



Making Open Data Real HMG consultation - August 2011

Response to consultation

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The following is the response from the UK Council of Health Informatics Professions (www.ukchip.org.uk), specifically where the aspects identified can apply to the health and social care space, and in the light of similar criteria in the sphere of the Government IT and its related informatics professions.

The comments are made following the structure of the report. Thereafter, additional responses are summarised under the headings provided by the consultation, and are referred to by 'Our Ref(OR)' where appropriate.

Our Ref (OR) /pageNo of relevant questions	Quoted section	UKCHIP comment
1 / other	Ministerial Foreword - Our proposed approach is, fundamentally, about creating both „pull“ (a right to data) and „push“ (a presumption of publication). With these forces, we will begin to embed openness and transparency in how we run government.	Where data relates to a sparse population it runs the risk of inadvertent identification of individuals. Where data may be presented under the 'push' principle, it should be possible for a data subject or a professional information handler to raise concerns re the above.
2 / other	Ministerial Foreword - my intention that no personal data will be shared with any third party as part of this initiative. We will consider this issue in further detail, in particular the use of anonymisation and pseudonymisation techniques to protect personal data.	.
3 / Page 25	4.2 For the public sector, Transparency and Open Data are about helping people find the right doctor for their needs, or the best teacher for their child, or	The significance of the examples, underpins the necessity that the

	helping a victim of crime track whether justice is done. It is about helping frontline professionals compare outcomes and improve them. It is about giving people access to their individual medical records so that they can manage their health better and make more informed decisions with their clinician.	professionals processing, preparing and presenting the data are properly registered as fit to practice and are supported by a professional code of conduct .
4 / Page 25	4.9 available for re-use under the Open Government Licence, except in very specific circumstances. There will continue to be exceptions, for example for personal data, data that through release might compromise national security or Ministerial decision-making. When considering whether or not to charge for data, a transparent business case [will be necessary]	Taken with recent decision <i>'Ministers force switch to private sector for patient risk prediction tools ... Ministers have controversially pulled funding from tools designed to help GPs and NHS managers prevent patients with long-term conditions from being admitted to hospital – forcing commissioners to buy in tools supplied by private providers (Pulse, 15.08.2011)</i> and the ability of Ministers to designate requirements for 'decision making', this area gives cause for concern..
5 / page 25	<p>5.1 Greater transparency of government potentially offers a transformative effect on UK public services, civil society and the economy. From enabling more effective accountability to driving social and economic growth, significant benefits could be realised through three main types of Open Data:</p> <p>1. Large, non-personal datasets collected routinely by public services e.g. Hospital Episode Statistics (HES) on NHS admissions and outpatient appointments in England;</p> <p>2. Right of individuals to access and control their own service user records e.g. a school or personal health record¹⁰;</p> <p>3. User feedback on services e.g. comments and suggestions from users of health, personal or social care services such as iwantgreatcare.org or bestcarehome.co.uk.</p>	<p>The report goes on to say 'BUT' <i>'the second category of data described above raises different issues, and is not considered further in depth.'</i> - which is inconsistent with, and does again highlight the concern also raised in point 4. above.</p> <p>Those registered professionals with comprehensive codes of conduct will have more power to reject instructions to take action that could touch on the concerns here and in point 4.</p>
6 / Page 25	<p>6.4 Despite this array of legislation and guidance, potential requesters and re-users of data face a range of barriers to accessing, using and re-using data that could generate economic or social value:</p> <p>a. Cost barriers resulting from historic ICT procurement and data management – information is held within government in a way that makes it costly to release, so requesters are refused on the grounds</p>	This section does not significantly address the ethical and subject consent issues which legitimately should be considered in 're-use of data'; and by which [registered] professionals should be able to refuse to carry out inappropriate data

	<p>of cost.</p> <p>b. Contracts agreed without consideration of Open Data principles – situations where public bodies have not considered in advance how data gathered might be made open.</p> <p>c. Formats, quality or timeliness – often it will turn out that data is collected, but the manner in which it is held makes it difficult to use and re-use.</p>	<p>handling requests; even in the face of a strong business case.</p>
7 / page 25	<p>13 See http://www.nationalarchives.gov.uk/information-management/ifts/cost-pricing.htm</p> <p>14 http://www.hm-treasury.gov.uk/psr_mpm_index.htm</p> <p>6.13 With the exception of allowing individuals access to their own personal records, at no point in this document does the data we describe refer to personal data. Transparency will not be extended at the cost of privacy. Releasing greater quantities of anonymised data brings with it complex questions about how we can ensure that personal data remains protected. We will consider how we will, practically, ensure that personal data is anonymised, particularly when they are released alongside many other datasets, which have the potential to be merged.</p>	<p>This section and the referenced sources fail to address the necessary requirement for professionals handling such information to act as professionals, respecting what is appropriate to do / not do with the data in question and rejecting instructions to handle such data in inappropriate ways.</p> <p>Professional registration through a voluntary body, such as UKCHIP, could give the individual significant support and guidance in these actions.</p>
8 / page 25	<p>7.2 Evidence suggests that choice matters to citizens, particularly around how users engage with public services.¹⁵ While many of the public do not associate choice with an ability to drive up quality standards, the evidence shows that – where it exists – choice can be an effective mechanism for improving standards.¹⁶ The Open Public Services White Paper sets out a vision for putting people in control, either through direct payments, personal budgets, entitlements or choice. Providing comparative information enables offering meaningful choice to become a reality in public services. Equipped with an understanding of variation in service quality, we can make more informed choices about which services are most appropriate to us or our family members. At present, it is not easy to compare the quality of public services.</p>	<p>Context is necessary when ‘providing comparative information’; but care must be taken to avoid conflating data which in itself is anonymised but collectively may give a clear pointer to the identity of a subject (especially in the health space – those with rare clinical conditions who live in sparse population areas may be so identified).</p> <p>Effort must be input to frame and explain extracted data that may be derived or deduced, seeing it does not become identifiable, and that decisions made by its use are well-informed.</p>
9 / Page	7.4 At present, Public sector bodies are not easily	As with point 8, it requires

