



A Scottish Health Council report on participation and online technology

Briefing Paper

Introduction

This briefing paper reviews how prevalent online technology is and how e-participation and social networking can provide the NHS in Scotland with tools to support the participation of patients and the public in healthcare services.

Prevalence of the internet

The UK Government collates statistics on internet access and usage via the Office of National Statistics Internet Access Survey¹. The 2010 survey measured home access to the internet and individuals' use of the Internet across the UK. Over three quarters of the Scottish adult population used the internet in 2010. Internet usage increased with income and educational attainment and decreased with age. Key findings from the survey show that:

- Around three quarters (73%) of households in the UK had internet access in 2010 although this fell to around two thirds (64%) of households in Scotland. Over three quarters (78%) of people in Scotland used the internet at home or from other sources such as work, the library or their mobile phone. Three in ten (31%) internet users in the UK connected via a mobile phone.
- Sixty per cent of those aged over 16 in the UK accessed the internet every day in 2010 (up from 35% in 2006) while 18% of the UK population never accessed the internet (down from 35% in 2006).
- Internet usage in the UK decreased with age from almost all 16-24 year-olds to four in ten people over 65 (99% for 16-24 year olds, 96% for 25-44 year-olds, 89% for 45-55 year-olds, 78% for 55-64 year-olds and down to 40% of those 65 or over).
- Of those individuals who indicated that they had an illness or disability which limited their activities, four in ten (39%) had never used the internet compared to around one in seven (14%) who had no illness or disability.
- The proportion of people who used the internet and sought health-related information in the UK was just under four in ten people (39%) but this differs with age (27% of 16-24 year-olds, 42% of 25-44 year-olds, 39% of 45-54 year-olds, 44% of 55-64 year-olds and 36% of those 65 or over).

The increase in access to the internet has also led to an increase in service user and public involvement in public service delivery. A study² into the role of co-production between citizens and professionals in the delivery of public services in five European Union states (including the UK) reports that there is greater involvement by citizens in service delivery which is, in part, driven by advances in Information Communication Technologies, in particular the internet. Specifically e-participation tools and social networking sites have assisted this increase in participation.

¹ http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5672

^{2"}If you want to walk fast, walk alone. If you want to go far, walk together": Citizens and the co-production of public services, Dr.Elke Lóffler et al, commissioned by the French ministry of Budget, Public Finance and Public Services 2008.

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E-participation tools

E-participation tools enable citizens and service users to give feedback online on services and issues affecting them as well as to engage with public services. Such tools include:

- online forums or message boards;
- electronic surveys or polls;
- e-petitions;
- online focus groups; and
- webcasting.

Online forums (or message boards)

An online forum or message board allows people to take part in a discussion by leaving comments in the form of posted messages. Depending on how the forum is established users can be anonymous or they may need to register with the site to post comments. In some cases a comment posted by a user needs to be approved by a moderator before it is accepted and is seen by the other users of the forum.

Online forums have been around for quite some time and advantages are that they can be a cost effective way of gathering user or public feedback. However, thought needs to be given to determine how representative users on a forum are and how to market or advertise the forum so people know they can use it. There is also a requirement on staff to continually moderate the forums and encourage user participation through posting new content.

Examples of online forums/message boards include:

NHS Online, which is for use by NHS Employees http://www.nhsonline.net/forum/article.asp?MessageId=5210

MacMillan Cancer support, which has an online community portal http://community.macmillan.org.uk/whatsnew/default.aspx

Patient Opinion, which allows patients to describe and share their experience of a service http://www.patientopinion.org.uk/Opinions?postingType=comments&nacs=G107H

Online surveys or polls

Online surveys or polls are straightforward tools which can be completed electronically either via email or on a website. Web-based survey services allow simple analysis of frequencies of responses to each question although generally cannot provide more complex analyses, for example if there are statistically significant differences between groups. Benefits include ease of design and administration and reduced costs by eliminating hard copies and postage costs. Surveys can target large groups of people and be completed quickly. Again thought needs to be given to how representative survey respondents are of the population as a whole as some sections of the community are less likely to have access to the web.

Information about how to conduct electronic questionnaires with links to tools for support is available on the Scottish Health Council's website: http://www.scottishhealthcouncil.org/shc/pfpi/toolkit/Electronic_Questionnaires

E-petitions

E-petitions allow people to have their petition live on the internet rather than just on paper, which means the petition can be made more widely available to a larger audience. Some organisations that use e-petitions also have separate discussion forums which allow signatories to discuss the issues relating to the petition. Supporting information can also be made available to give a background to the topic and put the petition in context.

