

27 October 2011

Dear Sir or Madam

Making Open Data Real: A Public Consultation

The Patients Association (PA) was founded in 1963. We are an independent national charity operating in the UK, which highlights the concerns and needs of patients. Through our Helpline, correspondence and research we learn from patients the key issues that are of concern and campaign to improve the healthcare we all receive. Our work includes:-

- Campaigns to support Patients' Rights
- Lobbying Government to address healthcare issues affecting patients
- Speaking out for patients and carers
- Providing information and support to help patients

Information is essential to allow patients to make effective choices about their care and to effectively scrutinise the operation of the bodies which are treating them. With the move to greater decentralisation of healthcare, the question of what a public body is becoming more pressing. The definition of a public body need to be based not only on their statutorily prescribed function but also on the tasks a body undertakes. Creating a more open and transparent system will help ensure these bodies are properly scrutinised, but the operation of information legislation, in particular the Freedom of Information Act needs to be better defined. We also have concerns about patient confidentiality with an information sharing context and the effect the cost of information collection may have on health services.

We hope that you will find our specific comments below informative and helpful. I would be more than happy to answer any questions you may have with regard to our response.

Regards

Yours faithfully,

Dr Caroline Hacker,
Director of Policy and Campaigns
Patients Association.

Public Bodies

- We appreciate the effort to better define what is meant by a “public body”. The scope of the term has caused significant confusion previously meaning that bodies that prima facie are undertaking a public function are not in fact covered by the relevant information legislation.
- The Patients Association have come across several examples of bodies which are carrying out public services have been able to avoid providing information. In particular, we know that Local Involvement Networks (LiNs) are immune from the Freedom of Information Act (FoIA).
- The Devon and Cornwall Patients Forum tried to access information about the operation of their LiNs but were informed that because it was volunteer led it was not possible to ask them to provide information under the FoIA. This is despite the fact LiNs provide an important public function.
- Patient experience of LiNs has been extremely patchy and a survey conducted by the Patients Association in March 2011 found that patients have been generally unsatisfied by the performance of LiNs.
- Ensuring that bodies like LiNs are able to be effectively scrutinised by the public may result in an improvement in their performance. HealthWatch, which is due to replace LiNs and bodies like must have the resources to be able to properly respond to request for information about their operation.
- In addition, as public bodies increasingly outsource their functions to private bodies, this is hampering the public’s ability to access information on their operation and properly scrutinise them.
- For example, the Patients Association has made a request under the FoIA for information which included staffing levels. Several Primary Care Trusts (PCTs) responded saying that because staffing was outsourced to an outside company, they did not have access to this information. However, the majority of PCTs were able to provide this information despite their human resources system being organised in a similar way.
- With the move to Any Qualified Provider, we are concerned that this problem may become more widespread as services commissioned by GP led consortia are provided by private companies or social enterprises and how they relate to the “public body”.
- There needs to be a much clearer definition of what is meant by a “public body” which includes not only statutory bodies but also any body providing a public service. It must also go further and include bodies which have been commissioned by a public body to undertake functions that are the responsibility of the public body to secure.
- It is also important that guidelines on what a “public body” is are consistently followed.

- On several occasions, after sending a request under the FoIA, bodies such as PCTS have told us that they cannot provide us with the requested information because it would cost too much to gather the data. However, within the same request other bodies have been able to provide the requested information.
- There is no obvious accountability for denying access to information on the basis of cost and indeed, we are concerned by the general inconsistency in responses. Who can organisations appeal to if the body they are requesting information from deny them access to the information?
- There need to be clear guidelines on maximum costs for accessing information and an effective accountability process to ensure that public bodies are not using cost as an excuse to avoid publication of information.

Access to personal records

- One of the most common reasons patients contact the Patients Association is to find out how they can access their own medical records.
- Under the Data Protection Act 1998, patients have the legal right to access their medical records.
- Aside from patient awareness about this right to access, many patients phoning our Helpline have told us that they have faced obstacles when accessing their records which have included being told that a fee was necessary, redacting of records and denial of access altogether in some cases.
- Each individual's ability to access his or her own medical records are as important as the general public's ability to access information on the performance of public bodies. Both types of information inform patient choice.
- Individual rights to access to personal information need to be considered as part of the open data agenda.
- We note the omission of the Access to Medical Records Act 1989 (which covers access to records of deceased relatives) within the scope of this consultation and believe that it should be included with the open data agenda.

Presumption in favour of publication and Patient Choice

- There needs to be a strong presumption in favour of publication. Meaningful information is essential for patients to be able to make effective choices about their care. Embedding the need for openness and transparency into the operation of health services will make it easier for patients to access the information they need.

