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NHS
Institute for Innovation and Improvement

Armchair Involvement

Practical technology for improving engagement

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The NHS Institute for Innovation and Improvement and Involve have been exploring how new technologies can be applied to old problems in order dramatically improve services. We wanted a clearer idea of the opportunities for public and staff involvement in the NHS through multimedia technologies and to uncover whether these advances will help to reach those at risk of exclusion from involvement using traditional methods.

The future possibilities for participatory technologies look very exciting indeed and there is a great deal of enthusiasm across the NHS for using these tools to reach people, better understand their opinions and to encourage involvement in service improvement. It is this energy for improvement that this Armchair Involvement project hopes to capture and inspire.

This guidance aims to highlight the benefits of investing stakeholders' time and energy into new interactive formats; the trade-off being their potential to stimulate improved communication and to enable provision of tailored health advice and service information on the individual's own terms.

Our approach has been to ask key thinkers and leading experts from health, information, television, multimedia, horizon-scanning, telecommunications and service design what today and tomorrow's world looks like. We encourage you to visit the armchair discussion forum and contribute your own experience and opinions.

We hope that this guidance will provide a valuable insight into both the immediate and future potential of developing technologies to have a positive impact upon how patient care is planned and managed.

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Thank you to all who gave up their time to contribute valuable ideas and insight to this report through interviews, surveys, meetings and provision of comments and images. A list of contributors features in the appendices.

1. Introduction

The NHS Institute for Innovation and Improvement commissioned Involve to run the Armchair Involvement research project in Spring 2007 with the intention of exploring the ways in which public, patients and staff can use a wide variety of technology in order to engage more effectively for NHS service improvement outcomes. Such applied technologies are here referred to as tools for Armchair Involvement as they are representative of the way in which participation can be enabled and enhanced by innovative use of technology in order that communication may take place more fully on the individual's own terms, perhaps quite literally from their own 'armchair'; indeed from wherever suits them best.

There are many current and emerging initiatives that are playing and will play a significant role in shaping the essential everyday conversations between the NHS, patients, staff, carers and the public. This document seeks to discuss some of the trends and possibilities which may impact upon the ongoing implementation of these technologies with the proviso that no matter how smart, technologies alone are not a panacea for service improvement.

It is only through innovative application, wider co-ordination and all-round commitment to[1] these technologies as tools[2] within a culture of engagement that the potential benefits of increased participation in health and healthcare can be realised. It is hoped that an increasingly participative approach to everyday interactions will increase the capacity of the NHS, and indeed its users, to drive health service responsiveness and to provide support where and when needed[3]. In producing this report we recognise that there is a distinct area around telemedicine and remote care which is related to technology based engagement and involvement. Whilst this report touches on that vast topic, it will focus primarily on technology as a tool to assist better communication with an emphasis on fostering a more participative and responsive culture.

In the first instance, this report is aimed at NHS staff, and all of those seeking information about the potential of such applied tools. We hope that it will be of benefit to discover more about factors that may affect successful uptake, and to introduce tools in simple terms using examples to illustrate. The report is also intended to provide a wider perspective for those already familiar with implementing certain technologies in this field and to consolidate information on work that is scheduled, underway, or recently completed. This initial research and information gathering exercise will be followed by an event hosted by the NHS Institute for Innovation and Improvement[4] which will bring together key stakeholders from across technology, communication and health sectors to discuss and expand upon initial findings, to contribute to such examples as found in section 5 of this document and to take the initial observations forward. This research is designed to offer key inputs into the role of technology in shaping of the NHS' future relationship with staff, patients, carers and the public.

Context

It is widely accepted that the future healthcare challenges that the NHS will face over the next 5-10 years and beyond are set to stretch limited resources ever further. It is therefore ever more important to use those resources to maximum effect as a way of "encouraging greater public engagement in order to increase levels of health awareness and establish a more effective partnership between the public and the health system."[5]

The combination of a rise in the numbers of people affected by chronic conditions[6] along with the related issues of an ageing population[7], increase in obesity[8]; and an increasingly well informed public with higher expectations will place demands upon the NHS that simply cannot be met using the curative model of care. It is increasingly apparent that a drastic change in approaches to healthcare is required such as is now well documented.[9] It is believed that a key part of this approach will be a shift from a sickness (curative) service to a wellness (preventative and supportive) service. Practically speaking, this means greater focus on the patient's needs, the integration of health services with social care, and emphasis on a shift from hospital to home or locally based care.

In order to enable such change it is essential that the public are in receipt of effective support[10] to take more responsibility for their own well-being and approaches to healthcare which fits more comfortably with their own lives than the present system. The 2006 Royal Society report *Digital healthcare: the impact of information and communication technologies on health and healthcare* set out the premise that ICT clearly has the "potential to transform radically the delivery of healthcare and to address future health challenges." This is demonstrative of growing importance placed upon building technology into the development of a more responsive and personalised communications interface in both a public and patient engagement context.

In addition to such pressing need to change the way in which service is provided, there is also an incentive for individuals to participate in their own relationship with the health service more effectively as it has been shown that health outcomes can be improved by web-based interventions.[11] Evidence supporting the benefits of public involvement in the shaping of services is less developed.[12] In particular, whilst there is a limited body of evidence showing perceived benefit[13] reported anecdotal benefits such as those offered by interviewees contributing to this project show that more research into that evidence base is required.

Armchair Involvement tools as referred to in this document are the applied technologies that will enable such an involved approach to health and healthcare to be implemented in a more effective and efficient manner than may otherwise be possible. This report starts from the premise that it is through the innovative application of technology by enthusiastic and well-trained staff that the NHS will be enabled to work to meet the future healthcare challenges that we all face. However it is worth noting that the usefulness of the emergent infrastructure is highly reliant upon the quality and accuracy of the data it carries.

This report marks the beginning of a process of learning, debate and conversation for the NHS Institute and key stakeholders in light of the situation as outlined above; it is only through fully understanding the potential and limitations of each innovation that the best practical applications may be explored and actioned by those at the front line of our future national "wellness service"[14] - whether they be a member of staff, member of the public, patient or carer. With a view to consolidating information gathered in this research exercise in the most useful and transferable manner we have also produced the Tools for Armchair Involvement

section of this document (Section 5) which gives examples of current and future Armchair Involvement initiatives and aims to act as an introduction to the various terminologies and practical potential. This offers a key database for those requiring a fuller picture of or greater familiarity with Armchair Involvement tools.

2. Research

Involve have worked to produce this document with the assistance of key thinkers in the field. These include leading experts from health information, television, multimedia, horizon scanning, telecommunications and service design. (See Appendices for full listing.) Our aim is to provide an overview of the overall potential and limitations of technologies to impact positively upon service improvement and experience over the next 5-10 years , how this may be affected by various trends and where the pitfalls may lie.

The aim of the research process has been to highlight current work and to explore ideas and potential improvements to current engagement strategy taking into account existing and future trends and possibilities. This document is structured in the following way: an analysis of research results, presentation of key findings, Tools for Armchair Involvement (section 5) which provides an introduction to various applied technologies with practical examples, giving an overview of current and potential Armchair Involvement methods. This discrete section is designed to be understood by any party with an interest in Armchair Involvement initiatives and to promote knowledge sharing. Readers should note that this is not an exhaustive list, though it aims to act as a solid introduction to the area and has been written with a view to being built upon further by interested parties.

Methodology

The methodology used to gather information reflects the broad and speculative scope of the project which seeks to identify key points requiring further attention. The research has drawn on a range of resources in developing its analysis as follows:

Interviews: took place face to face and via telephone with 22 key stakeholders representing a diverse range of perspectives. These were informal in nature although guided by a standard schedule of questions and included representatives from national media, the Department of Health, charity and social enterprise amongst others. See appendix A for a full list of participants.

Iterative survey: completed anonymously online in order to allow full and frank comment. The iterative process aimed to produce a high level of deliberation and qualitative feedback on issues in question. Results from all three rounds are available here.

Discussion workshop: attended by a group of key stakeholders including representatives from service design, patient representation, technology and ICT, and the Department of Health. At this event initial research outcomes were shared and the progression of the project was discussed.

Desk based research: including web based searching covering the topics of engagement outcomes, current and future pilots of armchair involvement tools, as well as informal telephone conversations gathering advice and information.

Definitions

Terms such as "participation" "public participation" "patient involvement" and "involvement" are often defined slightly differently by individuals, and there is overlap within those definitions[15].

This was reflected in the research process as interviewees offered varied reflections on the term "participation":

"Participation is everybody feeling that they have the ability to contribute."

"It is joining in the decision making process- whether it be your own care or the running of your local hospital."

"It's about people feeling , feeling and being involved in, whatever process it is, feeling they own it and they can influence it."

"I think potentially its very powerful, but initially at least it's largely on an individual level and the aggregated community participation probably still needs some work and some volumes built up."

Indeed throughout Involve's work in the area; involvement and participation are consistently taken to mean a plethora of different things to different audiences in differing circumstances[16]. Therefore we have chosen to open the definitions to the most inclusive terms possible to reflect the broad scope of this research process:

Involvement and Participation

For the purposes of this document, we seek to understand involvement as having three levels, the most engaging of which is termed participation:

- **Information:** At its most pared down level, involvement is about effective information provision: to all of the right people, at the right time in the most accessible way for that individual's needs.
- **Feedback:** Involvement is also about providing an opportunity to give feedback and response to information and service provision in a structured or conversational fashion.
- **Participation:** In its most complex and engaging form, involvement is a method of encouraging participation in service provision on a number of different levels in a more continuous and discursive way.

Involvement in healthcare can also be understood in two modes:

1 Personal involvement with the Health Service whether in terms of wellness prevention or healthcare relationships on an individual level

2 Group involvement in the shaping of services from either staff or user perspective

3. Results and Analysis

This section details the outcomes of the research and identifies key themes, drivers and findings which will influence how technology can be used to aid participation in a health service context. The themes identified were around expectation and deference, preventative healthcare, sharing experiences, informed decision making and improved outcomes:

Great Expectations?

Interviewees and respondents asserted that public expectations of the NHS are increasing countered by a decrease in deference towards authority and a faster-paced more responsive consumer driven service economy. The expectations were centred around being consulted and involved in healthcare decisions; being able to access clear information quickly and easily; finding a solution or cure for conditions and illnesses; and experiencing an efficient, approachable and responsive service.

"The pace of change in other areas of society is fast and technologically advanced. Most of the public doesn't consider the NHS until it needs to use its services and then expects a great deal from it."
Interviewee

This quote reflects how NHS is set to face greater pressure to perform in a more efficient and effective manner, to provide a patient centred experience and also, internally, to provide better working environments and involvement for staff. There is work being done to meet expectations through the IWL[17] (Improving Working Lives) initiative, but the area of involvement and partnerships is perhaps the least well developed. Communication technologies can be used to join up systems more effectively for improved working practice and service experience, and can provide savings.