Additional information and examples of e-petition systems are included in the links below:

Scottish Parliament's e-petition web page http://epetitions.scottish.parliament.uk/

ipetitions is a free tool that allows you to create your own online petition http://www.ipetitions.com/

The Consultation Institute has a page dedicated to e-petitions (with links to tools that allow you to develop your own e-petition) and a pdf publication called The Directory of e-petition Applications. http://www.consultationinstitute.org/resources/software-and-online-tools/

Online focus groups

Online focus groups are focus groups moderated over the internet. People can take part in a discussion from their own homes via a personal computer to the organisation's screen and at the same time either talk over the phone or via the computer. The focus group moderator can use the screen to show visuals or materials and facilitate the discussion just as in a normal face-to-face focus group. Online focus groups are facilitated by using web conferencing software such as WebEx.

The advantages of this approach are that there are no travel costs for either the participants or the moderator, there are no room hire costs and focus groups can be run across a wide geographical area. However, it is worth noting there is also a cost to using the technology to facilitate online focus groups which can vary depending on the product used.

An example of how an online focus group is conducted is described on Wikipedia: http://en.wikipedia.org/wiki/Online_focus_group

Webcasting

A webcast is essentially an online video which can be broadcast live or recorded and played back on demand by the user. Webcasting is becoming a popular tool to conduct presentations without the need to attend a meeting or an event. Benefits include getting your message across to a wider section of the population as well as potentially saving money compared with the costs of organising an event. Some local authorities have started to webcast their council or committee meetings.

An example of webcasting in the NHS can be seen from NHS Choices YouTube channel http://www.youtube. com/user/NHSChoices

An example of webcasting from the Scottish Parliament's Holyrood TV can be found at www.holyrood.tv

Social media and social networking

Social media is the term used to describe the different methods and technologies which help users to share information and content online. The most popular social media platforms include sharing photos and video content, blogging (regular updates relating to a specific person, business or community) and social bookmarking which allows people to share all types of content with other online users³. With regard to participation the most relevant social media is social networking. Social networks allow users to connect and interact with other users to share views and other content.

Social networking has become a global phenomenon with many people using sites such as Facebook, Twitter, Bebo, LinkedIn and Youtube. There are around 30 million Facebook users in the UK alone⁴. Having joined these sites (or communities) people can share common interests, collaborate with each other and create new content. This 'user generated' content can empower people to express their views as well as learn about the views of others⁵. As well as using these tools for a purely social purpose they can enable people with shared interests to connect and express their views on a range of social, economic and political matters via the likes of online petitions. This has happened recently in response to recent UK and Scottish elections as well as protesting about cuts in various public services.

Public service organisations such as local authorities, police and the NHS are now frequently engaging their citizens and service users using social media and social networking sites. This offers a new form of relationship between the public sector and its citizens allowing users to express their views earlier in the participation process as well as to receive real-time feedback. By engaging citizens in this way public sector organisations can use 'crowd sourcing' which is essentially sourcing ideas and solutions from the public. This has the benefit of⁶:

- developing an understanding of issues from a citizen/user perspective;
- facilitating discussions between citizens;
- bringing new people and fresh thinking to problems; and
- promoting early engagement.

Prevalence and potential impact

Figures from the national Office for National Statistics study on use of the internet show that over four in ten (43%) of internet users use the internet to post messages to chat sites, social networking sites and blogs. This varies considerably with age group, for example three quarters of 16-24 year-olds undertake this activity compared to around half (49%) of 25-44 year-olds, three in ten (31%) 45-54 year-olds, two in ten (19%) 55-64 year-olds and only 8% of over 65 year-olds. While no figures are given for under 16 year-olds it is generally regarded as very high.

A recent report by internet measurement data company Experian Hitwise, states that social media is the fastest growing sector online in the UK, growing by 17% year-on-year in 2010. For the first time ever in 2011, social media became the single biggest activity online, overtaking the Entertainment category⁷.

This extensive use of social networking is having an impact on other media. For example, one commentator⁸ predicts that an impact from online news feeds and social media is that local and regional newspaper circulation will drop by between 20-30% by 2012. This will obviously have an impact on any organisation that is trying to reach people via these local media, public sector organisations in particular. Clicky Media also reports that email use among younger age groups is declining due to the preferred use of communication by both texting and social networking sites.

Some useful further reading on social networks and their use in the NHS can be found in the paper 'The power and perils of using social networking tools in the NHS' produced by NHS Faculty of Health Informatics 2009.

³ http://www.clickymedia.co.uk/social-media-marketing/what-is-social-media/ ⁴lbid.

