Developing health literacy policy in Scotland: A case study

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Introduction

In 2011, the Scottish Government convened a National Health Literacy Action Group (NHLAG) to prioritise actions that would raise awareness of the impact of inadequate health literacy for all parts of the population in Scotland and stimulate a responsive, enabling culture to address the problem. Addressing health literacy requires a societal response, with significant contributions from education systems and communities. However, it also requires a healthcare system that is responsive across people’s entire lifespans. It was to this that NHLAG decided to devote its focus as a starting point.

This case study describes the approach, rationale and processes that NHLAG took to formulate Scotland’s health literacy action plan, Making it easy. It describes the key actions that were developed and discusses the progress that has been made to implement these actions and the outputs that have been achieved. While much has been achieved, we also describe the learning that will help inform further progress.

Background

The provision of health and social care in the UK is a responsibility devolved to the four nations of England, Wales, Northern Ireland and Scotland. There is universal healthcare provision under the National Health Service (NHS) across the UK, although differences exist in the provision of social care. The Scottish Government, through its Healthcare quality strategy (Scottish Government, 2010) and 2020 vision (Scottish Government, 2011), has held a quality ambition for a safe, effective and person-centred healthcare system, along with an integration of health and social care and support for self-management to enable people to live at home or in a homely setting. There is strong emphasis in Scotland’s culture and political ethos of respecting and promoting people’s human rights and addressing inequalities.

Within this context there has been a growing realisation that the issue of health literacy has been a significant factor in determining people’s ability to safeguard
their own health and to get the most from their health and care systems. While this has long been a public health concern in promoting health and preventing disease, it is now an increasing challenge to the wider health and care systems as people are living longer with multiple long-term conditions. The growing demands and expectations that modern medicine is placing on people often overwhelms their abilities, undermining the safety and effectiveness of healthcare. Those with the greatest health literacy needs face the greatest challenges and poorest outcomes.

A Scottish Government scoping study looked at the national and international evidence on the impact of health literacy (Scottish Government, 2009). It was clear something had to be done. However, it was less clear what needed to be done. The study concluded that, because the issue of health literacy was central to so many policy areas, a stand-alone health literacy policy may not be necessary. Instead, it recommended the establishment of the NHLAG to prioritise areas for further development and integrate these into existing and emerging policies and programmes (Scottish Government, 2009). This challenge represented an exciting new frontier for healthcare and in enterprising fashion an expert group of health literacy pioneers was convened to prioritise actions that could make a difference. The action plan, Making it easy, was published in June 2014 (Scottish Government, 2014).

**Approach**

The NHLAG was convened in 2011 bringing together a representative panel of people working in the field encompassing public health, policy, academia, clinical practice, rights and health equity and health and knowledge information. It was chaired by the Chief Executive of The Alliance, representing third sector organisations and people with disabilities, living with long-term conditions or providing unpaid care. In addition, the Scottish Government appointed a GP as a national clinical lead for health literacy. The group met approximately every four weeks for two years. It was a collaborative and evolutionary approach that traversed key milestones:

- defining the problem and concepts
- developing an overarching ambition
- defining the specific scope
- devising and prioritising specific actions.

**Defining the problem and concepts**

The first task of this diverse group was to get a coherence of understanding around health literacy and how addressing it was going to be of benefit. We realised that, while insufficient health literacy was a common problem that had a significant impact on people's wellbeing, there was little evidence for what could be done about it. On the one hand, this lack of evidence can inhibit health economies
from addressing the issue, but on the other hand, it offers an opportunity to innovate and evaluate. Doing nothing did not seem an option.

We began by exploring the usefulness and limitations of the multiple definitions of health literacy. While they are helpful in explaining what health literacy is, we found they are perhaps limited for the following reasons:

- They locate the problem of health literacy with individuals rather than the complexity and unfamiliarity of the health and social care environment (Baker, 2006).
- They focus on people’s abilities. While people with poor cognitive and social skills will be most affected, even highly skilled university academics can struggle with unfamiliar contexts (WHO, 1998; American Medical Association Ad Hoc Committee on Health Literacy, 1999).
- They overlook the impact of culture, socialisation and health beliefs.

