

NHS-HE Forum Response to “Liberating the NHS: An Information Revolution”

First Draft for Comment and Further Contributions

1. Background: NHS-HE Forum - Who We Are

The NHS-HE Forum¹ was set up in 2001 for IT and networking managers from both the NHS and Higher Education, with an interest in achieving two-way communication between NHSNet (now replaced by N3) and JANET, the network for education and research, managed by JANET(UK). It is an informal group that relies on the influence, ideas and action of its individual members to make a difference.

The NHS-HE Forum was chaired by its founder, Professor Roland Rosner, then Director, Education & Information Support Division (EISD) at UCL until 2008 and is currently chaired by Ted Woodhouse, recently Director of IT at Leeds Teaching Hospitals NHS Trust. Membership includes key decision makers in NHS and Higher Education IT and Informatics and active practitioners in these and related fields.

The NHS-HE Forum electronic discussion list has 288 members in its community, as at the end of December 2010. There are NHS-HE Forum meetings twice a year and annual Scotland NHS-HE Forum meetings.

Objectives of the Forum

- To promote access to health and medical journals and other electronic content by healthcare staff, researchers and students
- To achieve two-way communication between NHS and HE networks, enabling **secure anytime, anyplace, anywhere** access by healthcare staff, researchers and students

In 2005 this led to the NHS-HE Forum adopting the NHS-HE Connectivity Project in association with JANET(UK) which has as its objective:

“To achieve good inter-operability between NHS and Higher Education (HE) networks that enable secure anytime, anywhere access by medical, nursing and allied profession students, clinical teachers and researchers”

But the work of the Forum is not solely geared to technical issues, as these alone will not automatically improve knowledge access across the NHS and Higher

¹ Further background at <http://www.nhs-he.org.uk/index.html>

Education sectors: members of the Forum have identified significant other barriers that impede NHS staff and students who work, teach and learn or for other contractual reasons have need to access information. Issues around access to licensed or otherwise restricted content (for example e-journals, knowledge bases or e-learning objects) are a large part of the work of the Forum, so that both connectivity and content issues can be tackled side-by-side.

2. Approach to the Response to the Consultation

This response is concentrates on those aspects of “Information Revolution” that are relevant to NHS-HE Forum objectives. Individual members of the Forum will have a range of other views and contributions to the consultation and will respond directly or as part of other groupings for these.

3. General Comments

Firstly the NHS-HE Forum is delighted to have been given this consultation opportunity. It is recognised that the Information Revolution is a Strategy setting out some key principles and directions of travel, and is not an implementation plan. As such the NHS-HE Forum welcomes the document and its contents and does not take issue with any of the major thrusts. It is understood that the implementation Information Strategy is to follow and will not be open to consultation. We have therefore taken the opportunity of commenting on items that are possibly at a level of detail below the consultation document, or are omitted from it, or more relevant to the implementation plan.

4. Main Themes of Comments

The comments are based around the following themes:

- Connectivity and Access
- Support for Research Use of NHS data
- Handling Patient Consent
- Content Issues

5. Connectivity and Access

5.1 Network Connectivity

Although recognising the success of N3 within the confines of the previous strategy, we believe the objectives of the consultation document will be best supported by removing the network as far as possible as a barrier to collaboration and communication between partner organisations. The proposed much increased involvement of “the patient” in online activities with the health service and the encouragement of alternative service providers suggests that the use of a mostly “open network” for communication is going to be the best way forward - as long as there is a realisation of the existing policy position of building

security elements in to the applications rather than relying heavily on boundary defences such as control of network access.

As part of the new strategy we would like to see shared network infrastructure across the public sector partners that work so closely together, and will do so even more in the envisaged future. Health with Local Authority services such as social care and schools is a key area for collaboration that should not be encumbered by network barriers. But the area of most interest to the NHS-HE Forum is of course collaboration and joint working between health and education & research, particularly higher education.

Since the last strategy we applaud the work that the DH/NHS has undertaken to develop further coordinated approaches to NHS Higher Education collaboration. In particular:

- the awarding of Academic Health Science Centre status after a bidding process to Cambridge University Health Partners, Imperial College Healthcare NHS Trust, KCL Health Partners, Manchester AHSC and UCL Partners. These University and NHS Trust organisations and partnerships bring together most visibly the tripartite mission of provision of clinical services, clinical education and clinical research.
- The various levels of research networks and research units and collaborations created by the National Institute for Health Research, each involving Universities and Trusts.
- The 17 Health Innovation and Education Clusters (HIECs) created in the last year.
- The development of the Embedding Informatics in Clinical Education e-ICE programme²

These particular developments though are just further specific examples of the general collaboration and joint working that exists in virtually all NHS organisations providing care in association with the majority of Universities. Many clinical staff are involved in clinical teaching and/or research and undergraduate students spend significant part of their training on clinical placement in the NHS. It is still the case that this joint working is significantly hampered by issues of connectivity and access across NHS and University systems, often leading to what is often termed “the 2 PC syndrome” with a clinician with one PC connected to the NHS and another to the University. This is not only wasteful of resources but more importantly hampers the collaborative work.

