

ONLINE ACCESS TO HEALTH INFORMATION
Issues of inclusion for disabled and other patient groups

Tuesday 8th March 2005

A Facilitated Workshop

REPORT

1. Background

- 1.1. The British Computer Society Disability Group and The Thalidomide Trust continued their collaboration began in the autumn of 2004 to raise awareness about the issues involved in providing secure online interaction between patients and health and social care professionals, within the context of the agenda for inclusion and access to services, via a follow up to workshops held in the autumn of 2004 on Direct Electronic Patient Data Entry.
- 1.2. A report on the two workshops held in 2004 is available in a downloadable file.
- 1.3. Via a series of short contextual presentations designed to stimulate open discussion, the workshop addressed the issues of what has happened since October 2004 and what should be done during the next 6 months to make more things happen. Participants engaged in discussion with the speakers and continued with an open forum leading to agreement on the conclusions, the outputs and actions - the next steps.
- 1.4. The workshop was run under the aegis of the International (Standing) Conference on Assistive Technologies Programme, and aimed at: disabled people and organisations representing disabled and elderly people; patients' representative bodies; health and social care professionals; national and local government departments and agencies; academic institutions and commercial organisations.

2. Participating Organisations

- 2.1. There were participants from the following organisations:

Association of Disabled Professionals
British Computer Society Disability Group
Citizens Online
European Federation for Medical Informatics

(Healthcare Planning and Modelling Working Group)
Leonard Cheshire Foundation
The Thalidomide Trust

- 2.2. Participation was via input supplied by email prior to the event or presentation and discussion on the day.

3. Continuing Professional Development

- 3.1. This event qualified for 5 hours or 2.5 points under the British Computer Society's Continuing Professional Development Scheme.

4. Introduction and Context Setting

Brian Layzell
Chairman, British Computer Society Disability Group

4.1. The Vision

- 4.1.1. A universally available facility for patients to interact with health and social care professionals remotely - allowing patients to enter into structured consultations prior to physical attendance at eg a GP surgery or hospital clinic etc thus reducing or eliminating the need for expensive, long and sometimes unnecessary journeys by disabled, elderly or otherwise infirm or housebound patients for whom mobility or communication may be an issue. A facility that should be an integral part of telemedicine and telecare services.

4.2. The Need

- 4.2.1. The need for such a facility has been demonstrated successfully many times over, in the UK, mainland Europe, USA and worldwide. In 2004, in several workshops and other meetings held in London, the subject was aired extensively with both health and social care professionals and patients' representatives, with successful examples of pilots, trials and routine operational services. The outcomes were all positive and there was general consensus that In the UK there is evidence from the NHS Information Authority's own internal research that some 60% of all patients want access to health services via their own PCs from within their own home.
- 4.2.2. The current national moves towards this are welcome but they stop well short of allowing full interactive consultations with clinicians. Why? And, why has nothing happened at a national level since then? There

was an additional impetus for something to happen soon because of a recent report by the Office of the Deputy Prime Minister's Exclusion Unit, in which it was stated that the majority of elderly and disabled people are dissatisfied with the quality and efficacy of their health care and find real problems with access to services and communication with health professionals.

4.3. The Expected Outcome

- 4.3.1. The purpose of the workshop was to address the possible practical solutions to making this facility readily available to all and agree what actions those with an interest in promoting the take up of such facilities could or should take during 2005.

5. Personal Advocacy for Comprehensive Health Access System: Disabled Patients' Perspective

**Professor Berrisford Boothe
representing The Thalidomide Trust**

- 5.1. Professor Boothe articulated the concerns of the disabled patient when faced with the need for health intervention. He made a convincing case for the concept of the "informed and "expert" patient, specifically in the context of a disabled person, but with more general applicability as well.
- 5.2. He illustrated his argument with three personal anecdotes in which he described situations where he had sought emergency health intervention and had been faced with the lack of clinical knowledge and experience in dealing with his specific musculo-skeletal characteristics, as a result of which he suffered from unnecessary and inappropriate treatment which had a serious adverse effect on his condition and his subsequent life.
- 5.3. He emphasized the point that if there had been the opportunity to provide advance information about himself, or, if there had been an accessible source of expert knowledge available to the attending clinicians, the diagnosis, treatment and outcome would have been much more effective - clinically, personally and economically.
- 5.4. The full text of Professor Boothe's presentation is available in a downloadable file.

