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Effective Ways to Use Non-personal Information in Healthcare: Workshop Report

*University College London
15th - 16th April 2004*

Introduction

New information technologies are being introduced in the UK National Health Service as resources for the acquisition of clinical knowledge. These are forcing working practices to adapt and are affecting and challenging perceived roles, relationships and expectations of patients and health professionals alike. *Effective ways to use non-personal information in healthcare* was a two-day workshop hosted by UCL Interaction Centre at University College London intended to provide a forum for practitioners and researchers working in the area of clinical health information delivery to come together to discuss access to health information, and to consider how the various challenges and opportunities relating to electronic information provision can be managed most effectively.

For the first day of the workshop, the theme for presentations and discussion was information provision for and access by health professionals. Talks were given by Julius Weinberg (City University, London), Roger Slack (University of Edinburgh) and Anne Adams (University College London). The theme for the second day was information provision and access by patients. Presentations were given by Mig Muller (NHS Direct), Jane Wilson (Whittington Hospital and Medi-notes), Andrew Herxheimer (University of Oxford) and Henry Potts (University College London). On both days, delegates formed into three groups for breakout sessions in which they discussed and reported back on: information quality and use, social and organisational context, and user requirements and training in relation to the respective daily theme (health practitioners/patients).

This report summarises each of the presentations and the reports by the breakout groups.

Day 1 - Information provision and access by health professionals

Julius Weinberg (day1)

The workshop opened with a talk by Julius Weinberg entitled 'The realities of creating online library communities'. Julius discussed ongoing work by his team at City University in developing The National electronic Library for Infection (NeLI)—a specialist digital

library/internet portal within The National electronic Library for Health (NeLH). NeLI is a resource for healthcare professionals providing information about the investigation, treatment, prevention and control of communicable diseases. It includes quality-assessed evidence, FAQs, online discussions, lectures and personalised alerts.

Julius focused his talk on a model the project had adopted for content provision and quality assessment; this is to develop an online expert community who act jointly as contributors, users and reviewers of information. Julius argued that a 'publisher' model, where content is sourced and bought, would be prohibitively expensive. Part of the task of the NeLI team, then, is to provide users with tools for publishing and making quality judgements about information on the site.

Julius related the kind of community that his team are trying to develop to a 'normative community' according to Komito's (2001) framework (a group of individuals sharing similar experiences and norms of expected behaviour), and also to Stewarts (2001) idea of 'communities of practice' (groups that emerge around a discipline or work-related problem rather than organisational membership). Julius pointed to a cycle—that for NeLI, engagement depends upon participant benefit, but that participant benefit depends in turn upon community engagement. He argued for initially identifying the community and their needs and constraints, and discussed how the City team had done this by engaging with various medical associations. Such work, however, is potentially limitless and it can be difficult to match different interests. Once a community is established however, log file analysis becomes possible through which interests can be determined, and the City team are also doing this kind of work.

At the end of the session, discussion focussed on the question of how to motivate engagement. It was said that a motivating factor for peer reviewing within an academic setting was that it validates expert status, and consequently the kudos associated with a source publication is an important variable. This points to a need to raise the profile of NeLI. Julius discussed efforts at City to approach medical organisations for official sanction, although this could be a long process. He also discussed the fact that reporting of adverse reactions was currently generally inadequate, and that this had been discussed as a method for attracting participation. Other points made were that it might be useful to look at how collaborative open source software teams operate, and also that there may be possibilities for reviewing articles through interaction monitoring. On the question of developing an international focus, Julius said that there is interest in covering tropical diseases but that they are constrained by resource limitations. It was also mentioned that within communities, members communicate with each other, and the suggestion of promoting discussion by establishing reading groups was discussed.

Roger Slack (day 1)

The second talk was by Roger Slack who discussed research by The Social Informatics Cluster at The University of Edinburgh. The Social Informatics Cluster is an interdisciplinary group who perform ethnographic studies looking of human activity in the settings in which technology is used. The goal is to inform designs that are better matched to people's needs. Roger described the work as predicated on the idea that important situational factors can often appear relatively mundane and can consequently be overlooked by technology developers; for example, existing artifacts may have affordances that are omitted in digital substitutes. As part of this work, the group have been working on an EPSRC funded project looking at the everyday practical

accomplishment of 'information giving' by healthcare professionals to inform training and system design.

