

Guidance for Patients on Safe Record Keeping

Tender Specification

24 January 2011

1 Introduction

Putting patients at the heart of everything the NHS does.

Equity and excellence: Liberating the NHS, 2010

'You have the right of access to your own health records. These will always be used to manage your treatment in your best interests.'

NHS Constitution, Jan 2009

'..the Government announced new measures as part of its Growth Review, which set a deadline for patient access to their online GP held records by the end of this Parliament. We support this commitment as a first step...'

NHS Future Forum letter to the Secretary of State for Health, Jan 2012

In our recent response to the Department of Health's 'Liberating the NHS, An Information Revolution', we concluded that to become equal partners in their health care, patients will require greater access and control over their records. This includes the ability to create and maintain their own records. We identified the need to develop clear and simple guidance on how to use shared and patient controlled records effectively and securely.

BCS Health is seeking tenders from suitably qualified organisations and individuals to develop this guidance. This work is being undertaken in collaboration with Department of Health Informatics Directorate (DHID)

2 About BCS Health

BCS Health is part of the BCS – The Chartered Institute for IT which is a registered charity. BCS Health is the umbrella group representing the many specialist member health groups in BCS. BCS Health provides leadership in this sector, acting as a source of professionally recognised expertise, under-pinning the outward-facing role of BCS, and ensuring that contributors to Health Informatics are recognised and respected.

3 About the Department of Health Informatics Directorate (DHID)

NHS Connecting for Health (NHS CfH) is now part of the DHID. NHS CfH continues to maintain and develop the NHS national IT infrastructure. This infrastructure includes a number of national services and a range of national applications.

4 Scope and Deliverables

4.1 Target Audience

This guidance is targeted towards users of any public or private health and social care organisations, including the NHS, that hold personal identifiable information on them.

4.2 Definition of Health and Social Care Records

This covers any record that contains user-identifiable information pertaining to an individual's health or social care. This information could have been created by the provider or users themselves.

The record can be in digital format either held on physical media, personal computers or accessed via secure online portals. Paper held records are deemed out of scope. Examples of records include:-

- Healthcare records in Primary Care
- Healthcare records in Secondary Care
- The Summary Care Record
- Social care records
- Condition specific records (e.g. Renalpatientview.org)
- Patient-held records (e.g. Maternity)
- Electronic Personal Health Records

4.3 Security Processes and Systems

We recognise that different organisations will employ different security solutions to prevent unauthorised access to health and social care records. Detailed and specific security guidance is not within the remit of this project.

4.4 Content

The guidance should provide comprehensive cover of all the important areas of consideration for safe record keeping. Example areas would include:-

- Granting permissions and sharing arrangements. These can include other individuals, other healthcare providers and data-mining organisations.
- Protecting against coercive access.
- Suggesting hardware and software safeguards for receiving, storing, accessing and sharing data.
- Developing safe behaviours including spotting scams.
- Detecting and acting on breaches of data security and confidentiality.

The guidance should propose a set of principles that adopt a pragmatic approach for safe record keeping. It is essential that it should be focused on the needs and envisaged requirements of the users.

4.5 Output Format

The core content of the guidance should take the form of a self-contained report.

The report must meet Crystal Mark™ standards. The cost of seeking Crystal Mark™ approval is borne by the winning bidder. We welcome the use of any additional material in any format.

The guidance must be adaptable to a variety of different formats and settings such as leaflets, radio and television broadcasts and online channels, or provided as a toolkit to software suppliers for inclusion in help guides.

4.6 Endorsement and Dissemination of the Guidance

The winning bidder is not required to seek endorsements for or disseminate the guidance. However, supporting material to allow BCS to seek endorsements should be prepared.

5 Project Management

5.1 Methodology

We expect to see evidence of a structured approach to project management such as PRINCE2 or equivalent in the tender. A project manager should be appointed to oversee operational aspects of the work. BCS will only be providing oversight through the steering committee.

We envisage that the consultation process will be iterative in nature with involvement of patients and other stakeholders at all stages of the process.