Some interviewees and survey respondents also identified a generational shift in public expectations of involvement in health;

"One of the big problems of health delivery is that people aren't questioning enough really. That's partly generational, older generations have respect for doctors that precludes them from questioning or asking exactly what they want." *Respondent*

It is important to recognise that increase in expectations and assertiveness does not apply across the board, and to develop methods of engagement which enable people to become involved in personal health up to a level at which they feel comfortable. It is also important to acknowledge that what patients may want can differ from the treatment that clinical indications show that they need. Although expectations of personal involvement are generally increasing, there are significant parts of the population where this is not the case- assertiveness and willingness to assume the opportunities for greater control that are offered by technology should not be assumed.

Prevention is better than cure

One of the aims identified of engaging people more closely in their personal health and well-being is to increase the number of quality of life years they experience; preventing illness and prolonging life. The shift within the NHS in focus from sickness and cure to wellness and prevention reflects the fact that the management of long term medical conditions and other issues relating to old age are of increasing concern. These trends are discussed in greater detail in the Wanless reports which also outline that a more engaged public with higher levels of well-being will assist in relieving the financial pressure of such situations by remaining healthier for longer. However, an international comparison study by the Picker Institute found that;

"Despite the strong official commitment to developing a patient-led service, our results suggest the UK is not performing well when it comes to involving patients in their care."[18]

Technologies alone cannot substitute for a strong culture of and commitment to involvement in practice of preventative health and wellness. However, they can supplement such practice and make support more responsive for individuals who are making their own self-care or lifestyle choices. Encouragement can be provided remotely to people via technological means, from informational text messaging services to online interaction in forums or via web conferencing. The increased scope for personalised information provision in a wellness context that web and mobile phone technology brings with it is also important in getting wellness and lifestyle messages across in a more targeted way - to the right people in their preferred mode of access.

The provision of effective support to those who take up the use of technology when they require human interaction must be emphasised as an essential part of the process to be included from the planning stages of implementation. Yet technology can provide tools to promote health literacy and to reach groups which may not otherwise be easily targeted - there is a need for balance and consideration when considering which tools to use, and what level of human support may also be required behind that interface.

The other main purpose of supporting this shift in emphasis from curative to preventative healthcare is the substantial projected cost benefit as outlined in the final Wanless report. Armchair Involvement tools could contribute by enabling people to find information, to make more informed choices, and to communicate more effectively with the NHS in a cost effective way, making greater use of the internet. This could contribute to a reduction of demand on the NHS in line with the 'fully engaged' scenario as outlined in the interim Wanless report.

"Fully engaged – levels of public engagement in relation to their health are high: life expectancy increases go beyond current forecasts, health status improves dramatically and people are confident in the health system, and demand high quality

care. The health service is responsive with high rates of technology uptake, particularly in relation to disease prevention. Use of resources is more efficient."

Sharing Experiences

There is great potential for technology to facilitate more efficient and effective information sharing for staff for patients and for the public.

The NHS as one of the largest employers in the world has a team of around 1.3 million people to communicate with and to motivate. The need for a more engaged and connected workforce can be met in part by using new communications technologies to support active participation in information sharing and more efficient communication across the service.

Teambuilding, for example could also be developed independently of physical location using online social networking tools, although the value of face to face interaction as a way of cementing relationships must also be considered when constructing online communities, whether they be staff or patient driven. The recording and sharing of experience via webcasting is another way of promoting experiential learning in a more immediate and effective way than using written information alone. This is explained in the box below.

Webcasting

Web-based video clips such as those seen on the site YouTube could allow staff to share tips and experiences as well as cutting edge knowledge. The advantages are that anybody with access to a webcam or cameraphone could record their own snippet of information and then post to a central site or YouTube channel to get that message across to others; demonstrations can be represented visually rather than described through text and illustration.

This could go a long way to avoiding duplication of effort across the service, but as with all video dependent sites and channels, success can be affected by slow internet connections, number of participants and quality of content. The great advantage is that information could then be contributed and accessed at the convenience of the individual- on demand- and could build into a library of visually engaging and up to date resources. Patient Voices and DIPEx provide some video information in specific areas of concern; both are still being added to. There is enormous potential for a central staff information hub with democracy of access in terms of DIY uploading.

The experience should not necessarily end with the close of the video clip- platforms such as YouTube allow comments to be posted and discussion around the topic to take place. This interaction and discussion could add further opportunity for a deeper level of feedback or participation than simply viewing.

Webcasting and teleconferencing will be made a more widely accessible option for three reasons- the availability of cheap, increasingly high quality recording equipment, the increase in capacity and knowledge around computing technology and faster broadband internet access; as one interviewee commented:

"Broadband could be very useful - continuing professional development for doctors and nurses"

Interviewee

The public's experience can also be shared via web forums or ratings services which could provide the ability to post messages, photos and videos, and to share health related and lifestyle information. Groups may also be formed around various illnesses or long term medical conditions, such as diabetes support organisations expert patients groups which are already in existence and are putting such types of information sharing to good use- a trend which could be furthered. Technological means such as social networking platforms or text messaging and phones all offer the potential of support provision to those groups and other organisations, allowing them to form more flexibly around individuals' communication needs rather than say requiring regular attendance at face to face meetings which may be a barrier to participation.

"Sharing of patient experiences is really useful. I think patients will and do organise it themselves anyway the NHS could do alot to support it if they don't support it people will find a way of doing it anyway. I think it's where all the real action will happen. It would be better if the NHS could engage with that- that would be the chance to get across the preventative primary type of activity- to get involved in that activity in the space people want to be."

Interviewee

Another advantage of many technologies such as text messaging services, emailing or social networking sites is that the user may share information or enquire anonymously which can break down barriers to participation around sensitive issues, for example on sexual health issues for young people.

However, in order to secure this outcome it is important for the NHS to seek out where people are already using technology to share information and make real connections with each other and to build around that usage pattern rather than to try and enforce new ways of working onto public, patients or staff.

There are several advantages to taking this approach; resources would be saved in setting up and maintaining additional information services as many excellent forums are already in existence and are being used by an active network of people such as CancerBackup or

Netmums for example. The co-existence of NHS services alongside such independent organisations could nurture diversity and choice.

Additionally, discovering more about how different demographics of the population want to access information, such as young people's usage of YouTube or text messaging for example would enable resources and information to be targeted more effectively to the correct audience on their own terms.

"It's important when assessing how the technologies will affect the relationship between the NHS and public that we think of particular cases. It's of little benefit to say 'how will mobile phones change the way we keep in touch with our doctors?' … rather we should think 'how do we currently keep in touch with our doctors, how could this be improved, and what technology can enable this." *Respondent*

This also applies within the NHS, for example building upon and developing the interactive information sharing and multimedia potential of the website NHS networks for staff and users.

Decisions and Information

With an increase in the range of future choice of care and wellness will come a greater responsibility for individuals to make decisions affecting their health. Therefore there is need for the NHS to assist people in terms of effective information and support provision so they are enabled to take this responsibility in a safe and effective way. The implementation of initiatives such as the healthguides version of Map of Medicine pathways tool is one such example of targeted, high level information provision. There were a number of risks of using technology to engage people remotely that were pointed out to us during the course of the research.

"People may be overwhelmed with responsibility and not able to cope with that. There's certainly an increasing feeling that technology is a way of sort of dumping on patients." *Interviewee*

This assertion was repeated in a number of interviews and also in the survey results and desk research. There is currently a drive from within the health service and externally to ensure that such information is provided to people in more accessible and personally tailored fashion. Initiatives are set to become still more tailored in the future with the advancement of genetic testing, such as the OPERA (Online Personal Education and Risk Assessment) familial breast cancer project which is due to launch in 2008[19] and which will allow users to personalise information by inputting familial history information. The possibility of an accreditation scheme to mark out trusted sources of health information on the web would be

one way of tackling the issue of quality, and guiding people to the most reliable and useful information from amongst the vast number of web pages relating to health.

A google search for keywords -heart disease advice- brings up around 2,070,000 webpages, -cancer prevention- brings up an astonishing 57,300,000.[20]

Although increased information provides many opportunities there is a danger of information overload[21] - the possibility that patients and staff will have difficulty in filtering out and putting to use such vast amounts of potentially useful information that they are now able to access at the click of a mouse button. Not only must people must find ways of prioritising and filtering that data to make it useful for themselves, but organisations must also seek to segment and tag[22] their information in ways which allow flexibility of dissemination across different platforms to users with differing needs. To support this, the personalisation of information provision was mentioned by many interviewees as being an area which technology can contribute very positively. The NHS Choices website reflects this by seeking to provide information in segmented ways that can be increasingly personalised by users as the site develops.

Whilst technology has the potential to aid decision making processes for patients and staff a number of multimedia and offline decision-aids which can guide people through the process of decision making are available[23] and are known to be effective[24]. However, the importance of the relationship with the clinician in such processes must not be forgotten.

"It isn't just about information at all, it's about how you can make it most accessible to patients, and patients don't want to take the responsibility often so it's a real key triangle between the patient, the doctor, and the information. The doctor is still necessary, or the clinician is still necessary I think to translate that into action."
Interviewee

This relationship may continue its evolution into more of a partnership approach spurred on by the advent of the Electronic Patient Record which is currently in development.

"People can get information that's tailored to their own individual needs through the record. So, if they had asthma for instance then they could automatically bring up all sorts of things to do with asthma including a national voluntary agency and so on, also they can be informed about all the tests they've had done and all the explanation and understanding of those."
Interviewee

Staff decision making around policy and service development can also be affected positively by user input and health service interviewees consistently mentioned the positive aspects of involving users in their work with the public. Technology can be a positive enabler in these circumstances as a way of gathering feedback in a cost and time efficient manner via web or text polling, and eliciting participation in terms of e-panels, user groups connected by the internet.

Electronic Patient Record

Potential

Electronic patient records are a way of coordinating information from across the varying digital and paper records systems that are currently in operation- however they can be much more than just a computerised filing system.

There is great potential for the record to improve patient safety, to inform shared decision making, and to contribute positively to self-care strategies. Features that can be added on such as creating information prescriptions at the point of diagnosis could be linked to the system.

Scans, recordings of consultations and other multimedia content could in time be added or linked to the record in order to provide a fuller picture for staff and patients alike of an individual's medical history. The ability to give virtually instant access to healthcare providers in other countries could provide important assistance to those travelling abroad, with reciprocal arrangements possible in the UK.

Implementation: addressing concerns

There are some concerns and risks, primarily regarding third party access and security of data which can be minimised through initiatives such as fingerprint security access, or by allowing full patient ownership of the record. Certain at risk individuals for example those with certain mental health issues could be considered for limited or supervised access schemes in order to avoid harm or distress. It is worth noting that the patient record system would only be as useful and accurate as the information it contains – the inputting and accurate maintenance of the record is essential to its success.

Safety can be improved by the facility of patient access to their record- any errors can be corrected by patients themselves, and patterns of behaviour can be more effectively documented in order to support self-management. The record can be used as a tool around which a more equitable patient-clinician relationship can be based. Web based decision aids or tailored information sources could be linked to the system in order to help individuals make more informed decisions about lifestyle or healthcare choices. Localised information could also be provided, linking individuals to conveniently situated support or fitness groups.