Roger discussed two studies of toxicology advising. The first was of triage nurses using a TOXBASE—a database of substances, toxicity and management strategies—within The Poisons Information Bureau. Health professionals can contact The Poisons Information Bureau for advice on cases. In the study, nurses were asked to 'talk-aloud' whilst dealing with imaginary case scenarios. Video and audio recordings were made, and the audio recordings transcribed. The findings showed the nurses using TOXBASE, as well as consultations with other sources (such as colleagues), to confirm or 'ratify' existing knowledge. Related to this, they also demonstrated the inherently social nature of triaging (e.g. talk, gesturing towards parts of the computer screen) particularly in complex cases, and showed how nurses used paper notebooks in order to make a personal, informal record of each call. TOXBASE includes a dosage calculator that the nurses would often use, but they would also work through the calculation on paper, record the result, and review the case following the call. Roger pointed out that noting things down on paper is faster than typing, and provides a useful resource during a call, particularly when dealing with uncertain information and repair of information changes.

The second study was an analysis of recorded calls taken by Information Officers also working with TOXBASE within the Poison Information Bureau. Here the information officers acted as information intermediaries. In common with the triage nurse in the previous study, many callers to the service were seeking ratification. In many cases calls would end with statements such as "that's what I thought, I just wanted to check". The study also showed Information Officers adapting to the caller's knowledge as revealed through the callers comments. Roger related this to Maynard's (1991) idea of 'perspective display sequences'. The study also demonstrated how a call dialogue could include information officers making information requests to the caller in order to clarify or make sense of the problem. Discussion of the session revolved around design recommendations and the use of notepads in preference to typing. Suggested explanations included that note-taking may require less cognitive effort than typing, and that writing might be easier than typing when holding a phone.

Breakout Session Reports (day 1)

For the day 1 breakout session, delegates formed into three groups, each given one of the following topics to discuss as they relate to clinicians:

- information quality and use
- social and organisational context
- user requirements and training

Information quality and use

During the reporting back, the group dealing with information quality and use made the point that quality not only relates to content and presentation, but also to application in practice. They emphasised the challenge of dealing with variation in the contexts of information use, and suggested a shift in emphasis from content to context, and the idea of judging the 'contextual validity' of information. They also drew attention to the cultural prioritising of certain types of knowledge over others, such as the randomised controlled trial over experiential knowledge, and argued that this issue is often confused with quality. They raised the question of who should the arbiter of quality? Should this be

upstream in the information chain ('just in case') or downstream ('just in time'). The suggested a focus should shift towards the latter and enabling people to develop their own skills in information appraisal.

Social and organisational context

The 'social and organisational context' group began by defining 'clinician' as including anyone working within a clinical setting. They emphasised the need for cultural change within the NHS in relation to technology, training, embedded hierarchical structures, flexibility (there are 1.3 million people in the NHS and one-size does not necessarily fit all), attitudes and language barriers (including those existing between different professions and their respective cultures). They made the point that the NHS is traditionally a risk adverse organisation and that this relates to the dissemination of written information. The group discussed increased information access being brought about by digital technology, how this will inevitably break down traditional barriers between professional groups, and how informal processes are naturally adapting to this. They also mentioned important organisational considerations for intranet use such as content maintenance and raising awareness of information availability.

User requirements and training

The '*user requirements and training*' group began by focusing on information systems design and defined the challenge as being one of creating intuitive, fast systems that provide integrated access to multiple resources. They argued for an iterative, participatory design approach involving users at all stages, and argued for the need for design to be informed by relevant studies as well as being 'ecologically informed' i.e. guided by an understanding of the situation of use. They considered the fact that new information systems are constantly being introduced into the health service, and that users must often learn skills afresh. They considered standardisation for promoting common, familiar and therefore transferable interaction knowledge, but recognised the conflict that this might have with the idea of systems tailored to specific needs. In relation to training, the group discussed the need to cope with the changing landscape of available systems and the cost that learning incurs for the user. Beyond this, they argued that training should be tailored to need, should recognise the need to teach specific and transferable skills, and should be available through multiple routes and formats (i.e. media).