It is hoped that the “Information Revolution” will be an opportunity to tackle these issues. The joint work that has been done on the N3 JANET Gateway³ has helped significantly, and there is more benefit that can be taken from it with the

² <http://www.connectingforhealth.nhs.uk/systemsandservices/capability/health/hidcurriculum/index.html>

³ <http://www.nhs-he.org.uk/future.html>

Phase II project proposals⁴, but it is only a partial solution in the longer term and for the future set out in the consultation document. Of course we are aware of the Public Sector Network (PSN) development but as yet it is not totally clear how this will achieve these objectives because of the current default security stance of IL2. Much that the two communities (health with education & research) wish to do together can potentially be achieved over unassured networks, with only certain activities requiring a network assured to IL2 or IL3. So we very much support the DH position that a more flexible model that recognises this would lead to cost savings and an increase in productivity and collaboration.

We welcome the position statement on PSN that has been made by the DH Informatics Directorate and are pleased to be working in partnership on PSN activities. There are though two aspects that we would like to be considered further:

- The PSN offers the potential for a longer term structure for dealing with IL2 and above. It's a little disappointing that the NHS has yet really to engage in early implementation work towards direct connection of N3 to the PSN. This would potentially allow richer and more cost-effective collaboration than expecting to handle this via more indirect routes (such as through the GCSx gateway).
- The importance of health engagement in regional public-sector shared-service networks should not be underestimated. There's a body of evidence building that significant last-mile cost savings can be achieved in a well-engineered and well-governed shared-service network, and that these activities also promote collaboration. Health involvement in such networks would be welcome (with a presumption that, subject to due diligence, these represent a strategic way forward).

5.2 Blocking of web facilities in the NHS

A related issue is the blanket blocking of a large number of bona fide websites, and Web 2.0 tools such as blogs and social networking tools, at many NHS sites. Although recognising there can be issues with some sites and tools, we believe the appropriate balance has not yet been struck and the NHS information governance arrangements tend to lead to "allow by exception" rather than "block by exception" approaches. The benefits from the sites and tools for patient and professional interaction, knowledge management, education and research are often lost with little justification and only made available to individuals after significant effort and bureaucracy.

The Forum recognises that the bandwidth available to NHS sites from N3 is limited and that this is a factor in restricting access to blogs and social networking sites. The Forum believes that as access to video and other rich media content becomes more prevalent increases in the bandwidth available at affordable costs

⁴ Outline at <http://www.nhs-he.org.uk/forum/November24th2010/MT%20update%20Forum%20Nov%2010.pdf>

to individual sites will have to be provided. The suggestions made in section 5.1 above on network connectivity can help tackle this in a cost effective way.

We believe more could be done centrally to provide good practice guidelines on the use of such web-based tools with a more balanced approach to the risks. The SHA Library Leads IM&T Group have taken the initiative with this by publishing a list of websites which are central to NHS activity⁵ and therefore should not be blocked. The NHS-HE Forum is about to embark on a related project, chaired by an NHS Trust Director of Informatics, to look at best practice in this and related areas e.g. identifying web-based tools that have a risk assessed place for use in clinical education at NHS sites⁶. It would be appropriate for some of these efforts to be coordinated or tackled by NHS IT policy and standards.

The relationship with web based tools will no doubt be necessary with the welcomed support for patients holding their own health records if they wish, and this is likely to be through tools such as Google Health Records, Microsoft Health Vault and the many others on the market which are likely to display web 2.0 features. Similarly NHS organisations are increasingly urged to make more use of social media to interact with the public but NHS staff in the same area are prevented from accessing these developments from NHS devices.

5.3 Identity & Access Management

We also welcome the move made by the DH over the last year to create an NHS strategy for identity and access management. The education and research community has itself, led by the Joint Information Systems Committee⁷, created a federated access management environment over recent years resulting in the UK access management federation for education and research⁸. We believe that an NHS access management strategy that supports federation using open standards such as SAML2 is key to “joined up” working across sectors. As an example, it would improve access to NHS e-Learning resources by medical and other health science students where they currently have to have a distinct NHS login where authentication against their University ID would suffice for such access, as it does not involve any patient identifiable data. Similarly there would be great advantage if the credentials already incorporated in NHS smartcards could be used to authenticate for access to federated services, whoever provides them and where the appropriate licences are in place⁹.