Improved Outcomes?

"There is a growing belief among policy-makers that patients/citizens can contribute to quality improvement at both an individual and a collective level."

Patient Focused Interventions: A review of the Evidence
Picker Institute (2006)

Involvement in the management of healthcare is thought to increase patients' feelings of control and empowerment, and to have beneficial health effects. Although there is much more work required to produce robust evidence in this area, the evidence based research paper Patient and *Public Involvement in Health: The Evidence for Policy Implementation* (DH 2004) suggests that;

"Patient involvement increases patient satisfaction. Benefits also include greater confidence, reduction in anxiety, greater understanding of personal needs, improved trust, better relationships with professionals and positive health effects."

It also identifies that in terms of benefits to NHS staff;

"Professionals value the personal rewards of patient involvement but also see the process as a means of managing consultations more effectively."

And in terms of public involvement, that;

"Public involvement influences the policies, plans and services of NHS organisations and increases the confidence, understanding and skills of the people who participate…Partnerships enable learning, resources and expertise to be shared across health economies."

The Picker Institute/Health Foundation paper *Patient-focused interventions A review of the evidence* provides a rigorous evidence based assessment of a vast range of interventions, some of which are technology based. The results of these studies are relatively positive, although not entirely conclusive and further research is called for along the following themes; the benefits of technology for involvement in terms of information giving, health literacy, public engagement in the shaping of services, and benefits of involvement for staff.

Another recent Picker Institute research paper; *Engaging Patients In their Healthcare: How is the UK doing relative to other countries?* (2006) further supports the case for involvement in terms of service sustainability, emphasising that:

"Engaging patients in their healthcare and encouraging people to take responsibility for protecting their health are seen as the best way to ensure the sustainability of health systems."

And in terms of cost savings that,

"Patient engagement is a key component of the strategy to keep future healthcare spending within manageable limits."

It would seem therefore that the case for engagement is growing stronger, but that further rigorous examination of the effectiveness of varying approaches and methods used is required. A more considered and developed understanding of the individuals' relationship with new technologies could be attained through increased emphasis on research which focuses on real life usage patterns and attitudes to taking on new technologies in healthcare.

Overview : What have we learned to date?

There is currently a wide variety of work being done to pilot new ideas, mainly web-based, digital TV and text services, but little in the way of co-ordinating efforts and sharing of learning. Some of the work is driven by the NHS or Department for Health, and a number of interviewees noted that much is also being done outside the NHS through more informal networks on web based forums, along with independent websites with national reach such as Patient Opinion, Cancerbackup, and the Alzheimer's society amongst others.

Whether top down or bottom up, there is a need for these endeavours to be more co-ordinated. The six DH backed projects run as part of ICTRI (Information and Communication Research Initiative) are good examples of the current work being done in this area, particularly regarding the telemedicine and chronic disease management aspects. A number of interviewees identified the need to find better ways to share learning, of using technology to enable more effective engagement. The information contained in section five of this document, Tools for Armchair Involvement seeks to go some way towards kick starting this process.

Non-NHS contributors to the research also highlighted the need to develop better ways in for externally produced new ideas to be taken up by the NHS and for innovations generally to be taken up more effectively. It was suggested that further piloting of small scale projects continues to be an effective approach, cases where this is already happening for example the mihealth breast cancer information pilots[25] were praised being forward thinking by several interviewees. Risks around investing too heavily in particular technologies without being certain of outcomes could then be minimised through such techniques.

"They need to develop a kind of culture and operation where its possible to try on these things and pilot without going through endless hurdles because sometimes its just better to do something. That's how innovation happens… Basically you have to find some space within the culture of the NHS to enable that to happen."

Interviewee

Another suggestion mentioned primarily by non-NHS contributors was that of the support of the development of technical expertise in departments charged with commissioning work on technology based tools for involvement. Up to date knowledge of the technologies available and the success and shortcomings of existing pilots could be a truly valuable resource in terms of saving time and money.

"I think the biggest risk is lack of knowledge about what the options are. I think the biggest risk is lack of info about what can be done as opposed to what is being done." *Interviewee*

The existing work around using technology for staff involvement and teambuilding is currently limited[26] and many of those we spoke to could place few good examples of work in this area, this shows a low awareness of the work being done.

"I'm not sure that there is anything targeted directly at staff experience outside of that which is related to particular programmes of work... in terms of a consistent piece of work, I'm not sure it's there."
Interviewee

Participants argued that there would be benefits from further attention in this specific area particularly around increased or dedicated on demand services for knowledge sharing. Sharing knowledge and experience more effectively was highlighted by a number of survey respondents and interviewees.

"I think one of the strongest areas is around the sharing of experience- being able to provide a sense of 'I'm not alone in this' I think that's doable in a broadband world."
Interviewee

There also continues to be a great concern over ensuring equal access to services and preventing a gap between those who can access technology and those who can't. The possibility that the digital divide (inequality of access to technology) may be deepened by the uptake of new technology was mentioned frequently by interviewees and survey respondents.

"I think, for me, the whole kind of divide issue is so much the biggest risk that it overshadows others."
Interviewee

"The elderly and vulnerable population will be at increasing risk of alienation."
Survey Respondent

As this possibility is at the forefront of many people's minds in the area, they showed action is being proposed to avoid such a scenario by using a multi-channel approach to information provision and access to opportunities to participate[27]. As one survey respondent put it:

"Technology will increase impact only if it is matched with the message and the audience. The right one for a specific message and to a specific audience. We have to be careful not to create new barriers to access. We don't have to get every message to everyone, so we can pick the technology for the purpose. Let's really

understand how the target audience get their information before we get excited by the widgets." *Survey Respondent*

However, a significant minority of interviewees did not see the digital divide as a problem, rather stating the identification of such a concept as being an excuse for inaction in this area. This feeling was also reflected amongst survey respondents:

"I disagree with the comment that access to digital and information communication is only accessible to the middle and rich classes. More and more access to this medium is available through mobile phones and is being accessed by all. Plus libraries across the country now have accessible computers for the public to use for free which are internet linked."

"We are entering an age where increasingly older people are IT literate, access to technology through digital TV, mobile phones, etc. is becoming universal, and Web 2.0 technology empowers people in new ways. People will have the tools. It's giving them the confidence to take control of their health that is the biggest challenge.
Survey Respondents

Supporting this, there is some evidence to show that once such excluded groups are provided with the opportunity and basic skills to access information via the web. There is in fact some evidence that they are able and in some cases more willing to do so such as the ongoing CHESS[28] project run in the USA which provides a computerised patient support system to breast cancer patients from excluded groups. Other examples of excluded groups gaining greatly from the use of ICT are included in the 2005 report from the Social Exclusion Unit *Inclusion Through Innovation: Tackling Social Exclusion through New Technologies*.

There are certainly barriers to access including literacy and language issues but some of these could be limited by the application of accessibility tools such as page readers and translation tools. The 2005 study found that *"Usually those with more experience of using ICTs had a more positive view of them, while those with less experience tended to be more negative."* This would suggest that it is the effort made to introduce people to technologies and the benefits they offer in the first instance which is the significant factor. The development of suitable, tailored tools that make it worthwhile for such groups to engage with technology past that first encounter is a key area which could be addressed by seeking to involve them in the design process of that experience from the outset. The co-design work done by open health by the Design Council, and Experience Based Design project commissioned by the NHS Institute from Luton and Dunstable Foundation Trust working with thinkpublic are good examples of how engaging people in a process can increase feelings of empowerment as well as usability and satisfaction.

Public engagement processes such as mass deliberative exercises are also an example from the USA that we investigated during the course of this research. Please see the box below for further information on the California Speaks healthcare example which demonstrates good outreach to excluded groups and mass scale public service consultation in action.

California Speaks

On August 11 2007 Arnold Schwarzenegger, the governor of California led a state-wide conversation on the future of Healthcare in California – California Speaks. Billed as the world's biggest ever single day face-to-face citizen engagement process, the ambitious initiative engaged around 3,500 people at eight simultaneous events across California. The process came in response to Schwarzenegger's proposed comprehensive health insurance reform for California (January 9 2007). The aim of the proposal was to create nearly universal health insurance coverage in the state.

The process:

The aim of the public engagement process was to discuss proposals for reforming California's health care system and send a message to state leaders about the public's priorities. The process used is known as a '21st Century Town Hall Meeting' in the US, and as a 'Citizens Summit' in the UK. Gordon Brown's recent Citizen Juries were run on the same model as these. The difference here was the scale of the process. The main site in LA involved1000 people and each site was linked via a live video link, similar to Live8.

Probably the most interesting part of the process was the use of low tech community meetings, which could be connected to the larger meetings through a webcam and voting over the internet. The process was explicitly supported by the Governor and the democrats who spoke at the various events.

Impact

It is hard to be able to see the precise impact of the process thus far. We do know that the process mobilised hundreds of participants to contacted their legislators by phone or mail, encouraging them to act on health care reform this term.

Before the end of the regular legislative session in mid-September, Governor Schwarzenegger called a special legislative session specifically to address healthcare reform. Negotiations between the Governor and legislative leaders have continued throughout the special session. Many of the areas of negotiation surround the issues of greatest concern among CaliforniaSpeaks participants such as making sure any required healthcare coverage remain affordable and holding insurance companies accountable for regulating costs.

As of this writing, no bill has been passed and the Governor and legislative leaders are still continuing the negotiations.

Which technologies are considered to be most important in the future and why?

A multi-channel approach to involvement was widely emphasised throughout all of the research gathering exercises, and although the future inevitably remains uncertain, particular innovations stood out as being important for future engagement, as they were mentioned as being key across the board. These are discussed below in terms of internet and mobile phone technologies and are then broken down into more detail with reference to the practical applications of the technology in the tools section of this document alongside the less widespread or lower profile tools which were also highlighted by the research process as being important.

Although we have highlighted some of the more regularly identified technologies from the research gathering exercise, each one is only part of that multi-channel approach. As survey respondents put it:

"There is no one method of reaching everyone today, we all consume information in different ways, so we have to have many communication channels. The basic message is to make our communications two way- always- and to have someone respond." *Respondent*

"We need to capture patients' experiences and views on health care via different methods and options. One size will not fit all and various tools for engagement need to be explored."
Respondent

Consequently, in addition to key tools as discussed below it is worth mentioning that others were seen as being important particularly to the improvement of accessibility and information provision for excluded groups. Specifically, the potential for Digital TV or mobile phones to reach those households without internet access[29], and the incorporation of translated information and other targeted aids to communication such as the speech software tool as now used on the NHS Direct website. Further information can be found on the wider range of tools for accessibility highlighted in section five of this document.

Mobile Phones to all in one devices

The mobile phone seems set to continue its evolution from a person to person voice communication tool into being a multimedia and multi-function communications unit with

various capabilities over the next 5-10 years. With the features that 3G phones[30] offer, we are beginning to see a shift towards communication and entertainment devices that also have phone capability, rather than the other way around known as Smartphones. Mobile phones and PDAs (Personal Digital Assistants) were consistently highlighted as a key tool for involvement by interviewees, survey participants and steering group members.