Anne Adams (day 1)

The final talk on day 1, entitled 'Information Empowerment and Exclusion', was presented by Anne Adams from UCL Interaction Centre. Anne reported on a series of qualitative case studies into digital library use which form part of the 'Co-evolving roles and technologies in the NHS' project (EPSRC e-Society programme). These studies looked at the structures of 'communities of practice' surrounding digital library use in organisational settings, and were guided by the ideas that learning is a social activity, dependent upon social structures, and that organisations and poor technology design can exclude users. The settings for the studies were: a university library, a provincial hospital, an inner London hospital and an outer London hospital. Methods used included focus groups, observation and in-depth interviews with information users and librarians.

From the studies, Anne identified three types of interaction pattern:

'Library based interaction' – Here, digital libraries were accessed inside a designated library area. Where this was the case librarian/user interaction tended to be poor, with users feeling disempowered and marginalised. The library was perceived as 'remote' and 'academic', and librarians were perceived as protecting resources. Awareness amongst users of digital libraries was poor.

'Location based interaction' – In this scenario, systems were available within the library and also in the workplace (ward). Findings showed that computers on the wards tended to polarise users along the lines of their abilities to use them and perceived rights of access, and friction existed around access rights. Junior clinicians tended to find systems easier to use with this presenting a threat to existing status structures.

'Team based interaction' - In team based interaction, librarians worked as intermediaries within the work-setting. In this case, users tended to be empowered through the development of relationships with information intermediaries and with intermediaries adapting their practices to individual and group needs. Intermediaries became able to predict information needs and support and encourage system use. Team-working was cultivated alongside an ethos of shared endeavour.

Anne finished her talk by relating her findings to a series of contrasting information intermediary roles.

Day 2 – Information provision and access by patients

Mig Muller (day 2)

Day 2 began with 'People and Health Information 'MIND THE GAP, PLEASE!' presented by Mig Muller of The NHS Direct Health Information Service. As well as nursing advice by telephone and a website for information, NHS Direct offer an extensive health information service by telephone, email and post. Mig discussed the 'gaps' that can occur between people and information, and how the consequent challenge of making information accessible, understandable, individualised and safe are addressed by the health information service.

In relation to users accessing internet based information, such as digital libraries, Mig highlighted the following problems:

- ♣ Users may lack computer/internet skills;
- ♣ They may lack access opportunities;
- ♣ They may be unable to assess source quality;
- ♣ Terminology can be confusing, e.g. mortality vs morbidity;
- ♣ Users may lack knowledge of what resources are available;
- ♣ Some diseases are so rare they do not appear on evidence-based databases;
- ♣ It is difficult to convey risk accurately and in a way that people understand;
- ♣ Some people have a surprising lack of awareness of their bodies. This is essential context for understanding what is wrong;
- ♣ Applying general information to your own case can be difficult;
- ♣ 'The facts' represent only one factor in complex decision-making—individual values are also important;

In response to these issues, the helpline is provided as a complement to the online NHS Direct service. It operates under the premises that: people need to understand

information before they can use it; that each person starts from a different point (in terms of background knowledge and what is bothering them most); and that the objective is to bring people and the information they need together—not to advise.

When people call NHS direct the first step is an assessment of whether they need information or advice on active symptoms. If information is needed, they are then guided through a structured information needs assessment interview. This is designed to find out what they know already, and what they need to know in terms of holistic needs or specific questions. Mig explained that limited amounts of information can be absorbed over the phone, but that more detailed information is sent by post including background information to help the caller understand their disease and the treatment (often using diagrams) and information on health services and support groups. At the end of a call the door is always left open for more information.

Mig made the point that information should be safe as well as easy to access, and described the specialist assessment tools used to ensure the quality of the leaflets they supply and explained that this is also being extended to books. Specialist staff can also assess other biomedical resources for more complex needs. Mig emphasised the need to meet people's 'holistic needs' and said that many needs may not be expressed, such as the need for information about carer support groups. She also explained how calls and information posted are frequently reviewed.

Mig finished by discussing the diversity of callers' information needs and reasons why these occur. For example, a caller may not have absorbed some information given during a medical consultation because of stress, or perhaps they didn't like to ask or the doctor assumed knowledge they didn't have, or perhaps they just want some information confirmed.

Jane Wilson (day 2)

The second presentation on day 2 was given by Jane Wilson of the Patient Advice and Liaison Service at the Whittington hospital in London and Medi-notes. Jane has experience writing and producing patient information leaflets within the acute health sector about conditions, treatments and hospital services as back-up to clinician/patient consultations. It is from this perspective that her talk, entitled 'www.isthisbestwaytoaccessinformation.com', offered a critique of the internet as a means for providing health information, and also of the NHS as an information provider and clinicians as authors of patient information.