6. The Physicians' Perspective

Professor John Bachman

Department of Family Medicine, Mayo Clinic College of Medicine, USA

- 6.1. Professor Bachman reprised the presentation he made at the first workshop in September 2004, but also addressed the underlying philosophy or rationale for using technology such as web portal, email etc to supplement the conventional ways of conducting history taking and consultation between patient and clinician, and demonstrated the increased accuracy of diagnosis and thus more appropriate treatment and successful outcome
- 6.2. He made the point that in terms of utilizing the currently readily available information and communications technologies (ICTs), in comparison with commercial and social acceptance and usage, health care was in a time warp and needed to become more consumer oriented to meet the needs of current and future generations of patients.
- 6.3. He described scenarios from his own practice where he uses successfully a combination of conventional face to face consultations, supplemented by use of email and online structured questionnaires. He stressed his belief that this approach could and should be available to all health professionals and patients, and that disabled patients could and should be treated the same as any other patient using this approach.
- 6.4. Professor Bachman's presentation is available in Powerpoint.

7. Potential workable and usable technologies to support patient and clinician interaction

Dr Richard Sills Specialist in Aviation Medicine, PPS Ltd

- 7.1. Dr Sills reprised the presentation he made at the first workshop in September 2004 and provided a more detailed work through of how a structured questionnaire such as Instant Medical History (IMH) was being used in practice. In this, his evidence supplemented and reinforced that of Professor Bachman.
- 7.2. He provided evidence from history and from current practice to support the general conclusion that there are clinical, social, economic benefits to be gained from the use of this approach - for patients, health and social care professionals and health care organisations.
- 7.3. He discussed how IMH might be tailored to meet the needs of specific clinical requirements and those of people with specific health conditions or disabilities and how they could interact successfully with e.g a GP surgery or hospital clinic.

7.4. Dr Sills' presentation is available in Powerpoint.

8. Summation of Presentations and Initial Discussions

Dr Claus Newman Medical Advisor to The Thalidomide Trust

- 8.1. Dr Newman provided a brief summation and some observations on the philosophy, practicalities and expectations of patients and physicians in adopting and using such a system, in which he articulated the benefits from and potential areas of danger in implementing on a wide scale, i.e. becoming a generally available facility.
- 8.2. His comments were taken into an ensuing general discussion on the concepts and the implications specifically for disabled patients in addressing the inclusion agenda.

9. Comments and Issues

- 9.1. The comments made and issues identified by the participants during the contextual presentations were taken into an open forum discussion. These have been synthesised as follows:
 1. could be seen as of proven value under certain conditions, although could be subject to misuse if used inappropriately - i.e. unmonitored;
 2. ought to be possible to have wide scale implementation in primary, secondary and tertiary care;
 3. could prove beneficial to groups of patients for whom attending a clinic or communicating with a clinician may be difficult;
 4. need to avoid or mitigate the risk of clinicians of becoming too reliant on technology as a substitute for face to face consultation and diagnosis;
 5. need to ensure that patients understand the process and can be helped through it if necessary;
 6. need to ensure that the algorithms used in the structuring of the questionnaire are robust and can be tailored to meet the needs of specific groups of patients;

