

Social media and e-participation in NHSScotland

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About this paper

This briefing updates a previous paper from June 2011 on Participation and Online Technology¹. This paper is for those who work in health and social care and members of the public who are interested in social media and e-participation. The paper summarises the prevalence of public access to the internet and use of social media for health purposes, including peer support, giving feedback and the rise of the e-patient. It goes on to highlight NHS Boards' use of social media and patient and public portals to engage patients, carers and communities.

This paper concludes that, while there is still the need for traditional methods of patient and public engagement, there have been encouraging developments in the use of e-participation in recent years in NHSScotland. However, there is variation in how NHS Boards are making progress in this area. Boards should aim for an equitable approach, where people's opportunities to engage with the NHS using e-participation are the same wherever they live.

Introduction

This briefing reviews progress on how NHSScotland is using social media and e-participation tools to support the participation and involvement of patients, carers and communities in healthcare services.

What is e-participation?

E-participation refers to the ability to engage with patients, carers and communities using online technology or social media. Social media describes web-based tools used to share information, promote discussion and build relationships. These tools enable people to create and share content, including text, images and videos, and connect directly with others. In this paper we use the term social media to include:

- blogs and microblogs (e.g. WordPress and Twitter)
- social networking sites (e.g. Facebook and LinkedIn)
- content communities (e.g. YouTube and Flickr)
- collaborative projects (e.g. Wikipedia), and
- internet forums and online discussion boards.

These tools can enable patients, carers and communities to access information; provide peer support for self management of long term conditions; make complaints or give feedback; influence local service development; or take part in a dialogue with their local NHS Board. The tools allow the NHS to disseminate information; connect with a wider range of

¹ Participation and Online Technology, Scottish Health Council 2001, available at www.scottishhealthcouncil.org/publications/research_reports.aspx

audiences; provide feedback to people about how their views have helped improve services; and build relationships through:

- online forums/discussions/message boards
- online surveys/polls
- e-petitions
- online focus groups
- webcasting
- online peer support sites and
- online consultations.

National policy context

Many recent Scottish Government policies and initiatives have focused on putting people at the heart of the NHS and maximising opportunities for service user and community engagement, feedback and peer support. These include:

- the Healthcare Quality Strategy²
- the Patient Rights (Scotland) Act 2011³
- the Patient Experience Programme⁴, and
- the forthcoming Adult Health and Social Care Integration and Community Empowerment and Renewal Bills⁵.

These policies and initiatives have been developed to help people become more active partners in their own care, to support self management through high quality information provision and peer support and to ensure that feedback from users drives improvements in service delivery and care.

Person-centred ehealth

Specifically in relation to e-participation, the Scottish Government's 'Person-centred eHealth Strategy and Delivery Plan'⁶ sets out five priority areas of activity as follows:

1. Improving information and providing opportunities for patients to give feedback – through improvements to websites, advice linked to electronic records, text messaging, social media and web applications (apps).
2. One-way communication (from the NHS to the person) – using a combination of email, text messaging and postings via patient portals.

² www.scotland.gov.uk/Resource/Doc/311667/0098354.pdf

³ www.scotland.gov.uk/Topics/Health/Policy/Patients-Rights

⁴ www.healthcareimprovementscotland.org/our_work/patient_experience/better_together.aspx

⁵ www.scotland.gov.uk/About/Performance/programme-for-government/2012-13/Adult-Health-Bill

⁶ www.ehealth.scot.nhs.uk/wp-content/documents/personCentredStrategy.pdf

3. Two-way communication (to and from the NHS to the person) – using patient portals, home monitoring devices (telecare and telehealth) and e-consultation.
4. Carrying out transactions – such as managing appointments and requesting repeat prescriptions through the implementation of the patient portals that are offered as part of the two GP Information Technology systems now in use in NHSScotland.
5. Peer support – providing ways that people can communicate and support each other through greater use of web forums, social media and improved access to information.