Evidence shows that mobile phones are now widely used; recent Ofcom data[31] showed 116.6 active mobile connections on average per 100 of the UK's population- more than one per person. The ubiquitous nature of the mobile phone has driven prices down and made access more affordable. Resultantly, the wide reaching demographic of user profiles makes them appealing in terms of reach into potentially excluded groups[32] such as young people and those on lower incomes who may not have internet access as a household.

"That's one of the merits of the mobile- its good for hard to reach people it doesn't have the overheads of PCs and broadband - that sort of thing."
Interviewee

Currently mobile phones are primarily used for voice to voice communication, text messaging[33] and storing information such as photographs, phone numbers and diary information. However, multimedia messaging, teleconferencing and internet access are all ways in which handset functionality is set to be enhanced in the future with higher quality visual information and wireless internet access. These capabilities have existed for some time, but are currently in the process of trickling down into wider usage.

It is not just these existing functions which make mobiles a key tool for participation. Functionality allowing internet access gives the mobile phone further appeal as a convenient all in one communications tool for the individual seeking information as well as interaction. In the future embedded monitoring sensors including for example GPS capability, pedometers, blood pressure measurement will expand the capability of such devices still further.

The all in one appeal of a portable ergonomically designed device fits in well with people's communication needs. It is worth noting that although some questions are still being debated around the safety of mobile phone use; the way in which the phone can act as a communication tool, a way of accessing and storing information and as a device which can document and share experience via voice and video recording gives the mobile phone/all in one communications device a particularly strong appeal.

The Internet

"I think that it is radically changing the way the public interconnects with organisations be they public or private." *Interviewee*

The internet offers a vast array of opportunities for people to engage with health issues on various levels- from the provision of more targeted and personalised information such as the information prescription that is currently being piloted, as well as improved feedback mechanisms including email, to user-driven forums and information sharing.

The World Wide Web, the interlinked webpages that exist on the internet, will continue to be important as a communication and information tool if current trends[34] of growth in internet use continue, as people's familiarity and trust deepens in terms of what level of engagement they are prepared to undertake online. For example, making purchases, trusting information given from official sources without the need for person to person confirmation, giving out personal information and details are all examples of trusted interactions rather than simply seeking information online as a supplement to other sources.

"There's a lot of talk about mobile phones and ipods, but I think its people using the internet in a way they hadn't a few years ago." *Interviewee*

The spread of cheaper broadband access will increase download speeds and therefore enable better streaming of video on demand and other multimedia features. Access to inexpensive home computing hardware and open access software will also remove some of the barriers around cost for many individuals and organisations in future.

There is much discussion of the participative web in terms of Web 2.0 which is a perennially disputed term that this report has sought to avoid for reasons of clarity. This movement towards participation and collaboration on the web that is sometimes loosely termed Web 2.0 denotes the fact that the web is a democracy in terms of input[35] [36] and access and has brought about a certain shift in the balance of power of information and knowledge pathways in terms of the prevalence of user generated content and online interactions. A number of interviewees and respondents pointed out that the NHS should seek to support or compliment such bottom-up approaches, and to be part of the conversation without seeking to dominate it for reasons as discussed in the above section 'Sharing Experiences'.

The personalisation of information in order to reach specific audiences more effectively is a major feature of modern health information provision. Tailoring information in terms of subject, language used, format and presentation is something that the internet is well placed to advance as information can be segmented and presented in targeted formats, such as the NHS Choices website seeks to do. Automated email services can be subscribed to by interest group or geographical location, the increased use of RSS (Really Simple Syndication- a technique for gathering and filtering information automatically, further explanation of RSS here) can help people to filter information and make more efficient use of their time whether as patient, public or staff.

Feedback and data-gathering is also facilitated by the internet in terms of public participation in the shaping of services. Well-integrated feedback mechanisms can provide staff with important information in order to upgrade the effectiveness of the service by making changes suggested by patients. Delivering this feedback online or via email or text message could reach wider groups and improve response rates. Online panels have been used effectively by NHS Direct amongst others in order to shape the way the service is delivered.

Person to person communication via web forums, email or VoIP (Voice over Internet Protocol - further explanation in tools section) which is currently being developed for the NHS would not only make huge savings for the NHS in terms of avoiding paper and telephone costs, but could greatly increase the usefulness of interactions by allowing the linking of additional information and data from the web and shortening response times.

These are examples of how the NHS is using the internet to interact with the public and within the organisation itself, but one of the main features of the Internet is that it provides the public with a powerful means of creating their own information sharing and potentially, of effecting change through external pressure.

"If they won't come to you can go to them - in a way not an easy thing to do but it's probably the right place to engage."
Interviewee

4. Recommendations

This section provides information and inspiration to stakeholders who may be affected by or involved in the development and implementation of Armchair Involvement tools in the NHS.

Where next?

• Supplement not substitute

Technology should always be considered as a supplement to real life relationships and face to face interactions and not a substitute. Communication technologies can enhance service experience in terms of efficiency and satisfaction, but only if such interactions receive a satisfactory response where required. A usable interface must exist, and information must continue to move in both directions across that interface, enhanced and enabled by technology.

1. **We recommend that the principle of considering technology as supplement to not substitution of quality real life interactions should be at the heart of new technology based engagement across the NHS.**

• Share

Information sharing between patients, carers, staff and public with common concerns in specific areas is something which can benefit greatly from the implementation of technology, particularly through more innovative use of internet based tools. Collaborative websites, email subscription services, greater use and awareness of RSS feeds and many other such tools would all help to bring people together for service improvement.

2. **We recommend placing value upon learning for those who want to know more about cutting edge online tools for service improvement, with a view to involving and passing on knowledge to service users as an end result.**

• Nurture innovation

A culture change is required to create a more innovative, less risk-averse environment, able to take on new ideas for technology based engagement. New technologies offer opportunities to work in new and innovative ways. It is therefore important that the NHS recognises the need to encourage a more open and innovative culture which can not only respond and test new ideas from internal and

external sources, but which is placed to take on holistic visionary ideas and new ways of working enabled by technology rather than simply augmenting existing working patterns using digital means.

3. **We recommend an increase in the number and scope of new ideas piloted.**

4. **We recommend that the NHS Institute works to provide and advertise a safe structure to support the piloting of fresh ideas and new methods, helping those with ideas to take controlled risks.**

• Join it up

A joined-up approach is required to avoid duplication of effort, an accessible and up to date knowledge base, and a focus for energy in the encouragement of innovative practice. A central point to share information around Armchair Involvement pilots and technological developments was identified as being a useful resource.

5. **We recommend that an online point be created using the principle of social software, openly accessible to staff, patients public and business alike to freely input their own experiences and information.**

6. **We recommend the submission of basic information on all such pilots to this online point which will help interested users to avoid duplication of effort and to encourage collaborative working practices.**

• Evidence building

The benefits of greater involvement of individuals in their own health and wellness is backed up by a growing body of evidence, although this could still be built upon. Public participation in the shaping of services has more anecdotal than evidence based benefits - more research and evaluation is required around what works and for which groups. There is a lack of understanding around how technology relates to the individual in real life. Research could also help build evidence which could support effective targeted communication and involvement strategies, helping to use resources most effectively.

7. **We recommend ethnographic research into the ways in which staff, public and patients interact with technologies in real life situations.**

8. **We recommend a focus upon research and evaluation of staff involvement – how collaborative working and teambuilding can be improved through technology.**

• Valuing users

The opinions of the end user of any technology based interface should be highly valued. This is particularly important when seeking to engage with excluded groups who may not see technology as something that could be relevant or useful to them. Shaping the engagement process with the target audience should result in a more effective result for all involved.

9. **We recommend that engaging the end users in the design process for any technology based engagement endeavour initiated by the NHS should be a highly valued standard procedure.**

• Go to the people

Capitalising on existing enthusiasm and areas of innovation that have been taken up could be a far more efficient way of implementing new technology than imposing top down systems onto bottom up initiatives which may not secure the support of users.

10. **We recommend that the NHS map out where people are already using technology to make real connections with each other and to build around that usage pattern rather than to try and enforce new ways of working onto public, patients or staff members.**

• Learn from other sectors

There is opportunity for NHS staff to gain much from the knowledge of private sector innovations. This technological and systemic knowledge must be developed to a greater or lesser extent for all staff, particularly those charged with commissioning future armchair involvement tools.

11. **We recommend that a reciprocal learning forum be set up in order to exchange valuable knowledge between health and technology sectors. This should be linked into the central point for sharing mentioned above.**

• Personalise

Personalisation continues to be important in effectively targeting specific groups. Individuals expect to be treated as such, and to receive a more tailored and personalised. Customer service in the private sector has led the way and established this as commonplace.

12. **We recommend that options to personalise should be taken wherever possible. This applies both in terms of the method of delivery, be it mobile phone, internet or Digital TV etc.; and the style of delivery such as language used, accessibility issues,**

13. **We recommend the active participation of those groups in designing that personalisation process.**

• Develop decision aids

Further examination of the advantages and potential for multimedia or interactive decision aids would be of value to the NHS in terms of giving effective and transferable online support to patients staff and public in making decisions.

14. **We recommend that further development and robust evaluation of web based and multimedia decision aids be encouraged.**

• Getting the mix right

The digital divide and inequalities of access to technology should remain an important consideration when designing information dissemination pathways but should not be used as an excuse to hold back from producing information or seeking to engage using digital media channels. Consideration of the mix of media required in an involvement process including mobile phones, mass media and face to face where required should help the minimisation of such inequalities where possible.

15. **We recommend that each endeavour assess the mix of technology and traditional materials required in each instance – not relying entirely upon one medium.**

• Evaluate with users

Without fully understanding the needs, barriers and lifestyles of the end user; a technology based engagement idea is not likely to be useful to its target group. In a society with ever busier lifestyles, the advantages of using technology to engage seem obvious – particularly being less dependent on location and time for access. It is only the user group who can make the decision on whether this is useful.

16. **We recommend not only that new ideas be explored with independent and representative end users before being scaled up, but that users are also involved in their evaluation and assessment in a robust way.**

5. Tools for Armchair Involvement

Introduction

This document has been created as part of the Armchair Involvement project report as commissioned from Involve by the NHS Institute for Innovation and Improvement. It can be read alongside the Armchair Involvement research section (Section 3) for a deeper understanding of the topic as a whole, or used as a separate resource for exploration of the current and developing Armchair Involvement opportunities. This list does not intend to be an accurate predictor of the future, but rather aims to pick out the key trends and technologies that will affect the NHS' relationship with staff patients and the public over the next 5-10 years.

Scope

We understand tools for Armchair Involvement as being technologies applied for involvement- various communication technologies and trends that enable patients staff carers and the public to engage more effectively. Examples of Armchair Involvement as demonstrated in this document are defined as clearly and usefully as possible- many technologies and trends discussed are intangible or multifaceted terms (such as "internet") and may therefore cross over various boundaries, converging and interacting with one another.