25	able to benchmark their costs and the quality of their services against their peers and may have falsely high – or low – understandings of their performance	professional data handling in order to ensure that like-elements are being compared consistently and that sufficient context is made available for satisfactory comparison.
10 / Page 25	7.5 Benchmarking data on comparative costs and quality of services helps to drive up quality of outputs and outcomes, especially when peer-based competition is sharpened by public scrutiny. Additionally, the publication of meaningful data can improve user engagement and even input. For example, access to personal health records could encourage some to take a more proactive approach to their own health, while access to records can enable parents and students to engage more closely with the education process.	This section is at odds with the commitment made in points 2-4 above. Each case for use of person-identifiable data requires informed consent and cannot rest on a business case alone. Professionals who have been registered and adhere to a relevant Code of Conduct are best placed to stand against any inappropriate requests for data use, manipulation or presentation
11 / Page 25	7.8 Finally, Open Data can be a driver of economic growth. A new market for public service information will thrive if data is freely available in a standardised format for use and re-use, particularly in the life sciences; population data mining and risk profiling; consumer technologies; and media sectors. At present the market for information on public services is highly underdeveloped. Open Data across government and public services would allow a market in comparative analytics, information presentation and service improvement to flourish.	The business driver expressed here is only valid in conjunction with ethical and professional criteria as above.
12 / Page 25	8.2 3. Corporate and personal responsibility: how would public service providers be held to account for delivering Open Data through a clear governance and leadership framework at political, organisational and individual level?	All staff in the 'public service providers' who process the data should be registered as professionals, whether working in the public sector, academia or any infomediary organisations.
13 / Page 25	8.7 This ultimately means authoring data in tools that are 'online by default'. It is only once it is easier to publish data on the internet than it is to store it in local files, or on paper, that the public sector can be expected to adopt a more open model.	If data is held 'on the Internet' or in a third party location it should be held securely (physically, technically and the like) and processed by professionals, to minimise the risk of anonymised data becoming de-anonymised by association or combination/deduction.

14 / Page 25	8.11 following - 3. Should we consider a scheme for accreditation of information intermediaries, and if so how might that best work?	All staff in 'information intermediaries' who process the data should be registered as professionals, whether working in the public sector, academia or any infomediary organisations; and their professions should hold registers assured by the Council for Health Regulatory Excellence/Professional Standards Authority or equivalent .
15 / Page 31-2	8.15 A failure to use datasets intelligently in the provision of public services can mean that we do not have a full understanding of the quality of customer experience, for example an understanding of the patient pathway from GP through hospital to outpatient. At the same time, high volumes of FoIA queries to central and local government ²⁷ require high levels of administrative resource. If more data is made proactively available, administrative burdens involved in answering requests may be reduced.	In order to minimise the situation described in 8.15, all the information handlers should be professionally registered and should be required to demonstrate their ongoing capability through continuing personal / professional development
16 / other	http://data.gov.uk/wiki/Public_Data_Principles	This Appendix 2 to the report does not address the crucial aspect of the professionalism and good conduct of the information handlers, which can be best served by a mechanism for registration, certification to rigorous standards and ongoing monitoring for Continuing Personal Development purposes to retain 'fitness to practice'.

Questions Report P6

1. Do the definitions of the key terms go far enough or too far?
Our Ref (OR) 1 and OR2 refer.
2. Where a decision is being taken about whether to make a dataset open, what tests should be applied?
OR1 and OR2 refer.
3. If the costs to publish or release data are not judged to represent value for money, to what extent should the requestor be required to pay for public services data, and under what circumstances?

OR4 refers

4. How do we get the right balance in relation to the range of organisations (providers of public services) our policy proposals apply to? What threshold would be appropriate to determine the range of public services in scope and what key criteria should inform this?