5.2 Steering Committee

The project will be governed by a steering committee comprising representatives from BCS Health, DHID, National Information Governance Board (NIGB), media organisations, patient groups and individuals with long standing interests in health informatics and in improving public involvement in healthcare.

The committee will meet at significant milestones in the project as advised by the project manager appointed by the selected contractor including:-

- 1) Detailed introductory review of the project plan.
- 2) Mid-Point review
- 3) Ratification of the guidance

In addition, the Project Manager will report to the committee on a monthly basis. This will include documentation on risks, issues, key deliverables against timescale and quality assurance of the project. A detailed financial statement is also required by the DH as part of the grant status funding of this project.

Quality will be assured by the NIGB, who will also provide the final sign-off before the endorsement process begins.

Members of the steering committee can provide links to existing networks of stakeholders. BCS Membership will be accessible to the project team. BCS and the Department of Health can also provide meeting spaces at no additional cost depending on availability.

6 Required Experience

Individuals or organisations bidding for this work must demonstrate prior experience of research/consultancy in the UK health informatics sector and in the production of material for public information and engagement. They should have relevant pre-existing experience, knowledge, materials, contacts and networks that they can draw on in carrying out this project.

Established credibility among and experience in consulting with a wide variety of patient groups and other stakeholders is desirable. A proven track record in delivering projects on time, to scope and within budget is essential.

Organisations bidding should identify the individuals who will carry out this work on their behalf.

6.1 Conflicts of Interest

Any potential conflicts of interest arising from this work must be declared as part of the bidding process.

7 Ownership and Acknowledgements

Ownership and intellectual property of this guidance will belong to the Department of Health. Organisations or individuals providing content as part of this project will be relinquishing any intellectual property and copyright rights to that content. We request that a signature on a form acknowledging this must be obtained when engaging these organisations and individuals.

The winning bidder will receive acknowledgement for their contribution to this project in the guideline and in publicity about it.

8 Bidding Process

Interested individuals and organisation are invited to provide proposals as to how they would meet the above requirements. Proposals should include:

- Your understanding of our requirements
- Any perceived issues and suggestion as to how requirements might be modified to ensure that the work contributes as effectively as possible to scope and deliverables as outlined above.
- A description of the methodology proposed.
- Evidence of previous work that demonstrates your suitability for this work, including details of organisations and contacts we can approach for references in relation to two of these.
- CVs of the individual(s) who will be carrying out this work.
- An indication of the person-days input for each of those people identified.
- Details of your proposed deliverables.
- Your fee for carrying out this work that should be inclusive of all expenses.

BCS Health and the DHID have funds allocated to support an input in the range of 30 – 50 person days of effort at prevailing consultancy rates. It is anticipated that this work will be conducted over a 6-9 month period.

Submissions should be sent by email to ✉ w.wong@bcs.org to reach us by Friday 24 Feb 2012. We will acknowledge receipt of all submissions within two hours of this deadline. Please contact the project coordinator, Dr Wai Keong Wong, if you do not receive an acknowledgement.

We will notify all candidates if they have been shortlisted or not before the Tuesday 6 Mar 2012. We will wish to meet shortlisted candidates on Wednesday 21st Mar 2012 at Room DR2, 7th Floor, BUPA House, 15-19 Bloomsbury Way, WC1A 2BA. We expect to make a decision within 5 days of this date.

We will select the individual or organisation we consider to offer the best value and not necessarily the lowest bid. BCS reserve the right not to award contract if they consider none of the bidders offer sufficient value or for any other reason.

The evaluation criteria that we will be using for the short-listing and selection process can be found at <http://www.bcs.org/dhid>.

8.1 Contract

This tender document and the response to it will form part of the contract with the organisation or individual who is awarded the tender.

9 Questions and Correspondence

Any questions regarding our requirements should be directed to our project coordinator via email to Dr Wai Keong Wong, ✉ w.wong@bcs.org.

In the interest of transparency, all questions that arise and are relevant to the tender process will be published at <http://www.bcs.org/dhid>.