It felt more pragmatic to define health literacy in terms of its impact on people’s health, care and health outcomes (DeWalt et al, 2004; Paasche-Orlow and Wolf, 2007; Berkman et al, 2011). From the literature, studies seem to show that poor health literacy principally has an impact on people’s confidence, knowledge, understanding and skills to:

- access and navigate healthcare (Williams et al, 1995; Baker et al, 1997, 1998);
- collaborate with their healthcare professionals (Easton et al, 2013);
- self-care and self-manage (Williams et al, 1998a, b; Schillinger et al, 2002) in order to live well, on their own terms, and with any health conditions they may have.

This was helpful to us as it allowed us to say that responding to people’s health literacy needs is about enabling and building people’s confidence, knowledge, understanding and skills. The key concepts that emerged to shape our approach are summarised in Box 28.1. We sought to find a working definition that:

- avoided a deficit approach;
- acknowledged the need for services to address the issues;
- took account of the wider population including, but not exclusively focused on, particular groups;
- captured aspects of health literacy beyond literacy and numeracy skills.

**Box 28.1: Key concepts underpinning Scotland’s health literacy approach**

- Health literacy challenges are very prevalent.
- Health literacy is not just an individual attribute, but is socially distributed and affects all of us.
• Individual health literacy is a hidden attribute and in particular, the stigma associated with low health literacy leads to people actively avoiding disclosure of any difficulties they may be experiencing during contact with health services.

• Low health literacy undermines people’s confidence, knowledge, understanding and skills to positively engage in their own health and healthcare, and the health of those they care for.

• Health and care systems unwittingly place demand, expectations and barriers that exceed people’s capabilities through over-reliance on written information, complex oral information and low awareness among healthcare staff when those they have contact with are struggling to understand (social disability model).

• Addressing health literacy individually and socially will bring reciprocal benefits.

• Redesigning and delivering healthcare to remove barriers and make it easier, more engaging and enabling is a worthwhile universal response to insufficient health literacy.

• Responding to people’s health literacy needs is central to programmes that focus on person-centred care, patient safety, effectiveness, shared decision-making, self-management support, health equity and human rights.

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**Developing an overarching ambition**

Our next challenge was to describe an aspirational vision or ambition. With any journey, it is helpful to know where you are heading. This may have seemed a simple enough task, but it became a fascinating exercise in gaining a shared understanding. It was clear that while health literacy was, on the surface, an individual attribute, it has an impact on all of us, whether as an individual, carer, family member, teacher, employer, community worker, politician, health manager or healthcare professional. It was also clear it had a social dimension, because good health literacy benefits us all, and we all have a role in enriching each other’s health literacy. Health literacy is therefore socially distributed. There are reciprocal enabling benefits of building collective health literacy as a society and in individuals – as long as we have positive social connection. This perhaps explains the interaction between social isolation, poor health literacy and health outcomes. The associated vicious and virtuous cycles are illustrated below, in Figure 28.1.

Our ambition therefore became: ‘We want Scotland to be a health-literate society that enables all of us to have sufficient confidence, knowledge, understanding and skills to live well, on our own terms, and with any health condition we may have.’

**Defining the specific scope**

Developing a health literate society is a multidimensional task with significant contributions to be made from: (1) child and adult education systems; (2) responsive health and care systems; and (3) communities (both real and online). This is visually represented in Figure 28.2, where people’s health literacy needs are met at the intersection of all these elements of a health-literate society.
We took evidence from educational experts and realised that Scotland’s National Curriculum was addressing functional literacy and numeracy along with digital literacy, with a focus on health, wellbeing and personal development. We also realised that there was a vast amount of activity, support and advocacy within communities, both in people’s neighbourhoods and online. While plentiful, the main challenges lay in making this support findable, accessible and networked.
with health and social care. However, significant work in Scotland was being
done to address this (ALISS, 2017).