⁵ Online Social Networks: Research Paper, Department of Communities and Local Government, 2008 ⁶Bristol City Council, 2010 at http://www.bristol.gov.uk/ccm/content/Council-Democracy/Consultations/e-democracy.en ⁷Carpe diem - Seizing the moment in Social Media, Experian Hitwise, 2011 ⁸http://danslee.wordpress.com/2010/01/26/your-seven-step-guide-to-getting-started/

Three NHS Boards (below) have both Facebook and Twitter accounts. These sites are used to update the Boards' followers on relevant health information such as service opening times during the holiday period, to communicate health promotion messages as well as recruit volunteers. There is a large following of community and voluntary organisations following the NHS Board sites which allows the Boards to get their message to these organisations' followers. There are also examples of the Boards using their social networking sites to encourage feedback via online polls.

NHS Tayside http://twitter.com/#!/NHSTayside http://www.facebook.com/NHSTayside

NHS Lothian http://www.facebook.com/pages/NHS-Lothian/165425872242 http://twitter.com/#!/NHS_Lothian

NHS Lanarkshire http://twitter.com/#!/nhslanarkshire http://www.facebook.com/nhslanarkshire

Benefits of e-participation and social networking

The general benefit of e-participation and social networking tools is that they have the potential to reach a wider audience than traditional engagement and participation methods and tools. This is due to the fact that people can participate from their own homes at a time to suit themselves. This has the potential to encourage greater participation particularly from those living in remote communities, people who are housebound or have disabilities, and those with little time to attend public meetings such as those with families or caring responsibilities. Some key benefits of social networking are that it:

- is time and cost efficient;
- can make it easy for service users to give their views;
- is a personal and informal way of engaging with service users and the public;
- enables service users and the public to have some ownership of the process; and
- allows people the opportunity to dip in and out of engagement as appropriate to their own time and interests.

Research also shows that most citizens do not want to get involved in organised activities when participating in public service delivery⁹. This is perhaps where social media and e-participation tools can play a part in encouraging those who would not normally participate with health services to do so.

Challenges of e-participation and social networking

It should be recognised that online participation complements rather than replaces traditional participation tools. This is because not all people have access to the internet particularly older people or those on a low income. In addition those with communication or literacy problems are also less likely to engage via online methods. Consideration should also be given to the fact that for some people there is no substitute for face-to-face dialogue, particularly in terms of relationship building.

According to a paper on the costs of e-participation¹⁰, while acknowledging the benefits, there are also costs in terms of developing the online tools as well as an increase in administrative workload to encourage people to take up online participation.

⁹ "If you want to walk fast, walk alone. If you want to go far, walk together": Citizens and the co-production of public services, Dr.Elke Lóffler et al, commissioned by the French ministry of Budget, Public Finance and Public Services 2008.
¹⁰Kim Viborg Andersen, Helle Zinner Henriksen, Christine Secher, Rony Medaglia, (2007) "Costs of e-participation: the management challenges", Transforming Government: People, Process and Policy, Vol. 1 Iss: 1, pp.29 - 43

Some key challenges include:

- e-participation adds to staff's existing workload as it complements rather than replaces traditional methods;
- it can take time and financial resource to develop an online portal;
- the need for an effective marketing strategy to signpost people to a web portal or social networking site;
- a requirement to develop a governance policy in terms of use for staff and users relating to confidentiality, data protection and privacy;
- the need for a management policy in order to co-ordinate staffing issues when comments are posted out of office hours.

Conclusion

While there are benefits and challenges to using e-participation and social networking the real driver to their use will probably stem from their increasing prevalence, particularly from mobile devices such as smart phones and tablets. As younger age groups mature these online tools will become the norm for many people. This is not to say we should ever rely totally on technology for engagement and participation in NHSScotland but that its use and potential in this context is likely to continue to increase.

At present social networking tools appear to be more useful for information sharing and communicating on participation and engagement issues rather than conducting participation, although this could change in future. As for e-participation tools these are more specifically geared for engagement and involve service users and the public in a more meaningful way.

A focus on using e-participation and social media tools within NHSScotland is starting to emerge. NHS Tayside (supported by NHS National Services Scotland) is piloting an EPORTAL which will allow people to engage with the NHS via online consultations and discussions and is intended to be rolled out to other NHS Boards across Scotland. Currently three NHS Boards (Tayside, Lothian and Fife) are piloting use of social media such as Facebook and Twitter to determine how best to use the media and share learning across other NHS Boards. In addition, the Scottish Government Health Directorate is currently in the process of working with Boards to identify and share standards and policies for social media. The findings from these pilots and reviews will be circulated across NHSScotland to enable other NHS Boards to develop approaches to e-participation and social media.

If you wish to make any comments on this paper then please contact

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