This strategy is a sub-strategy to the overarching eHealth Strategy 2011-17 which aims to deliver transformational change underpinned by the use of Information Technology. The eHealth Strategy has six strategic aims, one of which is to use information and technology in a co-ordinated way to:

“support people to communicate with NHSScotland, manage their own health and wellbeing, and to become more active participants in the care and services they receive.”⁷

⁷ <http://www.scotland.gov.uk/Resource/0040/00409128.pdf>, p15

Access to the internet and prevalence of social networking

Before looking at how prevalent social media and e-participation tools are within the NHS in Scotland it is worth understanding how different sections of the population currently access online sites and social media tools.

Internet access

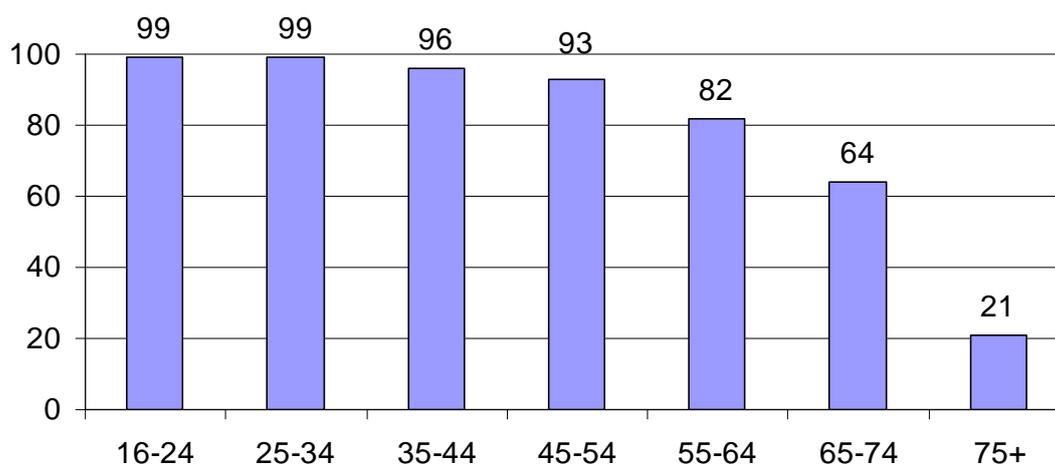
A summary of the latest Office for National Statistics (ONS) research on internet access⁸ shows that around 85% of people access the internet in the UK. In Scotland around 84% of people access the internet. Internet use is linked to various socio-economic and demographic characteristics including age, sex, disability, and earnings as well as geographical location. For example, adults who are less likely to have used the internet include the elderly (in particular those over 75) and people with a disability. Generally, internet access increases with income and education and decreases with age. Key points from this research include the following.

- Access to the internet varies across local authority area within Scotland from a low of 78% in North Lanarkshire to a high of 91% in East Lothian and Midlothian.
- 15% of people in the UK have never accessed the internet (a drop from 35% in 2006), and half of these people have a disability⁹.
- Almost a third (31.7%) of people in Scotland with a disability do not have access to the internet compared with around one in ten people (10.6%) who do not have a disability.
- Men (85%) were more likely to be internet users than women (83%).
- While almost all people aged 16-44 have used the internet, use declines down to 21% for those over 75 in Scotland (see chart below) and this age group accounts for almost half of those who do not access the internet.

⁸ Office for National Statistics, Internet Access Quarterly Update, Q4 2012, 20 Feb 2013, www.ons.gov.uk/ons/rel/rdit2/internet-access-quarterly-update/2012-q4/stb-ia-2012-q4.html

⁹ The definition of disability is that given in the Disability Discrimination Act, which is people who self report a physical or mental impairment that has a substantial and long term adverse effect on a their ability to carry out day-to-day activities.