7. would need clinician buy in across all professions, specialties, disciplines etc, but may work better for some than others, and perhaps an approach to some specific professional societies etc might allow a suitable trial to be set up;
8. would be more appropriate for some individual patients, or types of patient, than others, but it would be worthwhile conduct a trial using a specific group of patients and their usual health professionals;
9. should be managed in such a way that patient's expectations could be met and not allow them to assume that by using a structured questionnaire they will automatically have all the solutions to all of their health issues;
10. would only work properly with a change in attitude and culture within health organisations and in the public's understanding of how to interact with health care providers;
11. need to get an organization to agree to take on a product e.g. Instant Medical History and include on their website so that individuals could have access. If this were to be taken up by the NHS, it could be used to enhance the facility currently being introduced by NHS Direct;
12. could also be used to provide a private - i.e. organization specific - health information service giving support or advice to subscribers, beneficiaries, sufferers etc.;
13. other communities ought to become involved or risk missing out on valuable information that could be relevant to their constituents' longevity, well being, independent living etc.;
14. need to revisit the definition of disability as "any condition or affliction that interrupts the ability of the individual patient to fully implement necessary life objectives." This could thus cover not only disability but also all chronic health conditions etc.

10. Some Specific Questions and Answers

Q1. What timescale is envisaged for full implementation?

A1. None for full i.e. UK wide NHS etc. roll out. A controlled model pilot should be completed by 30th March 2006.

Q2. Who will specify the type of computer and telecommunication access required?

A2. No one. For patients, there is no specific ICT specification beyond the need to be able to access email and the internet. For GPs and hospital clinics etc the requirement would have to be built into or added to whatever in house systems are supplied.

Q3. Who (and how), will supply the computer hardware and software, maintenance, operating costs, including Internet access, adaptations etc.?

A3. This is outside the scope of the workshop, but all the usual sources would be relevant.

Q4. If people already have home computers will they be compensated for using their own equipment? (Tax relief?)

A4. This is outside the scope of the workshop, but not very likely!

Q5. Assessments will be required for user suitability both physically and mentally?

A5. Possibly, in extreme cases, but it is assumed that this would be down to specific patients and their GPs, or perhaps social services. In the proposed pilot, this would be part of the selection process for volunteers.

Q6. How will users receive instruction/education?

A6. In any national scheme, this would be available either online as part of the process of completing a questionnaire, or, from the participating surgery or clinic. Alternatively it could be made available via a national help line facility e.g. NHS Direct. For the proposed pilot, this would be provided by the managing organization, in advance of the start and would be available during the pilot online or via a help line.

Q7. Will equipment be updated periodically or upgraded to latest technology?

A7. Any software used would have to be reviewed to take into account new clinical requirements and it would have to be reviewed for conformance with commercial browsers and changed accessibility standards. No actual update of anyone's equipment is envisaged.

Q8. What consideration should be given to issues of e.g. keeping expensive equipment in the home, safety, space, ownership, insurance, etc?

A8. None specifically, beyond the normal advice to people to insure their personal possessions. If equipment should be supplied to an individual, e.g. by a charity etc., it would be down to the supplying organization to deal with insurance.

Q9. In cases where users live alone will other "call" mechanisms be available as at present?

A9. Yes. This would not be a "call" mechanism and so would not replace or supplement any existing facility.

Q10. How do individuals and services find out about the service? We are aware that publicity has been used in some of the pilot studies to inform patients and statutory services that the on-line consultation service is available, but what are the plans for ensuring that people and services are informed?

A10. This is outside the scope of the workshop, but if such a service were to be available nationally, it would be up to central and local government agencies, NHS organisations etc to publicise the details - just as for NHS Direct.

Q11. How do people opt in to the project? Will there be provision for those who do not have access to computer technology?

A12. This not a project. The intention is to use a control group of people from one specific community, but if others wished to participate the scope of the pilot could be extended. Because of the nature of the concept it will only work for those who have internet and email access, however, it might be possible to use external sites, e.g. facilities provided in GP surgeries or public access kiosks, internet cafes etc. But, note that the latter option is not considered secure and therefore not desirable.