⁵ See <http://www.libraryservices.nhs.uk/forlibrarystaff/information/technology.html>

⁶ E.g. issue graphically illustrated at http://www.nhs-he.org.uk/forum/November24th2010/NHS_HEForum241110_AHoweNLafferty.PDF

⁷ www.jisc.ac.uk

⁸ See <http://www.ukfederation.org.uk/>

⁹ This is a proposed N3 JANET Gateway Phase II pilot.

5.4 Use of International Standards where available

We believe that the Information Strategy should use existing open standards wherever possible, and assist in their development where they are not. There are opportunities in this approach e.g. the use of Eduroam¹⁰ in the international education and research community for visitor access to a network.

The education and research community is also an experienced and active user of open source applications. There is an opportunity for sharing such expertise if the NHS moves to more use of open source applications.

6. Support for Research Use of NHS Data

This topic has been of great interest to the NHS-HE Forum and has been receiving regular reports from the Research Capability Programme. The NHS-HE Forum strongly supports this initiative, and the development of a Health Research Support Service (HRSS) as access to anonymised clinical data in a clearly understood and timely way would be of great assistance to the clinical research community. It is encouraging to see explicit references and support for these things in the consultation document e.g. paras 4.11 and 4.12. We would be happy to engage further on the details here if necessary but hope that the HRSS business case is approved and implementation proceeds.

The NHS data for use in research will be made more valuable if the stated aim of capturing more clinically relevant data at the point of care to defined standards is achieved. If the data is on the clinically relevant aspects of that particular condition or treatment then as well as it being more likely to be of use to the clinician for audit and benchmarking, it is also more likely that it can be used to start to investigate and answer useful research questions. At present much of the data in national datasets has been driven by administrative requirements or definitions have largely been set in stone by how the NHS operated in the 1970's and 1980's. It is time to re-evaluate this more by disease or condition and across the pathway of care (many current standards are "transaction based"). If the data is captured to support operational clinical requirements then it will be more useful for all other uses of the data, including improved outcome measures, performance management, planning, and commissioning as well as research.

7. Handling Patient Consent

The NHS-HE Forum has been following and supporting a development to assist with the appropriate use of patient consent for images or other multimedia recorded in clinical settings that are then used for example in clinical education.

¹⁰ <http://www.eduroam.org/> and UK implementation at <http://www.ja.net/services/authentication-and-authorisation/janet-roaming.html> . Use of eduroam in the NHS is a proposed N3 JANET Gateway Phase II project.

This has resulted in the proposal to use the concept of “Consent Commons”¹¹ that builds on the widely used “Creative Commons”¹² used for Intellectual Property Rights for multimedia. With NHS support this could be an excellent example where agreed national standards and good practice guidelines could greatly improve the clarity on expectations at a local level to the benefit of all involved.

Of course it is recognised that patient consent is a much wider issue than use of digital media. The consent of patients for their data to be shared by other clinicians in support of their care is obviously a prime concern. Managing patient consent for their data to be used in clinical research is another key aspect of direct interest to the NHS-HE Forum. It would be good to see in the welcome support of a standards-based approach to the DH Information Strategy, that data standards and structures are agreed for the handling of patient consent in all its aspects so that automated approaches can be used for extracting consented data only for instance.

8. Content Issues

Currently both the NHS and universities purchase e-content separately and have access to different content from different content suppliers. However, the richness of access for academic staff is not currently mirrored in the access available to NHS staff as the prevailing commercial model is to supply separately to the two sectors. This differential access to content is a barrier to high quality patient care, research and education, as the NHS and universities are increasingly working more closely together, eg through Academic Health Science Centres, HIECs, and especially in educating the NHS workforce (both undergraduate/pre-registration and postgraduate/post-registration). It is disappointing that not more has been made of the Hill Report¹³, especially recommendation 44:

"There would be great advantages in the NHS and HE working together on joint procurement"

This would be of benefit to both sectors and would be in the interests of efficiency and effectiveness, as well as better value for the public purse, given that the NHS and universities separately spend large sums on the procurement of overlapping electronic content. What is needed is coordinated action at a variety of

¹¹ Williams, J., Hardy, S.& Quentin-Baxter, M. (2010). Proposing a 'Consent Commons' in open education – balancing the desire for openness with the rights of people to refuse or withdraw from participation. Proceedings of OpenEd 2010 Conference, Barcelona.

(<http://openaccess.uoc.edu/webapps/o2/handle/10609/4864>)

¹² <http://creativecommons.org/>

¹³ Hill P. Report of a national review of NHS health library services in England: from knowledge to health in the 21st century. NHS Institute for Innovation and Improvement; 2008 Mar. At:

http://www.library.nhs.uk/nlhdocs/national_library_review_final_report_4feb_081.pdf

appropriate levels – local, regional, national – so that the NHS and universities are able to work together in a way that meets their needs.

A longer term approach is with the continued development of the Open publishing movement and the sharing of content in an open way across the two sectors, which the NHS-HE Forum fully supports.

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