Internet users in Scotland by age group (%), 2012 Q4



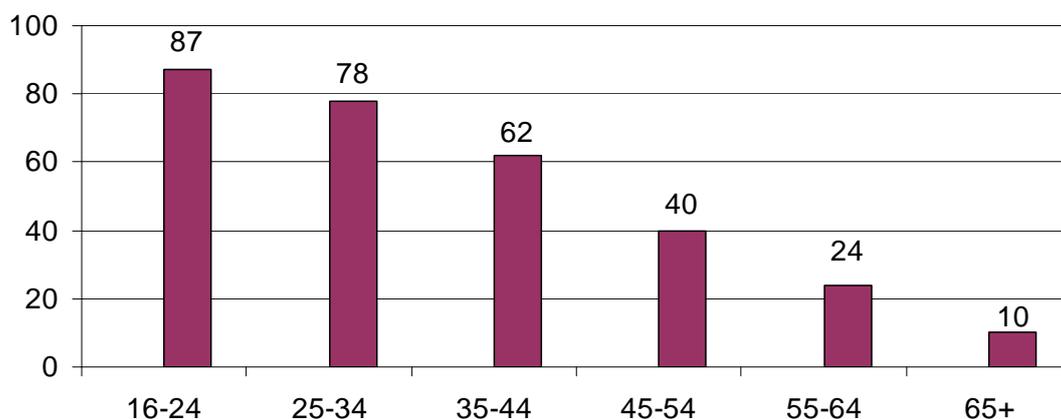
Mobile internet access and prevalence of social networking

ONS has also released research data for mobile access to the internet and use of social networking¹⁰. Some of the key findings are included below.

- In 2012 almost half (48%) of the UK population used social networking sites. This varies considerably with age as almost nine out of ten 16-24 year olds used social networking compared to only one in ten of over 65 year olds.
- Around six in ten people (58%) accessed the internet via a portable or hand held device and of these around a third access social networking sites using these devices (although this varied considerably with age from 72% of 16-24 year olds to only 1% of over 65 year olds).

¹⁰ Office for National Statistics, Internet Access - Households and Individuals, 2012 part 2, 28 Feb 2013 [Scottish Tables] www.ons.gov.uk/ons/rel/rdit2/internet-access---households-and-individuals/2012-part-2/stb-ia-2012part2.html

Proportion of Adults Using Social Networking Sites (%), 2012



These figures demonstrate what popular mechanisms the internet and social networking sites are with the general public.

A recent report on ‘Social Media in Mental Health Practice’¹¹ describes how mental health practitioners can use social media to help people recover and live well and states that social media use is now “woven” into everyday use for the majority of the population.

Social media has the potential to reach out to some groups that the NHS historically finds challenging to involve, e.g. working people, the housebound, young people, and communities living in remote and island areas. As younger age groups mature, these online tools will become the norm for many people and the potential to increase patient and public involvement within health and social care services can be realised, as a recent report on citizen engagement highlights:

“The rise and increasing pervasiveness of digital social media—Facebook, Twitter—have dissolved the many technical barriers to widespread and sustained citizen involvement in actually co-producing and co-delivering public services.”¹²

The public’s use of social media for health purposes

Peer-to-peer support

Around seven in ten (71%) people access the internet for health information in Britain¹³. The content people access ranges from lifestyle and preventative information to chronic and disease management information.

¹¹ V.Betton & V.Tomlinson. Leeds and York Partnership NHS Foundation Trust. Social Media in Mental Health Practice: Online tools for recovery and living well. March 2013.

http://www.leedsandyorkpft.nhs.uk/documentbank/2418_DMH_e_book_2_1.pdf

¹² P.K. Kannan & Ai-Mei Chang. IBM Center for the Business of Government. Beyond Citizen Engagement: Involving the Public in Co-Delivering Government Services, 2013, p6

¹³ Dutton, W.H. and Blank, G., 2011. Next generation users: the internet in Britain. University of Oxford: Oxford Internet Institute <http://microsites.oii.ox.ac.uk/oxis/publications> [March 2013]

According to Fergie & Hilton¹⁴:

“Appropriating, interpreting and commenting on this information has become easier and more common since the proliferation of social media technologies and the increasing number of users who use mobile and multiple devices to access the internet.”

This has led to an emergence of peer-to-peer health and social care support via websites and social networking sites such as Health Unlocked¹⁵ and Patientslikeme¹⁶. These sites allow patients to self manage their conditions by sharing their knowledge and experiences on their symptoms, treatments and care plans. Twitter has also seen a rise in patient communities over the last two years as this clip¹⁷ shows.

An interesting piece of research from MacMillan Cancer Support¹⁸ reveals that there are a number of reasons why patients are using peer support online, including to:

- access knowledge and information on their condition
- find alternative and complementary treatments
- raise awareness of their condition with others
- seek support from peers
- make social connections, and
- tackle isolation.