Therefore, for reasons of clarity and usefulness in this section, we have not sought to identify a particular technology type e.g. " mobile phone" but rather to look at technologies for involvement in a way that is far more closely linked to the application the use of the technology eg. "text messaging" or "on demand". We hope that this is a more useful categorisation system for those seeking to learn more about technology in terms of its practical potential.

This is by no means an exhaustive list of every variation of every option that is and that could be available within the next ten years to promote a more engaged culture across the NHS. However, every effort has been made to include all major Armchair Involvement tools as well as several significant niche innovations that have had or are considered likely to have an impact. Technologies have been selected in light of the results of the Armchair Involvement research gathering process. The possible advantages and disadvantages of using each Armchair Involvement tool are suggested, followed by the possible positive outcomes and risks in a service context.

The bigger picture

The tools described below are broken down into particular applications for the purposes of this document. However, this is an artificial division for reasons of clarity. One of the main advantages of these tools is their ability to form a meaningful, accessible and efficient whole system. The three characteristics – convergence, wireless connectedness and ubiquity are important to consider when taking a holistic overview of the potential uses described in the tools.

Wireless connectedness to the ability of various devices to connect to the internet and to one another without cables. The trend towards wireless will also enable greater portability and flexibility of use. Short range radio connections such as Bluetooth and Wibree will also bring greater pervasiveness.

Convergence has a number of definitions- this does not aim to be definitive. However, put broadly convergence describes the trend of combining various services or features in one device or network. It refers to the way in which traditional categories to describe communications technology are becoming redundant as providers, manufacturers and consumers seek greater convenience from products and services and so begin to combine them in new ways. Examples

of convergence include taking photos with a mobile phone and surfing the web via a television set.

Ubiquity as hardware and services become more widely available greater numbers than ever before will have access to technology and the power that brings in terms of knowledge and communication. Without continually increasing access to converged connected devices there would be little point in attempting the implementation of many of the ideas outlined in the list below.

Categorisation

The 24 Armchair Involvement Tools we have chosen to highlight are explored in this section in the following format.

Description: In this section the armchair involvement tool is described as clearly as possible.

Examples: Here, the existing and future applications of the tool are described.

Benefits and Advantages: The potential benefits and advantages of use are summarily explored from all perspectives.

Risks and Disadvantages: The potential risks and disadvantages of use are summarily explored from all perspectives.

Text messaging

Description:

Text messages are short, typed messages sent to or from mobile phones, they can also be sent from computers to mobile phones and vice versa. The most common form of text messaging is that which is sent person to person but text messages can also be used to interact with automated systems for example information request services, polling and voting systems and reminder and advice services.

Text message pilots for reminder services and information have already been running for some time with success - it is very likely that we will see further work around expanding the use of text messaging in larger scale versions of existing ideas and in further piloting of increasingly innovative and engaging applications.

Examples:

- **Reminder services** using text messaging help ensure that appointments are more likely to be attended. Medication reminders are also sent via text such as contraceptive pill services some of which are paid for others which are free, like this under 21s scheme

where the subscriber can actually choose the wording of the text message reminder, tailoring the service to take individual situation and sensitivities into account.

- Providing routine **test results** such as this system which provides all-clears only. Routine test results that require no further advice or context from medical professionals could be sent directly to a patient's mobile phone such as this pharmacist trial.

- Providing **specialist information** to audiences who have specifically requested it such as malaria information to travellers in risk zones.

- **Wellness and motivation** such as smoking cessation programmes. A successful example in New Zealand showed adaptability, reaching both Maori and Caucasian communities demonstrating the effectiveness of text in reaching excluded and mainstream groups alike.

- Text could assist the maintenance of **networks** to motivate people working to maintain wellness, e.g. eating, exercise etc such as the innovative Chick Clique example for teenage girls' health which combines text with other tools.

- **Polling** – providing opinion on any changes to services, an example being the first mass media facilitated health poll via text as featured on BBC's Watchdog in 2003.

- **Choosing**- simple selection process for preferred services such as appointments

- **Voting**- where appropriate, citizens could be invited to cast a vote for changes to a service via text message such as this example of youth parliament voting.

Benefits and Advantages:

- Allows people to subscribe to receive information specifically relevant to them without any further effort on their part as can be sent automatically until they request to unsubscribe

- Familiarity- text messages are widely used for informal communication, this means that many people are familiar with the technology and have access to a mobile phone and already receive trusted information via that device.

- Diverse- text messages can be sent from computers using automated systems not just via mobile phones

- Mobile phones are very popular- people like the convenience of mobiles and therefore use them frequently so there is less of a technology barrier

- Text is particularly popular amongst young people who risk exclusion

- Could help to remind people or provide various pieces of routine information with good cost effectiveness

- Has been proven to reduce the number of DNA (Did not Attend) appointments.
- Has been shown to be more motivational than printed information in certain cases

Risks and Disadvantages:

- Excludes those who do not or cannot use mobile phones
- Test result provision via text- there are risks around ensuring that the correct person has received and understood the information provided via text
- Expenses incurred could prove a barrier to lower income groups when sending messages, but should not impact upon receipt of a message.
- Not necessarily as motivational as person to person contact
- Not discursive if texting a system for an automated response rather than a person
- Text messaging is less frequently used by older age groups so would perhaps not be as suitable for contacting those groups at the moment, although this may change in future

Multimedia Messaging (MMS)

Description

MMS (Multimedia Messaging Service) allows mobile phone users to exchange multimedia messages on their phones over mobile phone networks. These messages consist of varied information such as pictures, animations, video clips, maps, data packets and business cards. MMS is generally considered a service for the more up to date third generation (3G) mobile phone systems.

Examples

- **Self-monitoring**, patients could send images or videos to clinicians for initial diagnosis saving time and travel in the first instance
- **Education and information** - can be augmented by video clips or animations to improve comprehension
- Better **communication** of image based information between staff, better use of individuals' time as scans and x-rays can be transferred to the required expert wherever they are. For example, the results of an MMS trial in Milton Keynes showed that: *"The time to decision was shortened in all cases resulting in better patient care."*
- For use in **assisting descriptive ability** of injuries such as this example

Benefits and Advantages

- Faster service within hospital settings as can reach experts wherever they are
- Potential to provide multimedia information direct to an individual's mobile phone
- Could save patients time and travel in the first instance

Risks and Disadvantages

- Low resolution images at present- accuracy is compromised depending on the technology standards used
- Small screens on many phones prevent quality viewing of multimedia
- Diagnosis via image alone may lower accuracy and reduce safety- further research is required around this
- Privacy and patient rights around image transfer and storage must be observed

Video conferencing

Description

Interacting using voice and live moving image across two or more locations. This can take place over ISDN digital phone lines, network IP (the way in which data is transmitted across the internet via a computer) or by using a suitable mobile phone. The Wikipedia definition is found here.

Examples

- Remote **early stage medical consultations** such as this neurological pilot
- **Training opportunities**, information sharing and demonstrations for staff, could provide extra support as in these Norwegian examples of psychiatric nurse and psychiatrist training.
- **Educational opportunities** for those managing long term conditions to take part in more experiential, interactive learning from peers or experts
- For use in **remote scenarios** such as this example from Lapland promoting access for those who find it difficult to travel
- Improving ease of access to **specialist** expertise – breaking down barriers around travel and time

- **Routine consultations** as described in this NHS Wales document which provides guidelines to those considering video consultations
- Enables **sign language** communication to take place at distance
- **Psychiatric** consultations can be conducted effectively- situations when no physical examinations are required
- Improved **information sharing** and enabling participation from staff and interested parties in shaping of services such as discussed in this Pennsylvanian example document

Benefits and Advantages

- More engaging than phone or email as provides visual information as well as being a truly two-way interaction.
- Helps to avoid long distance travel to specialist units or for patients living in remote areas
- Potential cost savings in terms of travel and time

Risks and Disadvantages

- Currently not commonly done in the UK - could seem intimidating at first in terms of technology and in being viewed
- Different skills are required and must be acquired, including the documentation and data protection associated with such media

Wireless monitoring sensors

Description

Tiny sensors embedded in devices which can be used by individuals to take readings of vital signs and health measures or can provide constant wireless monitoring and relay of readings back to a central point for further action.

Monitoring sensors are set to be an integral part of future healthcare in terms of engaging people in their own health and wellness using telemedicine. They must be considered in future when constructing engagement strategies.

Piloting and tests of different types of monitoring system are currently being carried out. They are expected to develop into widespread use over the next five years or so.

NB. Strictly speaking, measuring and monitoring sensors are a form of telemedicine; however remote monitoring sensors will enable people to measure and monitor a number of key health-related factors themselves and to relate to the health service using this information in entirely new ways. Sensors are included here as they are part of an interface that people will use to interact with healthcare providers in future; we focus upon sensors here only in terms of the ways in which they could affect such interactions and augment relationships and not as a diagnostic per se.

Examples

- Lifestyle and health and **wellness** encouragement – data gathered could include that such as distance covered walking or running like this example of an integrated system from Nike and Apple.
- **Remote monitoring** systems are already available such as this example regarding heart patients in the USA
- **Future devices** used will be more usable and ergonomically designed, possibly integrated with mobile phone and Smartphone technology using short range radio such as Bluetooth or Wibree to increase portability and convenience
- There is also huge potential for **blood pressure, heart rate and glucose monitoring** such as this prototype from Leeds University that uses a PDA to monitor such physiological indicators.
- A number of pilots with varying purpose are currently being carried out in the UK including this telemonitoring pilot which is part of ICTRI
- The **Norwegian** centre for telemedicine is a good source for examples and current thinking
- **Monitoring** of the health of elderly or vulnerable who live alone may allow greater independence for longer and potential cost savings for the NHS or social care
- The Well in Newham project

Benefits and Advantages

- Can give feelings of control, involvement and empowerment
- Reduces cost burden on the health service through helping people to stay healthier for longer
- Has good clinical outcomes – reduces re admission amongst cardiac patients for example this cardiac study.

Risks and Disadvantages

- Remote physiological monitoring requires willpower and active involvement from the patient in order to something about the results to have benefits- will people take up this idea?
- People may see the monitors as a safety net which will alert them to dangerous health indicators when they are happening rather than a way of avoiding detrimental behaviour patterns.

Digital Interactive Television

Description

Digital Interactive Television (DiTV) is a system through which moving images and sound are broadcast and received. In contrast to analogue (traditional TV) the information is compressed into computerised binary information which takes up far less bandwidth allowing more channels to be broadcast, and allowing interaction via the 'red button' system.

Digital TV is an important method for ensuring that homes without internet access are able to interact with health information from their own living rooms. The use of Digital TV to reach excluded groups is the major benefit of the service, although the evidence for numbers actually interacting shows limited take-up. The service is currently slow and inflexible when compared to the internet and so seems likely to remain niche unless significant alterations to the present system are made- which is a possibility.

Examples

- NHS Direct currently runs a Digital TV service providing access to health **information in the home**.
- Using the Sky version you can search for **local services** by entering your postcode using your remote control and you are presented with local service information.
- Pilots of **booking** GP services through the television are currently underway

Benefits and Advantages

- There is an opportunity to select personally relevant information through the interactive 'red button' service
- Digital TV is considered important as a way of reaching into homes without internet access, often those from the C2,D,E social grouping.