- Patients are important users of health information and relevant information must be in a format so that patients can make an informed choice of providers and also to understand the basic level of care they should expect.
- For patients in particular when they are making choices about their care, they are interested in the number of complaints a hospital has received and how they have been handled.
- Presently, the only national measure of the complaints handling performance is time taken to respond to a complaint. This provides very little insight as to whether the complaint was handled effectively and what changes have been implemented by the Trust to prevent the issue from recurring.
- Furthermore, the number of complaints made to a hospital may not reflect actual standards at the hospital but may reflect signposting to the complaints system at that hospital. Trusts that appear to have few complaints may not be recording this information or may have poor signposting. Conversely, Trusts with a large number of complaints may actually be very proactive in signposting individuals to their complaints procedures and engage well with the public. They may also implement effective changes in response to complaints that lead to real improvements in patient care.
- Trusts need to publish information that is clearly available to the public as to the nature of the complaints they are receiving, the results of their investigations and most importantly the positive changes they have put in place as a result of any investigative findings.
- Many patients who contact the Patients Association are unaware of their rights to information as enshrined in the NHS Constitution. Information provision needs to go beyond simply having the information available, the existence and potential use of this information needs to be effectively publicised if it is to be effective.
- There is also an issue with regard to response rates to requests for information. The FoIA places a 20 day statutory limit period in which the answering public authority must respond or give a valid legal reason why they cannot respond.
- The Patients Association has carried out a number of requests under the FoIA to PCTs and response rates have always been very low. A request on Tissue Viability Nursing had responses from 77 out of 147 PCTs and a request on Postnatal Depression 76 responses out of 151 PCTs contacted.
- There low response rates are despite there being a legal duty to respond. It is clear that there need to be stronger sanctions for breaching legal duties to provide information from valid requests from the public and other interested stakeholders.

Patient Confidentiality and Information Sharing

- The use of up to date and often real time information on trends emerging from general patient care could inform decision making to improve patient services. However, we are concerned that under the current ongoing health reforms that shared information may affect patient confidentiality.
- We are concerned that this may damage the doctor-patient relationship because if patients are unsure whether their information is going to be used or shared, they may feel uncomfortable sharing information with their GP or other healthcare professional. This could have an impact on their care as patients may withhold information their healthcare professional needs to make an accurate diagnosis.
- In our response to the Department of Health consultation on the Information Revolution we did not speak to this issue specifically. However, we felt that there was an issue with the IT system within the NHS being unable to support the sharing of information about patients between care settings. With the move to 'any willing provider' we were concerned that records may be lost or important details not recorded due to an increase in transactions with different providers.
- That being said, we do think that the sharing of medical records between healthcare professionals can be useful, meaning that patients' medical records could follow them through the NHS pathways making it easier for clinicians to keep track of any ongoing, long term health issues. However, in this instance, the concern is that the legislation appears to suggest that the Bill gives power to a range of bodies including the NHS Information Centre to demand patient information, requiring GP led consortia to comply.
- While amendments were made to the Health and Social Care Bill to introduce safeguards to protect confidentiality and provide effective oversight of requests and "requirements" by the public bodies for information, we still have several ongoing concerns.
- It has been suggested that the NHS Information Centre, which will be handling this information could act as an "honest broker" which would improve confidence in the system. However, most patients will not have heard about the NHS Information Centre and it would be difficult for them to judge whether it is considered an honest broker. Furthermore, the NHS Information Centre's role at present is to monitor health trends and it might be that these changes are too far a move from its original purpose.
- The security and confidentiality of patient information is paramount yet there is little by way of clarity or reference to guidelines within the proposed legislation to explain how patient confidentiality will be assured where information is to be shared.
- Patients need to be asked for their consent before sensitive information about them is shared in this way and we want to see a more robust and defined system in place to ensure patient confidentiality.

Cost of data collection

- Data collection and data sharing could be a useful tool on scrutinising and improving the function of services, particularly for patients.
- However, we do have some concerns about the cost of collecting information, particularly within the NHS which is being asked to make £20 billion of efficiency savings by 2014. The obverse side of this is that concerns about costs could prevent the changes which could make a difference to patients from coming to fruition.
- There will also be a cost with staff time. Healthcare professionals should be free to care, not overly burdened by data collecting.
- These issues need to be considered and proper resources provided for bodies to effectively collect relevant information without compromising their primary duty, which in the case of health services is to provide high quality, patients centred care.