The report goes on to highlight some of the health benefits of accessing social networking peer sites, such as those mentioned above, including:

- reducing feelings of isolation and loneliness
- increasing the feeling of empowerment
- aiding rehabilitation, and
- improving patients' ability to cope with their disease.

However, there are some concerns among people accessing health information sites that the information is not safe or accurate. There are also concerns that some health information sites are being used to promote private health products and services. In this regard health charities (such as MacMillan Cancer Support) and the NHS are now aiming to promote health sites which have been endorsed or vetted. NHS Inform¹⁹ in Scotland and NHS

¹⁴ Gillian Fergie , Kate Hunt & Shona Hilton (2012): What young people want from health-related online resources: a focus group study, Journal of Youth Studies, DOI:10.1080/13676261.2012.744811 <http://dx.doi.org/10.1080/13676261.2012.744811> [March 2013]

¹⁵ www.healthunlocked.com/

¹⁶ www.patientslikeme.com/

¹⁷ www.symplur.com/shorts/the-rise-of-patient-communities-on-twitter-visualized/

¹⁸ MacMillan Cancer Support: Macmillan's website: An evidence review, August 2012 www.macmillan.org.uk/Documents/AboutUs/Commissioners/MacmillanWebsiteAnEvidenceReviewAugust2012.pdf

¹⁹ www.nhsinform.co.uk/

Choices²⁰ in England help to do this by ‘signposting’ to credible health information sites. A recent development in England has been the development of a Health Apps Library²¹ which aims to simplify the process of finding safe and trusted health apps which assist the user to manage their own health. The apps are reviewed by the NHS to ensure they are clinically safe and relevant to those living in the UK.

Feedback apps

Some of the apps in the library allow users to give feedback via smart phones and tablets on the service they have received from both acute²² and primary care settings²³. Giving feedback via mobile devices is seen as a way to give near real-time feedback to health and social care providers. This allows healthcare providers to make improvements to their services much more quickly than traditional feedback mechanisms, such as large scale patient surveys.

The rise of the e-patient

Use of the internet for finding health information, peer support and also blogging about health conditions has given rise to the term e-patients (as well as e-carers). This term is used to describe patients (and carers) who use web tools to help manage their health conditions. These patients take a very active part in their healthcare which has also led to a ‘participatory medicine’ model of healthcare, described by the Society for Participatory Medicine²⁴ as:

“... a model of cooperative health care that seeks to achieve active involvement by patients, professionals, caregivers, and others across the continuum of care on all issues related to an individual's health.”

Examples of such e-patients and e-carers include Michael Seres who was opening speaker at the Scottish Health Council's social media event in February 2013. After coping with Crohn's Disease and then intestinal failure Michael became the 11th person to undergo a small bowel transplant at the Churchill Hospital in Oxford and blogs and tweets about his journey as a bowel transplant patient²⁵. Tommy Whitelaw also blogs and tweets about his experience as a carer for his mother who had dementia. His blog post ‘Tommy on Tour’²⁶ raises awareness of dementia with a wide range of carers, dementia patients and healthcare professionals.

²⁰ www.nhs.uk/Pages/HomePage.aspx

²¹ <http://apps.nhs.uk/>

²² <http://www.feedbackapp.nhslocal.nhs.uk/developed-in-partnership/>

²³ <http://apps.nhs.uk/app/gp-ratings/>

²⁴ <http://participatorymedicine.org/>

²⁵ <http://beingapatient.blogspot.com>

²⁶ <http://tommy-on-tour-2011.blogspot.co.uk/>

NHS Boards' use of social media and e-participation tools

As social media and e-participation tools have gained popularity amongst the general public more NHS Boards in Scotland²⁷ are also starting to use these communication tools.

Facebook, Twitter and YouTube

The main social media tools used by NHS Boards in Scotland are the three most popular used by the general public, namely Facebook, Twitter and YouTube. Around 18 months ago (September 2011) there were five or six NHS Boards using Facebook or Twitter, with only a few using both. At the time of writing (April 2013) there are now 18 NHS Boards in Scotland using Twitter and 16 using Facebook, with eight NHS Boards using YouTube to inform and engage with their patients and public.