- Simplicity- interactive digital TV has an uncomplicated interface. Users are guided through a number of different decision pathways using a familiar tool, the remote control

- The ability to create niche channels allows a more tailored and segmented approach to mass information provision

- People can select the information most relevant to them by choosing from a menu of options using the remote control.

Risks and Disadvantages

- Many interviewees pointed out that Digital TV is slow compared to the Internet which may put people off accessing information through this method rather than via a website.

- Actual participation in interactive services is currently fairly low, although more popular amongst younger age groups[37] although we may see future increase in popularity. *"The number of people who use digital TV interactively, the number of people who go into the interactive zone and you know do things like, send information, their postcode, is very very limited."* *Interviewee*

- People currently use their TV primarily for entertainment and not to seek information or interaction.

- *"I think red button TV is a moribund medium. It is very clunky I don't see much of a future for it beyond a teletext service which only has the merit of being there immediately and is integrated with the TV in that you can overlay it. I think that will become history very soon. It still seems second best to having the on demand capabilities of online."* *Interviewee*

On Demand

Description:

On demand refers to the trend towards consuming media whenever and whenever the person accessing the information requires it, usually used in relation to video clips, TV, film or radio.

"On demand is one of the key characteristics of media at the moment. Basically people want to be able to get what they want where they want on the device or platform they want it. Whether that's a phone, video ipod whatever." *Interviewee*

On Demand is an important process from the point of view of sharing experiences and information in a truly democratic way by individuals and small organisations. Taking an On

Demand approach is also useful for large information providers such as the NHS who are able to host highly engaging video content on their own websites which can be cost effectively accessed by very large numbers of people.

Examples:

- Experience sharing for **patients** or public around wellness, such as YouTube[38] videos on weight loss diaries smoking cessation information on asthma
- Experience sharing for **staff** and patients such as the patient voices website which features a number of wide ranging stories told by staff and patients about their experiences
- Staff sharing **knowledge** such as this YouTube video about benzodiazepine withdrawal this nursing video about hygiene YouTube also offers the facility to create specific 'channels' such as the MS Society and general channels such as dramatic health
- Dipex is an **information** sharing portal which helps people share their experiences of medical care and illness in a personal way
- Netmums website shows a screening of **video from ITV** on postnatal depression bringing mass media programming style to the web
- **Podcasting** of information enables sound or video files to be downloaded onto an iPod or other compatible device
- Children First for Health website has a section called **GOSH TV** (Great Ormond Street Hospital TV) including videos of young people's experience of the hospital care received

Benefits and Advantages:

- Anybody with access to the technology can now broadcast and share video information, and that access and knowledge base is increasing
- Can be used by individuals to share personal experiences that are difficult to capture and share by other means
- Can be used by organisations to share specialist information

Risks and Disadvantages:

- Quality depends entirely on the maker of the film
- Barriers around people not being able to use technology such as recording and editing equipment where required for more complex projects

User generated online content

Description

Blogs, wikis, online forums and patient opinion sharing sites- these are all ways of people getting their own voices directly heard either by their peers or by experts. The content itself is varied, and can feature video, text, audio, still images, but the origin is always with the user. User generated content is now part of the landscape of the Internet, and the NHS should be aware of its emergence and the opportunities that such a movement may bring.

However, this trend does seem to have been embraced by younger more affluent audience in general and so should not be considered a catch all solution to encouraging active online participation. Participants from excluded groups should be actively encouraged to join in any official endeavours. User generated content has been growing in popularity for some time and this trend look set to continue.

NB. The term Web 2.0 is often used to refer to user generated content or participative media such as blogging (user-created web journals) - the definition of Web 2.0 continues to be disputed and actually takes in a far wider remit than simply user generated content.

Examples

- **Motivational/support provision** for those affected by long term conditions such as dlife for diabetes lifestyle support , and experience sharing as demonstrated by this blog on migraines and diabetes forum
- **General patient experience** sharing separated into categories such as health central, and using video as well as a text only written forum
- For **outpatients sharing experiences** after hospital care such as this cardiology forum in the USA
- NHS Networks forum enables **NHS specific discussion** to take place in an official setting
- **Professional sharing of expertise** such as the ppix forum which enables staff to share best practice on public engagement
- The wellness community provides **peer support** and information for those affected by cancer

Benefits and Advantages

- Flexibility in terms of timings of interaction- people can post messages to a forum or noticeboard, or add to their blog any time that is convenient to them.
- Experiential learning such as expert patients' programmes can be helpful and supportive in providing people with time and understanding.

- People can fill in the gaps- if they have specific needs or concerns around for example a particularly rare condition, or a geographical area they can set up their own groups online.

Risks and Disadvantages

- *"For some members of society it's not touched them at all, and certainly some older people, you know, I think, are not engaged in that world at all. Although, you know, often it's simply a matter of making a start."*
  Interviewee

- Readers of such user-generated information may not fully understand its origins and the fact that the information may not be clinically accurate. For example, one interviewee pointed out an occasion where comments had been made on a large charity's forum which had been taken by a reader to be endorsed by that charity- they were in fact incorrect assumptions.

- *"At the same time as finding ways to convey authority you need to be prepared to loosen up a bit- if you're going to engage with the public they're gonna say stuff that's not strictly accurate, that's not always going to be carefully crafted- you need to manage that. There are all sorts of ways. You can have ratings mechanisms for rating quality of content."*

Social Software

Description

The term social software is normally applied to range of web-enabled software programs. The programs usually allow users to interact, share, and meet other users; it can be used for collaboration using wikis and blogs for example. Content is primarily user generated. The entry in the social software encyclopaedia Wikipedia goes into greater detail on variations and examples.

User orientated interfaces and applications have given social software great appeal and connectedness that gives value to users. Young people have particularly embraced social networking sites, and are more likely to use them without prompting than older people. Social software is currently going mainstream having originated in tech communities in the first instance some time ago. It looks set to continue development and become more integrated in future.

Examples

- The health Wikia allows people to **share** a wide variety of health related stories and information
- Staff could use wikis to **collaborate** on the production of projects, documents and information remotely
- **Sharing of research** could be facilitated more easily by the use of link sharing software such as de.lici.ous this could work well for expert patients groups and for staff specialising in particular areas to avoid duplication of effort
- Can increase **efficiency and connectedness** such as this example from Orkney NHS.
- Social networks can also have **privacy** settings which would enable staff or user groups to restrict access to specific users, enabling greater security for participants
- Social networks have potential for **localised** open support groups
- Facebook groups from Diabetes UK and the American Diabetes Association show potential for **support provision for chronic conditions**
- **Blogging** allows individuals to tell their own story and for others to comment and contribute to discussions, such as this psoriasis example
- LinkedIn and other **professional networks** help staff to make connections
- Instant messaging / status update tools such as Twitter could be used by staff to **co-ordinate** various processes around the hospital or clinic, and so improve patient experience in terms of reducing waiting within the hospital.
- Flickr is used to **share still images online**. Images in this report have been sourced through Flickr under a Creative Commons license.
- Creative Commons is a free tool that helps authors, scientists, artists, and educators easily **mark their creative work** with the freedoms they want it to carry

Benefits and Advantages

- Expert Patients stand to gain from an active social networking group in terms of support and information
- Can easily share multimedia content such as photos and videos rather than having to set up a dedicated website
- Free or cheap to join a network
- Easy to participate- a usable interface
- Self organising of groups is enabled

- The user is in control, requires minimal knowledge to set up a group

Risks and Disadvantages

- Can cut experts out of the loop completely- misinformation risks
- Security risks around information privacy also around meeting up in real life
- Social networking sites could decrease staff efficiency if misused

User-led ratings websites

Description

Interactive websites which allow service users to give feedback on service experiences to the site.

Application

- Patient Opinion is a social enterprise website which enables users to log in and rate various service experiences they have.
- NHS Choices is a DH website which includes an opinion giving service for hospitals through its 'choose services' section
- Non healthcare ratings websites are currently more developed and indicate future trends, good examples include TripAdvisor and Amazon

Benefits and Advantages

- Allows patients carers or staff to input information anonymously which may increase verity of information
- Allows NHS staff to get a snapshot of the patient experience and where this could be improved
- Could support a more open culture of trust

Risks and Disadvantages

- Nature of such sites is opinion based and so perhaps not always factually sound
- Equity in response and voice must be maintained
- Personal grudges may be aired inappropriately

Avatars

Description

An avatar is at its most simple, an on screen image representing a person, technology or organisation online. Most often this is a face with human characteristics although full body avatars or non-human representations are also used.

Examples

- Providing an **online face** for anonymous discussions on social networking sites such as SecondLife
- Providing a **changeable face** for healthcare examples such as FRANK drugs mugs aimed at teenagers and young adults
- **Humanising online interactions** and providing a friendly face for AI, as technology becomes more dominant- a more friendly interface may be required such as IKEA's Anna
- Can be used in forums or chatrooms such as this mental health example to **express emotions or feelings** that may not be easy to verbalise

Benefits and Advantages

- Can provide an approachable face and interface for a computer system
- Can provide anonymity but give some idea of personality for users of web forums or social networking sites
- Full body avatars can be used to show demonstrations of how to do things such as exercises or application of creams

Risks and Disadvantages

- Anonymity can contribute to malicious behaviour
- People not used to avatars may find them silly
- When developing original or complex avatars there may be a cost barrier

Email

Explanation

Email (electronic mail) is the exchange of messages stored on computer equipment by telecommunication most commonly over the internet. It is one of the most popular uses of the internet. An email is usually a text document, although you can also send other information such as images and sound files as attachments. Email can be distributed to lists of people as well as to individuals.

Examples

- **Sending photos** via email to specialists for diagnosis of skin complaints. The wider work of the Swinfen trust who specialise in low cost email solutions to health questions, particularly in the developing world
- **Email subscription lists** allow information to be targeted to users who have requested that information such as this example from Northumbria
- Keeping public and staff **up to date** with developments in the health service system as a whole, such as the Connecting for Health email bulletin
- Can improve **internal communication** efficiency
- **CHAIN** is a health care information exchange email network which provides a personally tailored information bulletin, created to your own specifications and interests

Benefits and Advantages

- Can be accessed at the user's convenience
- Quick to use rather than drafting paper correspondence
- Savings can be made in terms of cost and environmentally in terms of paper used
- Helps meet patient expectations - a Picker Institute survey showed that patients want to be able to contact clinicians via email

Risks and Disadvantages

- Unwanted third party access to personal information is a risk
- Not so permanent a record as paper
- Poor email management can impact negatively on staff efficiency

Information Kiosks

Description: Static booths or screens situated in public places with open access to those seeking out relevant information, often using a touch screen interface.