Jane distinguished a number of patient types: the 'expert' patient, the cancer patient, the young person patient, the majority patient, the other language patient, the elderly patient, the child patient, and the carer patient. She argued that different groups have different information needs and she criticised consultations with patient groups as often being conducted only with non-representative 'expert' patients. She argued that people do not necessarily want as much information as possible in order to make their own decisions about treatment, pointing out that one-in-five people in this country have low literacy levels and that overloading people with information is counter-productive. She argued that the NHS tends to be driven by risk management, politics and the media, and that this has resulted in a tendency to overload patients with information as an insurance measure.

Whilst the internet might provide better access to more information for certain groups, Jane argued the idea that the majority of patients have access to and want to use the internet. She said that many people are not comfortable with internet information, that reading from a screen can be difficult, and that the experience can be de-personalising. She also challenged the idea that patients know and are able to select the information they are looking for and argued that patients often respond better to a 'human touch'. She also argued that clinical experts are not always experts in providing information to people, and cautioned against 'patient friendly' information being understood to mean patronising information.

Jane discussed other electronic technologies used for delivering health information including CDs, touch screens, telephone, audiotape, television and video and pointed to a number of past failures, including: Patient wise for GPs, Doctor online, Medic-Direct. She made the point that since people need to re-read information many times in order to remember everything, information leaflets are particularly patient friendly as well as being more cost effective.

She ended the presentation by pointing out that the Department of health funds NHS Direct Online as a sole provider of health information in the UK and that there is no funding for information provision within the Trusts. Problems faced within the Trusts include the need for accurately translated information.

Breakout Session Reports (day 2)

In the day 2 breakout session, participants again formed three groups with each group discussing one of:

- information quality and use;
- social and organisational context;
- user requirements and training;

in relation to patients.

Information quality and use

The information quality and use group argued that information quality can be understood from a number of perspectives. These include not only content quality, but also quality of presentation and also the suitability of information for a particular application. They also argued that different groups—such as clinicians, librarians, pharmaceutical suppliers, patients and their relatives—perceive information quality differently. They argued that ultimately patients should be the judges of patient information quality.

The group presented a model dividing health information issues into four considerations: *source*, *medium*, *patient* and *feedback*. Considerations of source included the need for evidence based information that is reliable and current and perceived to be good quality. In relation to communication medium, the model identified questions of whether information is visual or uses audio, how it is delivered, whether it is anonymous and issues of language. In relation to patients, the model identified the patient's context as an important issue and drew attention to issues such as whether information is relevant, practical, clear, non-patronising, concise and perceived to have come from a trusted

source. Finally, the group identified the absence of a culture of feedback from patient to information source as an important issue.

Social and organisational context

The group dealing with issues of social and organisational context in relation to patient information drew ideas together under the heading 'culture and communication'. They distinguished the culture/personality of the doctor from that of the patient. For example, some patients may want to communicate whilst others do not. The group argued that health professionals should be flexible and adopt different roles depending on the needs of the situation. They also discussed how technology is changing and might further change existing working practices. For example it may be possible for electronic patient records to store more contextual, holistic information.

User requirements and training

The group concerned with user requirements and training argued that educating patients means going beyond providing information; that we should also provide them with information skills in order to help them to find and make use of information. They also argued that we each have different interpretive frameworks built around our own learning and experiences and that information provision should be enhanced to meet this challenge. They discussed the use of 'envisioning' as a means of eliciting patient's existing knowledge in order to inform the building of new knowledge. The group also argued for the provision of health education in schools, and for educating people when well more generally, and for the value of patient support groups. They discussed the value of mentoring and suggested the development of a new role within the NHS of 'information mentor'.

Andrew Herxheimer (day 2)

A short presentation was given by Andrew Herxheimer of the Dept of Primary Care at University of Oxford in which he gave a demonstration of DIPEX—a website which provides patient users with access to in-depth accounts of personal experiences of illnesses. Each account is in the form of an interview and begins at the point when the interviewee discovered they were ill. The interviews are video and/or audio recorded, transcribed and coded according to emerging themes. These themes are then summarised for each condition, and these appear on the site linked to the interview transcripts and video and audio extracts from the original interview.