NHS Boards tend to have more Twitter 'followers' than Facebook 'likes', ranging from a few hundred followers to over 4,500 for NHS Lothian on Twitter. Facebook 'likes' range from 40 to around 2,000 for NHS 24 with the exception of the Scottish National Blood Transfusion Service which has around 20,000 'likes'. While there are not many people subscribing to NHS Boards' YouTube accounts there are a lot of people viewing them, ranging from a few hundred to tens of thousands for some video clips.

In the main, NHS Boards use these tools to provide information to the community although in some instances there is also discussion and engagement and a probable increase in people using social media to give feedback on healthcare experience. The main use of Facebook, Twitter and YouTube social media tools for NHS Boards is to:

- distribute health information
- share community information, often in conjunction with other public services e.g. the police
- provide service information, e.g. opening times
- report positive and negative experiences from patients and public
- facilitate discussions on health issues
- provide health improvement advice, and
- engage staff.

Patient Opinion and NHS Scotland's e-participation websites

Patient Opinion is a website that facilitates the sharing of healthcare experiences between users and providers. Around four NHS Boards were actively using Patient Opinion^[1] in 2012, whereas now there are six Boards fully subscribed and another eleven using the service to some extent. Eleven NHS Boards were involved in the Scottish Government funded pilot of Patient

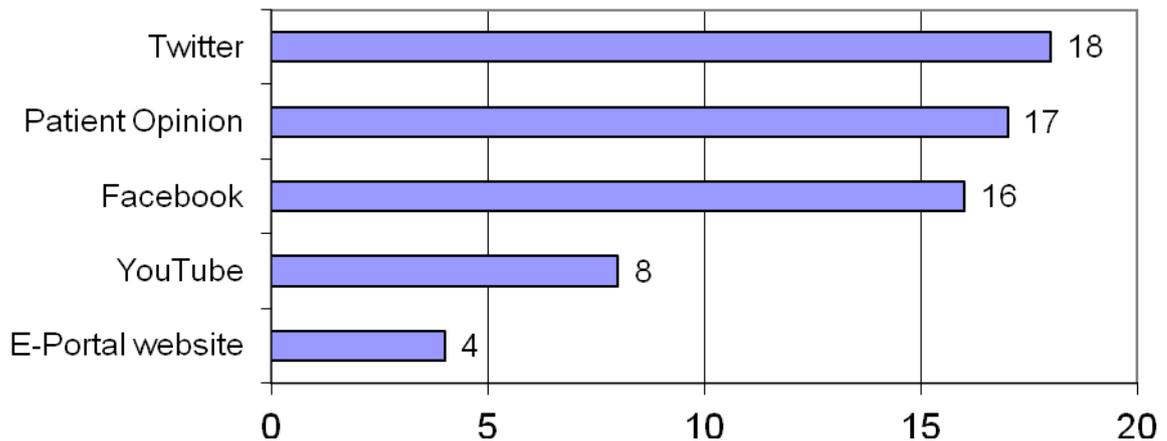
²⁷ There are 22 NHS Boards in Scotland (including Healthcare Improvement Scotland)

^[1] www.patientopinion.org.uk/services/nhs-scotland

Opinion. The Scottish Government recently announced that funding will be provided for Patient Opinion's roll out across all NHS Boards as a close to real-time feedback channel, and it is anticipated that it will be available in all Board areas as and when these remaining Boards become organisationally ready.

E-participation websites have been developed in Scotland, initially with NHS Tayside²⁸ and have now been rolled out to three other Boards (the Scottish Ambulance Service²⁹, NHS Ayrshire & Arran and NHS Grampian). These websites allow users to respond to local and national consultations, discuss local healthcare issues and enable users to give feedback on local healthcare services. It is intended to further roll out these e-participation websites to other NHS Boards in future.

**Number of Boards using social media/e-participation tools
(March 2013)**



Development of patient portals

Patient portals are being developed as part of Scotland's Person Centred eHealth Strategy. These are mainly at the piloting stage at present although some are starting to be rolled out more widely as well as becoming national portals. Two examples are given below which are highlighted in the eHealth Delivery Strategy highlighted on page 2.