Q12. Have the needs of individuals who use specialist technology (e.g. screen reading software, voice input software) been taken into account in the design of the package? What about those individuals who find reading/writing difficult? We believe that it would be appropriate to use questions that were in plain English in order that everyone has the opportunity to take part and to understand and answer questions effectively.

A.12. Yes, these issues will be addressed in the design of the questionnaires and the framing of questions, commands and instructions, but there will be some requirement for specific word

formation in order to obtain the correct clinical understanding of the symptoms being described.

Q13. Have the issues of different groups been examined, for example, is there an intention to use this service in relation to paediatric care, people with learning difficulties or the elderly with degenerative mental health difficulties (such as Alzheimer's Disease)? Some people would have extreme reservations if this project was to be rolled out in relation to paediatric care, as children's health can deteriorate rapidly.

A13. Yes, this has been addressed in previous trials and in those places where this facility is routinely available (mainly in mainland Europe and USA) and work is starting to produce tailoring for specific groups of disabled people. With regard to paediatrics, this would have to be a matter for local clinical judgement on when and to whom to offer this facility, but there should be no reason in principle why children could not participate, since their case notes would be subject to more frequent review.

Q14. Will individuals, GPs and consultants all have access to the same online information? For example, if a GP refers a particular patient to a consultant, and the patient then completes the online information, will the GP also be asked to comment on what the patient has written? Will the patient have online access to their notes?

A14. In general, if this were to be a national scheme, yes. However, it will be up to the clinicians to decide how much information relevant to diagnosis should be made available to a patient in cases where it might be deemed not in the patient's interest to see all clinical comments. Patients' right to see their notes are embedded in legislation and online history taking will simply mean that the questionnaire will form part of the patient record. For the purposes of the proposed pilot, specific protocols will be agreed with all participants.

Q15. In light of the fact that many people are also choosing to see consultants on a private basis, will this service be available to both private and public health and social care providers in order to provide an integrated service?

A15. In a nationally provided scheme it should be, because otherwise the concept of the Electronic Health Record will not be met as intended. However, experience suggests that this is not likely to be the case unless all health providers choose to implement it.

Q16. How will security, confidentiality, information privacy be provided to prevent unauthorised access to questionnaires while they are being completed and transmitted?

A16. In a nationally available scheme it would have to be addressed via existing policies, protocols, standards, codes of practice, professional guidelines etc. In the proposed pilot, the same will apply, but via local agreements between all participants.

Q17. Given the concern that some patient entered data projects have led to more time being spent by the clinician, presumably this does not have to be clinician time to verify/check entered data? Surely the real issue here is getting public and patients to know much more about the meaning of their data and thus further up the knowledge curve such that the time with the clinician is quality time with unnecessary time and/or visits reduced?

A17. Agreed. This should form part of the pilot criteria in order to point up an argument for national implementation.

Q18. Where might near- and on-patient testing and monitoring data fit into this development?

A18. It would not fit specifically into the use of a history taking questionnaire, but could have some applicability into how the result of such questionnaire are used clinically. Further, they might fit into a web based health information service, particularly if linked into the use of other technologies in telemedicine and telecare.

Q19. How would physiological data measured by an instrument/monitor and automatically entered by an electronic interface into the Electronic Health Record (EHR) or similar entered by the patient be addressed?

A19. It would not fit specifically into the use of a history taking questionnaire, but if the treatment included monitoring, then technology is available to allow transmission of data from the patient to the clinic, surgery or other monitoring centre. How it would then get into the EHR would be down to the systems and protocols in use at the time.

Q20. What about decision support algorithms for patients (as well as local carers generated by the monitored data)?

A20. These could be incorporated into a history taking questionnaire,

allowing a patient to get online advice direct at any time from the health service provider - e.g. NHS Direct.

Q21. How will provision and use of patient developed websites supporting self-monitoring and self care be addressed?

A21. In any nationally rolled out programme using online history taking, the use of other websites would probably continue in the same way as they are currently, i.e. individuals will continue to set up and use such websites, and some of these will be validated such that they would be used as references by NHS services e.g. NHSD Direct etc., but, there is a need for proper moderation and quality control over the advice given via health information websites generally.