OR3 refers

5. What would be appropriate mechanisms to encourage or ensure publication of data by public service providers?

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Questions Report P25.

OR3-I3 refer

1. How would we establish a stronger presumption in favour of publication than that which currently exists?
Adherence to data anonymity, transparency as to source, possible use and explicit Data Protection compliance
2. Is providing an independent body, such as the Information Commissioner, with enhanced powers and scope the most effective option for safeguarding a right to access and a right to data?
...and to ensure an obligation to privacy / data protection / security issues
3. Are existing safeguards to protect personal data and privacy measures adequate to regulate the Open Data agenda?
OR3 and OR5 refer.
The potential to conflate datasets require more safeguards and monitoring to be in place.
4. What might the resource implications of an enhanced right to data be for those bodies within its scope? How do we ensure that any additional burden is proportionate to this aim?
Organisations and individuals handling data originating in and used by such organisations have obligations to ensure that such data is not mis-handled or transferred into any environment where mis-handling or contravention of (inter)national privacy legislation may occur. Such organisations should be given power to refuse to condone or take part in inappropriate information handling; and all individuals working in those organisations should be subject to professional Codes of Conduct that support them in rejecting inappropriate use or use that may result in inappropriate information outputs from that use.
5. How will we ensure that Open Data standards are embedded in new ICT contracts?
All information handling contracts should require organisations to comply with legislation, and to ensure / encourage their information handlers to be registered professionals.

Questions Report P28

OR 14 refers.

1. What is the best way to achieve compliance on high and common standards to allow usability and interoperability?
Open and transparent data definition sets should be available.

Professional information handlers should be professionally registered and maintain their competences by ongoing continuing professional development(CPD) and adherence to their professional code of conduct.

Organisations should make available an inventory of the uses they are making of public data; a declaration along the lines of current Data Protection requirements.

2. Is there a role for government to establish consistent standards for collecting user experience across public services?

The effort required to establish consistent standards would be futile. Such effort should be used to gain maximum value from sectoral convergence, there should be efforts made to (at least) have interoperable standards declared, to facilitate legitimate information sharing subject to legislation, professional and policy guidance.

3. Should we consider a scheme for accreditation of information intermediaries, and if so how might that best work?

Infomediaries should be subject to the same criteria as public sector organisations. For example in the health space the Council for Health Regulatory Excellence / Professional Standards Authority is extending its remit to 'set standards for and quality assure voluntary registers' in addition to scrutiny and overseeing of the nine (health) statutory bodies. The registration bodies being assured cover all practitioners, regardless of employer (public or private).

Questions Report Page P30

1. How would we ensure that public service providers in their day to day decision-making honour a commitment to Open Data, while respecting privacy and security considerations.
One element that may contribute is the requirement for all public service providers' professional staff to be encouraged or required to adhere to a Code of Conduct and the principles of a profession, demonstrated by formal individual registration and ongoing CPD.

2. What could personal responsibility at Board-level do to ensure the right to data is being met include? Should the same person be responsible for ensuring that personal data is properly protected and that privacy issues are met?

Adherence to professional standards by all involved in information handling and the oversight of such processes, and an understanding of the relevant principles of sensitive information management, as practiced in the health space by Caldicott Guardians.

3. Would we need to have a sanctions framework to enforce a right to data?

We feel that this should be a wider responsibility, to both manage rights to data and to manage the converse, a capacity to refuse to share data where it would be inappropriate so to do. The emerging role of the CHRE/PSA could be invoked to ensure assured registration bodies operated under an appropriate sanctions framework.

4. What other sectors would benefit from having a dedicated Sector Transparency Board?

This question appears to imply a fait accompli. As information providers in various sectors converge, this concept should be reviewed on a wider level rather than specific to each sector.

Questions Report Page 31-32

OR 15 refers.

1. How should public services make use of data inventories? What is the optimal way to develop and operate this?
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2. How should data be prioritised for inclusion in an inventory? How is value to be established?
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3. In what areas would you expect government to collect and publish data routinely?
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4. What data is collected „unnecessarily“ ? How should these datasets be identified? Should collection be stopped?
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5. Should the data that government releases always be of high quality? How do we define quality? To what extent should public service providers „polish“ the data they publish, if at all?
Data should be processed professionally, most likely at or as near source as feasible and fit for purpose (typically complete, consistent, correct, and contemporaneous with enough context to ensure interpretation can be replicable and appropriate). Any data manipulation or deduction applied should be declared and any data re-versioning should be consistently and continually applied.

Questions Report page P33-34

1. How should government approach the release of existing data for policy and research purposes: should this be held in a central portal or held on departmental portals?

Data should be held as near to the source as practicable.
2. What factors should inform prioritisation of datasets for publication, at national, local or sector level?
Publication priorities should be informed by demand, ethical usage, public good and after a published risk assessment has been carried out.
3. Which is more important: for government to prioritise publishing a broader set of data, or existing data at a more detailed level?
It is not possible to give a generic answer to this question