- **NHS Ayrshire & Arran Patient Portal**

This is a secure website allowing patients to access and update their own health records online and operates at two medical practices. Patients can request appointments online; request repeat prescriptions; access test results; record, track and monitor their blood pressure; set targets for weight and other goals, and record and track blood sugar

²⁸ www.yournhstayside.scot.nhs.uk/

²⁹ <http://your.scottishambulance.com/Default.aspx>

level. The portal allows patients to become partners in their own care and has the potential to deliver healthcare services more efficiently and safely. An app for Smartphone users is being developed. There is evidence that the patient portal is being used as an alternative to visits and telephone calls.

- **My Diabetes My Way³⁰**

This allows users access to relevant parts of their electronic diabetes record, such as biochemistry tests, blood pressure, body mass index, foot risk scores, eye screening results and prescribing. Alongside the clinical data, patient friendly information helps to explain what their record means. This will give patients a better understanding of diabetes and greater involvement, empowerment and control of their care.

NHS staff use of social media

There are barriers to using social media tools for most staff in NHSScotland, due to IT firewalls and restrictive staff social media policies, although progress is being made in some areas where a clear case for use can be made. Despite this, some staff are using their own personal mobile devices (predominantly in their own time) and using social media to connect with fellow healthcare practitioners and share learning with their community of practice. Some good examples of this are the Twitter stream #nhssm which takes place every Wednesday at 8pm to discuss healthcare issues. There are also more specific health professional chats such as #wenursechat and #wepmds (paramedics).

In addition to Twitter feeds there are also health blogs such as Ayrshire Health Blog³¹ whose 'core group of contributors all work in the healthcare arena in and around Ayrshire'. The Cabinet Secretary for Health and Wellbeing has recently contributed to the blog page discussing the person-centred care agenda. ScotHealthMonthly³² is another useful health blog which summarises blogs by healthcare professionals from across Scotland on a monthly basis.

³⁰ www.mydiabetesmyway.scot.nhs.uk/

³¹ <http://ayrshirehealth.wordpress.com/>

³² <http://scothealthmonthly.wordpress.com/>

Conclusions

Social media and other methods of e-participation offer an increasing range of creative and accessible ways for people to get involved in their care and in shaping healthcare services. However, this is not to say we should ever rely totally on social media for engagement and participation in NHSScotland, especially when engaging particular groups of people. Community engagement practitioners need to be aware of the barriers to involvement when using social media – including access to technology, computer and online literacy, language skills and physical impairment – and consider how best to overcome them. The future of patient and public engagement looks likely to involve both online and offline approaches.

In a blog about citizen engagement Andy Williamson³³ states that:

“It’s not about online or offline:

- Effective engagement requires a blend of on and offline to maximise impact and to build a sustainable network
- Offline offers richness and depth, online more reach and flexibility.
- Online is a distribution channel to offline hubs.
- Mobile [phone and tablet] is increasingly important. “

Whilst this brings challenges to the NHS, as development work on e-participation needs to take place at the same time as providing traditional patient and public involvement, it also offers opportunities to engage with a wider audience.

There is some emerging evidence to show that e-patients and e-carers can have a positive contribution, not only to their own healthcare but also to that of others, and can help to improve health outcomes. At the same time some preliminary evaluation of patient portals suggests there is some potential to improve efficiency and effectiveness in healthcare delivery using these methods.

There have been encouraging developments in the use of e-participation in recent years in the NHS and beyond – some of which are highlighted in this paper but there is variation in how NHS Boards are making progress with this. We should aim for an equitable approach, where people’s opportunities to engage with the NHS using e-participation are the same wherever they live.

The Scottish Health Council’s vision for e-participation is that patients and communities influence and improve their healthcare treatment and services through online conversations, as well as traditional methods of engagement. We aim to achieve this vision by implementing our strategic objectives related to e-participation, which are:

³³ Andy Williamson. Engaging through a mist of distrust, Feb 2013
<http://www.andywilliamson.com/?p=681> [March 2013]

- to support NHS Boards to continuously improve their use of social media and e-participation tools to strengthen their engagement with patients and communities, and
- to be recognised as a key player in the emerging e-participation community, promoting learning and sharing of new techniques and approaches as they emerge, and seeking to model best practice through our own communication and engagement.

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