health research particularly for rarer conditions but may risk making individual service users identifiable.

2. The proposals also suggest that service users can make good use of information to connect and support each other; and also provide information that is of help to service providers. A service user/carer group member should be asked to comment on ways in which more open access to data about services would help them; or what they could do with more open access. This would be an opportunity to involve service users more in mental health: but they might know best what would work. There are obvious limitations: but again, nothing proposed here underlines the usual controls on personal data.

Specific points

i) Confidentiality

1) In considering patient data (process and outcome), datasets must be sufficiently large to preserve anonymity - as must each data subset.

2) There must be scrutiny by an "expert panel" or equivalent for each set of published data to ensure that 1) is assured. Although the Board should be involved in this process (and veto publication if necessary), if data from different organisations is going to be equivalent (as it must if the data is going to be useful), there must also be standards set centrally for publication.

3) It would be a mistake to make the same person in an organisation ensuring "right to data" and "protecting privacy" as this sets up a tension that could give rise to a conflict of interest and lack of proper scrutiny.

4) IT systems that contain patient identifiable data must have robust safeguards for protecting this information. This has been described within the Care Record Guarantee (2007).

5) Systems must have sufficient data protection to ensure that only patients who wish to view can access their records and nobody else.

ii) Utility

6) In psychiatry, what data would be meaningful in comparing services and organisations? Patient throughput? Patient process? Patient outcome ? (improvement [how defined]? - or recovery? - or suicide? - or other risk-laden behaviour?). Would this be possible given the disparity between Trusts and the populations they serve?

(Note the College document entitled Outcome measures recommended for use in adult psychiatry is relevant to these discussions see <http://www.rcpsych.ac.uk/publications/collegereports/op/op78.aspx>.)

7) A perceived negative outcome for a service or organisation may put them out of business to the detriment of the community they serve, rather than driving up standards of care - a combination of negative data, adverse media reporting and patients not attending (as a consequence) could result in withdrawal of commissioning.

iii) Research

8) Regarding research, box on p31 "urge to share data by medical researchers". It is not clear in this document whether the data referred to will include datasets held by universities since they are publically funded bodies and/or from research that is publically funded? Such organisations eg Research Councils have clear guidance on data-sharing. Pooling of data within and between organisations and access to public funded datasets already occurs and

is encouraged. There does have to be control and this currently resides with the host institution and a review panel; these processes seem to function well. Any change in process must not unduly add further burdens on researchers.

9) Throughout the document, benefits are alluded to but there is no description about how these will be evaluated. There needs to be an identified NEED for the data to justify the extra costs of making it available. Has the case been made convincingly? Generally this is not cost neutral and would require further tiers of administration. Can we afford this at present?

10) In addition to the protection of individuals, there may also be a need to protect professional reputations and services, if data is not used in appropriate ways with rigorous scientific methods, and objective, self critical evaluation. Safeguards are needed in order that data is used responsibly and to avoid a possible free for all by pressure groups or journalists. All data is open to interpretation and mis-interpretation - its access needs to depend on its potential use- hence safeguards on access are needed and limits on its use may need to be considered by responsible bodies.

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