Examples:

- Can be used to deliver **localised** health information such as map or contact details for clinics and GP surgeries, explanation of a particular hospital's departments and systems
- Could be used in **clinical settings** to provide secure access to electronic patient record or other data specific to that setting.
- Kiosks used in public places can **reach people** who may not normally interact with the health service using internet or digital TV

Benefits and Advantages:

- *"For highly localised information I think they're very good actually, and also, sort of, health promotion, lifestyle information where it's not particularly sensitive etc, that potentially works"*
  Interviewee
- Assists those without a home computer or without computer skills to gain access to current health information in an electronic format
- May be useful for accessing information in transitional places such as docks, airports, stations or learning zones such as libraries and schools,
- Can include translation facilities for visitors seeking further information

Risks and Disadvantages:

- *May become redundant "You know they were important at one stage, but if you could find your local pharmacist easily on your mobile phone, and nearly everyone's got one, and that goes with you rather than you go to a static point, in a way I think they're not very useful."* *Interviewee*
- *May not be appropriate "A lot of health information is pretty personal, and also actually potentially sometimes involves quite a lot of searching and assimilation of information, particularly treatment and illness content, and I'm just not that sure that that's an appropriate environment"* *Interviewee*

Multimedia and web based decision aids

Description: Decision support tools may be used for clinician or patient. They guide an individual through the process of decision making, providing key information to inform their viewpoint. Some have integrated personal data and so allow for high personalisation of the individual system. Multimedia elements are used in order to clarify information, online access enables cost effective and widespread dissemination as well as the facility to include interactive elements. Studies including the Cochrane reviews have shown that patient decision aids are appreciated by patient and clinician, and that they lead to greater satisfaction with decisions. Further work is still needed around implementing online or interactive decision aids and assessing comparative effectiveness.

Examples:

- Patient decision aids, whether online and multimedia or not have been shown to give patients a **more participatory** role in securing, effective, safe, responsive, and quality healthcare
- Videos and online information are used to **support decision making** around cancer
- **Clinician support** can help increase patient safety
- An example of a web based MMR vaccination decision aid **pilot in the UK**
- Patient decision aid pilots such as this example have taken place with **good results** in terms of patient satisfaction in the UK
- A **rigorously assessed** library of decision aids including many multimedia or online examples is available from the Ottawa Health Research Institute
- An example of an ICTRI backed piece of **current UK research** around decision support for ambulance staff
- The NHS Institute is supporting informed decisions in **urology and knee surgery**

Benefits and Advantages:

- Improved quality of decision, increased satisfaction
- Feelings of empowerment and involvement increased
- Expectations of involvement and participation may be satisfied

Risks and Disadvantages:

- Poorly designed decision aids may lead to ill informed decisions

- Low awareness of decision aids may lead to poor uptake
- Needs buy in from patient and clinician in order to be effective
- Often time and resource intensive to develop fully

Online discussion groups

Explanation: Online discussion groups are situated on websites, and support users to enter into conversation with one or more people by typing in messages. This takes place either via a bulletin board/forum system, or a live chat system. The main difference between the two is that the former is not dependent on all contributors taking part at the same time whilst the latter requires participants to be present at the same time as messages are relayed instantaneously as they are typed and entered, usually powered by Java.

Examples:

- Netmums is a **lifestyle orientated** website which caters specifically for new mums. It offers a forum to which users contribute information and share experience.
- **Web portals** such as about.com offer a number of live chat rooms including this chat example aimed at older people which takes place weekly at a fixed time
- Can be used to **consult with the public** on proposed service or policy changes such as the government's eConsultations
- Live chats can take place either as **one off special events** where particular experts or groups can arrange to meet and chat online at a particular time, or as **constantly available** chat spaces
- **Patient Citizen Exchange** website run by the NHS Centre for Involvement offers an online forum regarding patient and public involvement
- Forums or bulletin boards such as this mental health example can provide **support and advice** from peers or experts
- Could be used by clinicians to host **private, invitation only**, virtual support groups for particular sets of individuals or for staff members

Benefits and Advantages:

- Support from those with experience
- Ability to get a response from somebody- of feeling listened to

- Can include expert advice as well as experiential advice to those with long term medical conditions
- Can provide comfort and community to isolated or housebound people as well as practical information and support – many discussions are 'off topic' – not relating directly to the health issue in question
- Not necessarily time-dependent, forums can be posted to at any hour
- Enables people separated by distance to communicate with one another

Risks and Disadvantages:

- Information on boards or typed in chat rooms is not always monitored by experts- some information may be misleading or even harmful
- There is a need to rely on the individual to make the distinction between good and bad advice for themselves
- Forums discussing particular issues may need to be moderated carefully to discourage too many off topic conversations. A space for off topic should be provided in forums and chatrooms.

Electronic Patient Record

Description

A number of different versions of patient record systems exist, they are also referred to by a number of varying terms and acronyms, a common one being Electronic Health Record (HER). They are all basically a way of viewing a patient's medical record via a computerised interface.

Examples

- Could be **accessed independently** by patients with powers to input information.
- A **pilot in Salford** royal hospitals NHS Trust has had good results saving time and improving patient care
- **GP practices** are currently rolling out a pilot some practices have been active implementers of an electronic records service for some time
- Ability to create a **full care record** such as this example from Swansea which coordinates social care and health services leading to more personalised and joined up individual care

- Can be **integrated** with other initiatives for example healthspace an online health organiser that is being developed to promote wellness
- **Wireless** medical records are being piloted in Taiwan seeking to improve the quality and efficiency of care received

Benefits and Advantages

- Increase patient safety by reducing or correcting errors
- Improve shared decision making
- Improve feelings of empowerment and move away from paternalistic NHS
- More efficient/accurate transferability of records

Risks and Disadvantages

- Access is an issue, safeguards must be made against unwanted third party access
- Data protection and enabling secure access is a significant issue when implementing any such system
- Must have effective staff and patient trust and buy in to be of use
- Reservations exist in terms of security and privacy around holding all personal health information on a central database

PDA/Smartphone

Description: A PDA (personal digital assistant) is a handheld computer which includes personal information management features such as a contacts database and calendar, wireless versions also offer e-mail, web browsing. Smartphones offer all of the above including phone capabilities. Most PDAs operate using a touchscreen.

Examples:

- Breast cancer **information** pilot in Liverpool run by mihealth, monitored how people used PDAs to access relevant information
- Clinicians could use PDAs to improve **self organisation** and departmental communication
- Specialist medical **information software** is available for PDAs such as the epocrates mobile drug guide
- Specialist medical **organisational software** is already available such as patientkeeper and Allscripts in the USA

Benefits and Advantages:

- Tailored medical software is available for PDAs
- Wirelessness allows flexible access and portability
- Time saving potential for busy clinicians

Risks and Disadvantages:

- Transition is being made to next generation equipment at the moment, hardware should be chosen carefully
- PDA technology would bring new ways of personal working which many may be resistant to or may not have the skills to undertake

Connected mass deliberation

Description: Large numbers of people are linked together simultaneously to make input into decision making and policy. A combination of face to face methods and technologies including wireless voting, television and networked computer systems help people to deliberate and feed back effectively.

Examples:

- **California Speaks** deliberative healthcare event took place in eight separate locations across the state of California in the USA.
- Your Health Your Care Your Say **Citizens' Summit** took place in Birmingham as part of a larger consultation process, and was broadcast live on the web.

Benefits and Advantages:

- Has the potential to engage with people on a very large scale, regionwide or countrywide
- Can ensure a representational cross section of the community take part

Risks and Disadvantages:

- Need to ensure that the event itself is also followed up effectively
- Expensive to set up
- Involves a great deal of organisation and planning

VoIP – internet telephony

Description:

Voice over Internet Protocol is a way of enabling voice conversations over the internet or any IP network. Internet telephony is a popular use of VoIP and can be used to save costs on phonecalls by routing those calls over broadband internet instead of the phone network. A fuller explanation can be found here and the Wikipedia definition here.

Explanation:

- **Cost savings** can be made by making calls across the internet using systems such as Skype
- The NHS is developing its own system
- Whilst making calls over the internet, **additional information** can easily be browsed simultaneously

Benefits and Advantages:

- Cost savings for the NHS using its own system
- Can integrate video calls or data transfer as well as voice over IP
- Patients and public contacting the NHS via VoIP could see cost savings

Risks and Disadvantages:

- Technology barriers- initially staff will need training on usage
- Quality of call may not always be as good as landlines
- Data security issues
- A fast broadband connection is required for effective usage

PACS - Picture Archiving and Communication System

Description: A system which enables images such as x-rays and scans to be stored electronically and viewed on screens, so health professionals can access the information and compare it with previous images more efficiently. PACS offers many advantages in terms of efficiency and time saving for professionals. Specialist training is needed to use the system.

Examples:

- The Connecting for Health website brings together current information on the **NHS implementation** of PACS to date outlining the experiences of early adopters
- PACS has been linked to **Electronic Patient Record** systems and brought in enterprise wide such as seen in this example from the USA
- The **future of PACS** is a more integrated system as discussed in this article

Benefits and Advantages:

- By delivering more efficient imaging processes PACS will speed up the patient journey
- It removes all the costs associated with hard film and releases space used for storage
- Can be linked to the Electronic Patient Record
- Will eliminate problem of lost films

Risks and Disadvantages:

- Misuse of email as discussed here
- Quality of image can not be compromised as will impact upon diagnostic accuracy
- Systems must have high security to avoid viruses

Telephone - voice

Description: Landline or mobile connection to the telephone network using voice only. Telephone help and information lines have been around for some time and are becoming more developed in service and taken up by users. Telephones could be used more often to provide support to individuals. It is likely that simple voice to voice communication will be augmented in future either by information displayed simultaneously over the internet (see entry on VoIP) and may take place less commonly on traditional landlines, and more commonly via mobile devices.

Examples:

- **Coaching and support** over the phone as part of wellness, mental health or cessation programmes has proved effective
- **First point of contact** with health queries provided by NHS Direct
- **Specialist information** such as the Brain and spine helpline or CancerBackup infoline
- **Support for carers** such as this parent advice line providing information and guidance on children's' mental health issues

- **Encouragement** to attend screening

Benefits and Advantages:

- Good coverage and capacity for use- most people already have access to either a landline telephone or mobile phone
- The skills required to use a phone are commonly held by all age groups and sections of society, therefore there is a low barrier to participation
- An effective and cost efficient way of delivering support for wellness initiatives

Risks and Disadvantages:

- No way of showing or demonstrating as an assistance to voice description
- Excludes deaf or hard of hearing or diminishes quality of interaction unless they have access to specialist equipment – cost implications also exist in relation to this

Mass media

Description:

All major outlets distributing information across a variety of formats including television, print, radio and online. Mass media can facilitate targeted health campaigning or can contribute indirectly. The trend towards developing an online presence as well as the traditional newspaper or TV channel demonstrates a move towards the immediacy of web based communications.

Examples:

- A Cochrane review shows that despite poor primary research mass media does have some importance in health interventions
- Polycystic ovary condition **radio 4** web chat with expert Prof. Stephen Franks
- **Smoking cessation** is an area where mass media campaigns have had a positive effect
- **Channel 4's** Jamie's school Dinners raised awareness about children's diets
- **Times online** health section on website compliments print version
- **Daily mail** weight loss advice chat with diet doctors
- Popular programmes such as **Eastenders and Coronation Street** sometimes address health related issues both within stories such as this award winning mental health example , and in terms of additional helpline information provision given on programme websites and on TV.