In addition to the summaries, the interviews are organised by age and gender so that visitors to the site can find accounts by people like themselves. For each condition, the website also includes a section providing background information, a Q & A section, details of other resources (organisations, support groups, publications) and a glossary of terms linking back into relevant sections of the interviews.

Andrew was asked whether the site might be extended to include experiences of bereavement. He replied that this was not planned, but that a collection would soon be added called 'living with dieing'. He said that the project planned to have 100 collections of 40 to 50 interviews in the first five years, and that there is an extensive 'wish list' of conditions to cover. But he added that priorities could vary depending on the respective interests of funding bodies. Andrew was also asked about the difficulty of finding people to be interviewed, which tended to vary depending on the contact routes that were discovered.

Henry Potts (day 2)

The final presentation, 'What can we learn from how patients are using the internet?' was by Henry Potts of CHIME (Centre for Health Informatics and Multiprofessional Education) at UCL. Henry discussed an online survey of doctors experience of patients using the internet, and a pilot study looking at online patient support groups.

The survey of doctors asked how patients' use of the internet affected their health and their interactions with the doctor. The results showed that, although many doctors were unsure about patients' internet use, they judged patient's experiences as largely positive. 43% reported patients experiencing health benefits compared with 25% reporting problems. Significant benefits were: becoming better informed (62%), getting helpful advice (45%), social support (25%) and seeking medical help sooner (11%). Problems were: becoming misinformed (26%), gaining misleading advice (18%), misleading second opinions (17%) and risk estimates (13%), ordering dangerous or ineffective products (12%), and 'internet addiction' (11%). Qualitative results distinguished patients with unusual conditions, who became well informed and were an asset to doctors, and patients who tended to worry and who would "frustrate the most passive of doctors".

Perceived benefits for doctors included: patients coping better (35%), being more confident about self-care (34%), coming sooner for necessary healthcare (18%), and not seeking unnecessary healthcare (10%). Perceived problems for doctors included: longer consultations (64%), unnecessary investigations (44%) and treatments (22%), and patients less able to cope with symptoms (10%).

When asked specifically about physical benefits or harms, many doctors were unsure and many believed there had been none, but a small some benefits and harms were reported, including three deaths. Henry argued that these incidents were few given the number of doctors surveyed and the number of patients this would represent. Qualitative results showed that poor quality information was less of a problem than too much good information. Also, consultations that involved viewing material from the internet were considered useful although time-consuming.

Henry drew attention to the result that 25% of patients gained social support from online support groups, and the idea of the Internet extending beyond the provision of information. His work in this area focusses on cancer related groups of which he has performed an audit and pilot survey. The audit showed there were 308 active English language cancer related discussion groups. Henry reported great variation in the sites, many of which focussed on specific cancers with some specific to particular minority groups.

The pilot survey suggested that the groups were mostly considered extremely supportive, and had affected condition management and relationships with healthcare professionals. Qualitative results also indicated the value of communication between people experiencing particular cancers and treatments, and of being able to relate to others experiences. People also reported being disinhibited when communicating with the groups, and valued the lack of time constraints. Negative comments included occasional time-lags in responses, that other peoples' stories could be upsetting, and that the lists tended to be US centred.

Henry explained that future work would include extending the survey to a broader range of support groups, and developing short courses to inform healthcare professionals and patients.

Conclusion

Effective ways to use non-personal information in healthcare was a successful and productive workshop in which participants brought a good deal of expertise and knowledge into discussions of issues surrounding electronic health information provision. A strong sense of collaboration and consensus emerged during the workshop around some common themes. One key theme can perhaps be summarised as the idea of engaging with the context of health information use—of understanding real needs and real uses, whether these be for evidence based clinical information or for practical information about managing strategies or for social support. Under this theme is the idea of understanding and tailoring information and information systems to users' situational needs and understanding. A second key theme can perhaps best be summarised as the need to engage with the greater democratisation of information by understanding, how, under these circumstances, people and organisations relate to technology and to each other, of understanding how people can be empowering to make their own information quality judgements, and of understanding how communities can be motivated and configured to engage in successful information communication and management.

Presentation files for the presentations discussed here can be found www.cs.ucl.ac.uk/staff/S.Attfield/workshop