11. Conclusions

- 11.1. In principle, and subject to the concerns raised being properly addressed, the workshop reaffirmed the belief that online access to health and social care services would be very useful, as it will prevent very lengthy travel times and some of the unnecessary difficulties associated with accessing routine health and social care services by elderly, infirm and disabled people.
- 11.2. An online access facility, as proposed, would be very useful, but only as long as it is used in conjunction with face to face consultations, rather than as a replacement, and should not be seen as the only way by which people will gain access to health care. However, the body of evidence supported the contention that this approach is desired by and would be used by a majority of people in the UK, and should be made available as a service to those who wish to use it.
- 11.3. A product such as Instant Medical History should be generally available in the NHS in the UK, but to be really effective, it would have to be embraced by other agencies such as private and voluntary sector health care providers and local authority social services - to provide input to individual longitudinal electronic health records being developed.
- 11.4. To highlight the issues and the solutions still further, some work should be undertaken to record, catalogue and publish the patient experience of using such a system, which could be used as a model. This would involve a collaboration between a defined group of patients and their own GPs, using a product e.g. Instant Medical History, with one organisation taking on the trial management.

- 11.5. There is a parallel need for a comprehensive web accessible online health information network clearly will provide GP's with a critical advantage for quick assessment and appropriate directed care management.
- 11.6. The concept of the "informed" and "expert" patient should be encouraged and supported not only via existing services, but institutionalised so that patients, carers etc have access to all appropriate information about the treatment and management of specific conditions, and, are fully accepted as part of the professional care team.
- 11.7. There were some technical and cultural issues still to be properly addressed but these should not be seen as a bar or hindrance. They could be worked into any national trial and solutions found.
- 11.8. There was an opportunity for an assessment of the applicability of other ICTs to the question of how best to provide online access to health information and, how best to allow on line history taking and interactive health consultations.
- 11.9. There were three distinct products, viz:
 - a. the "one to one" history taking and diagnosis between patient and clinician;
 - b. the widescale broadcast discussion list for dissemination of outcomes, treatments etc. via a network;
 - c. the publication of relevant public and clinical information on a web site - with either open or secure access.
- 11.10. There was a need for action now, not later - but progress should be in measured haste, considered and controlled but not rushed, via a controlled pilot using a specific group of disabled patients and with the collaboration of their GPs.

12. AGREED ACTIONS

- 12.1. In response to a challenge thrown down by Professor Boothe, the workshop agreed to set up a pilot to address the issues and concerns identified in the workshop, and to have this running during 2005, with a review and publication of results by 30th March 2006.
- 12.2. It was agreed to run the pilot using a defined group of disabled people, drawn from a specific community, spread across the UK, and covering a range of disabilities. They would work in collaboration with their respective

- GPs to use a form of online history taking and to measure the efficacy for both clinician and patient.
- 12.3. The proposed timetable would be for a detailed proposal to be worked up and presented to the workshop participants by 30th June 2005. The pilot itself would run for approximately six months.
 - 12.4. The Thalidomide Trust representatives agreed to take this proposal back to their community, discuss with others how to put this idea into practice and confirm their intention to lead on this work.
 - 12.5. The Thalidomide Trust representatives would take the lead in producing the specification for the pilot, defining the outcomes and undertaking the management of the pilot.
 - 12.6. It was agreed to offer the pilot and the results to the NHS and to The Office of The Deputy Prime Minister to use as a control group in any wider national NHS led pilot, as envisaged by the previous workshop held in October 2004.
 - 12.7. Other participants agreed to consider acting as champions or advocates for the concept
 - 12.8. The BCS Disability Group agreed to maintain a list of participants, and other interested parties that may be identified in the future, to keep them informed of progress.
 - 12.9. There would not be another formal meeting, but future actions would be handled via email discussions, managed by the BCS Disability Group.

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