- **Celebrity-centred campaigns** can help raise awareness and dispel myths around illness such as Magic Johnson's HIV campaign in the USA or Lynn Faulds Wood's bowel cancer campaign in the UK
- **Television phone-ins and features** such as those seen on This Morning or Richard and Judy provide focused advice on health topics with an expert present to answer questions.
- **BBC website** provides health information
- **GMTV** have worked on raising awareness through their TV programme and website

Benefits and Advantages:

- *"The main advantage of TV is its mass audience, its mass audience plus celebrity whether you like it or not"* Interviewee
- TV is a powerful and accessible medium which can be accessed easily
- Integration of formats including websites, TV, radio and print can create very high awareness of specific issues
- Different formats and presentation styles can reach different groups more effectively
- Health and wellness information can be highlighted without seeming too official or dictatorial

Risks and Disadvantages:

- Can tend to focus on sensational rather than more mundane but important aspects of health and wellness
- Accuracy of information reported or focused on must be maintained at a high standard or mass misinformation will result

Websites

Description

A number of web pages linked together, accessed via the internet. Websites can include text and multimedia or interactive content, they are incredibly versatile and can be developed in a variety of ways. Websites bring together a number of different features depending upon their purpose, enabling people to find information, to communicate, or to contribute content. A cross section of health websites with widely differing purposes and styles is highlighted below.

Examples

- Children first for health is an example of a **child-centred site** including a 'dear doc' Q+A section, A-Z of health, dedicated boys, girls and age-group sections and information about hospital care including a video diary section.
- Dipex enables patient experience exchange through use of **video**
- Map of Medicine (for clinicians) and healthguides (for public) site provide access to **treatment pathways** in an easily accessible graphic format much like a flow chart
- Cancer Backup and Cancer Help websites demonstrate differing **approaches to information** giving around cancer
- Patient UK provides a **wide range of health information** in a very simple format; it also has an online forum.
- Ivillage is a popular **lifestyle portal** which features health information
- Teenage health freak and Doctor Ann's virtual surgery provide information tailored towards **teens**, an email Q+A section as well as quizzes and surveys add to the interaction on these friendly linked websites
- NHS Direct provides **official information** on health including a step-by-step self help guide, local service locator, magazine section, health encyclopaedia and an information request service
- NHS Choices provides a **magazine style** interface with three channels- live well, health A-Z and choose services.
- **Whole community** websites such as talk2Croydon take a community based standpoint
- Dlife provides a dedicated multimedia lifestyle site for those living with **Diabetes**
- **OPERA** (Online Personal Education and Risk Assessment) genetic breast cancer project is due to be launched in 2008 by Cancer Backup. It will be a web based tool providing tailored information which will enable users to seek help or advice more effectively according to their specific personal situation.

Benefits and Advantages

- Websites are incredibly versatile, and can be tailored to cater for individual groups, for particular access issues, and for different levels of engagement
- The potential number of people accessing websites is increasing as access to internet connections increases
- Simple websites can be extremely cost effective to set up and maintain

- Democracy of access- anybody with basic technical know-how can now set up their own website
- One webpage can easily reach vast numbers of people, unlike one printed page

Risks and Disadvantages

- Websites are less likely to be accessed by certain sections of the community or those without internet connections in the home
- Complicated websites can be expensive to develop and maintain

Language accessibility tools

Explanation

A variety of specialist tools enabling improved access to information for those unable to access conventional sources for differing reasons relating to language.

Examples

- **Translation tools** such as this example which translates web pages as well as inputted text are readily available on the web
- **Read aloud tools** such as Browsealoud which is used by NHS Direct can assist those with literacy or sight – related access issues to web pages

Benefits and Advantages

- Increases accessibility, improves communication and comprehension

Risks and Disadvantages

- Some translation tools are less reliable than others
- Read aloud facilities are not enabled on all websites

Online surveys and quizzes

Explanation

A survey or quiz hosted online requires participants to take part by accessing a website which features the survey test or quiz. This web address can be sent out via email or text message or featured as a website link. Free or inexpensive software is available to allow set up of simple surveys quickly and cost effectively and to gather and make use of the data electronically.

Examples

- Surveys can be used to find out more about **staff opinion** on specific issues such as the RCN Foundation Trust online survey
- Surveys are currently used by the NHS to find out **patient opinion** on a national scale, there is potential for more localised online surveys
- An example of a **long term exercise survey** being used for research in the USA
- Quizzes can be used **to raise awareness and educate** participants about a variety of health issues such as healthy eating. The online method could be particularly useful for targeting subjects seen as embarrassing such as this example from a sexual health clinic based in Newcastle.
- Patients or public can independently set up surveys online to get feedback on opinion of specific services or of health related issues
- **Self assessment** style quizzes can help flag up areas of concern such as this example focusing on stress
- Quizzes can be used to help drive home **learning for staff** such as this simple example aimed at doctors involved in recruitment

Benefits and Advantages

- Electronic administration can save time and money
- Instant automated feedback provides responsiveness
- Simple free or cheap survey or quiz production options are available online
- Convenience of online access may increase response rates
- Simple interactive way of assisting information provision and education
- Anonymity may help to increase veracity of survey results

Risks and Disadvantages

- Questionnaires and surveys must be well designed or the results will be flawed
- The user profile of the internet will affect who can be reached with an online survey rather than postal, phone or face to face approaches

6. Appendices

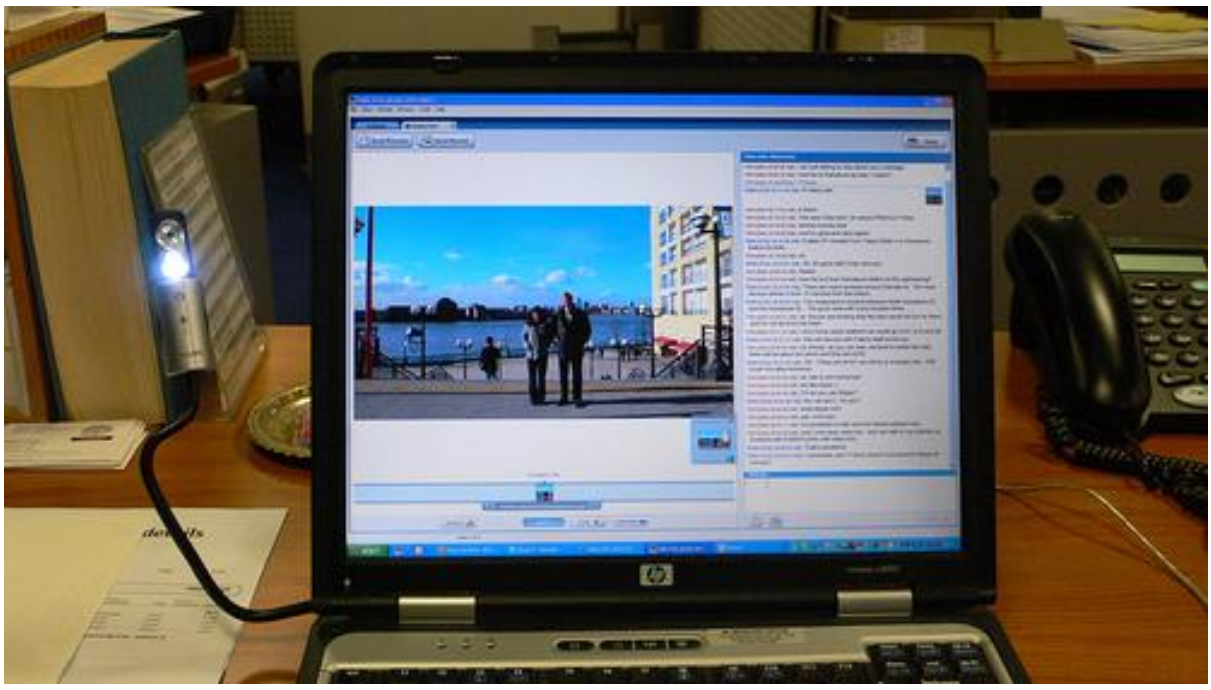
Appendix A

Contributors and Interviewees

Adam Gee*	Channel 4
Adrian Rees-Hughes*	NHS Direct
Angela Coulter*	Picker Institute
Bob Gann*	DH
Bob Sang	Sang Jacobsson
Brian Fisher*	NHS Alliance
Christoph Schmaltz	Headshift
Don Redding	Picker Institute
Elise Craft	DH
Emma Pryke*	DH
Harry Cayton*	DH
Harry Woodroof*	DTI
Hilary Cottam*	Participle
Ian Brittain*	NHS Centre for Involvement
Ian Drysdale	Think Public
Ian Kegel*	BT
Ian Pearson*	BT
Janette Bennett*	BT
Joanne Rule*	Cancer Backup
Karen Foy*	NHS PPI
Kerstin Braun	MS Society User
Maggie King*	DH
Mark Easton*	BBC

Mark Mugglestone	NHS Institute for Innovation and Improvement
Michelle Harrison	Henley Centre
Mike Short*	Chair, Mobile Data Association (O2)
Nick Hunn*	Mobile Data Association (Ezurio)
Nigel Dacre*	10Alps TV
Paul Hodgkin*	Patient Opinion
Sarah Pearson	ACB UK
Shirley Large*	NHS Direct
Tim Burke*	BBC

* Interviewee



Appendix B

Question Schedule

Focus: What are the key drivers for change in the NHS' relationship with patients and the public are at present; particularly in terms of participative technologies; and what could they be in ten years time?

Technology

- Which types of technology do you perceive as currently being most useful in fostering participation?
- What is your view on the way in which participative technologies are currently being used to help patients staff and the public participate in the NHS?
- Which emerging technologies do you see as most useful in the future?
- How do you see uptake of participative technology progressing within the NHS or in other institutions over the next 5-10 years?
- What risks do you foresee in the next year, and in ten years time, associated with the uptake of participative technology with and without the NHS?
- Which available technologies (if any) do you see as currently being underutilised in terms of their impact on participation and involvement in the NHS or in other institutions?

Participation

- What do you understand as 'participation' (in terms of any institution)?
- What social/cultural trends do you see driving change within *and* without the NHS and healthcare system?
- What do you believe is currently driving participatory culture in the NHS and in institutions?
- What do you perceive as being the major benefits of seeking a more participatory culture in the NHS?
- What are the risks associated with participatory culture in the NHS both today and in 10 years time?
- What are the current key initiatives to improve service and/or staff experience using participatory technology that have worked and why?
- Which initiatives haven't and why?
- Who is currently doing the best work in this area?

Apppendix C

Survey information

http://www.involve.org.uk/armchair

Appendix D

Creative Commons Attributions

All taken from www.flickr.com **– all other photos courtesy of** nhs photo library

3 Martin Kingsley
5 Jessicafm
11 Brian Pennington
16 Chris Gladis
20 Yaniv Golan
22 Jennifer Danielson
23 Beth Kanter
29 Bitterjug
59 Herry Lawford
61 Brian Hession

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