What struck us (and the public) as being of overwhelming concern was the lack
of responsiveness by the health and care systems to the demands, expectations
and obstacles it was unwittingly placing on its users. This would need to be our
main priority and focus, not just to address health literacy in Scotland, but also
as an urgent rights and equity issue. As a national health and care system, we
needed to get our own house in order.

Devising and prioritising specific actions

This was a lengthy and in-depth process. It involved conducting a literature
search of evidence on the effectiveness of health literacy interventions. We also
looked at ongoing work in other countries with mature health and care systems,
such as Ireland (NALA, 2017), the US and Australia. Based on our findings, our
underlying concepts and ambition, we prioritised four areas of focus that we hoped
would initiate and sustain a movement of health literacy responsiveness within our
health and care system. We realised this had to start by raising awareness among
professionals and administrators of the hidden issue of insufficient health literacy
and its impact. We hoped to foster a health literacy culture and community of
practice that would adopt and spread existing best practice, as well as generate
innovation in new enabling approaches. This was particularly important at key
learning and patient safety points within the system. From this starting point,
four main objectives were developed:

• Raise awareness of the workforce and the capabilities of professionals to support
improved health literacy responsiveness.
• Improve access to useful health literacy techniques and resources.
• Promote the development and spread of new tools and innovations.
• Enhance transitions of care, which are key learning and patient safety points
in healthcare.

We were also mindful of the need to build in evaluation. Evaluating the impact
of health literacy interventions is still a challenging and developing area. Since
our main goal was to initiate health literacy action, our evaluative priority was to
explore what possibilities would emerge and how, rather than focus on specific
health, personal or economic outcomes. In order to meet our main objectives,
we developed four strategic actions:

• Develop a workforce awareness and capabilities programme.
• Develop a ‘go to’ online health literacy resource.
• Embed health literacy practice into existing person-centred and patient safety
improvement programmes.
• Establish a national health literacy demonstrator site.
Progress achieved from Making it easy

The learning and progress in implementing our actions from Making it easy is summarised below. A more detailed account of what has been achieved was published in Making it easy – Progress against actions (Scottish Government, 2017a).

A national health literacy resource for Scotland, The Health Literacy Place

The Health Literacy Place website (www.healthliteracyplace.org.uk) was developed by NHS Education for Scotland (NES) in 2015, and quickly became the principal resource for health literacy tools and support in Scotland. It was used to support the implementation of changes in the other action areas and to broaden awareness of the issues. An introductory video on the website and social media presence aided this. The web presence also supported a national network of health literacy champions, who, having attended central workforce educational events, would return to their local area to spread change.

Workforce skills and awareness

To achieve the broad task of raising awareness of health literacy and building the skills of the workforce, a range of methods was used between 2014 and 2017. Educational sessions in collaboration with NES were regularly held and covered ‘Health literacy awareness raising’ and ‘Health literacy train the trainer’ events. These were intended both to teach specific tools and techniques, and to equip staff to spread the message back to their local organisation. Remote learning was aided by the development of an eLearning module (see www.healthliteracyplace.org.uk).

The principles of Making it easy were encouraged to spread. Attendees from the sessions were encouraged to report back on how well local management were becoming involved and how local policies or literature were changing. Through the national demonstrator programme reported below, a collaboration with Dundee University also led to the inclusion of health literacy on their course for trainee nurses. This highlighted the importance of being aware of the issues and provided the skills necessary to improve patient care. NES also worked to improve the signposting to useful health information by working with other sectors, such as public librarians.

Promote and develop the spread of health literacy innovations

To ensure changes to practice were kept simple, educational efforts were focused on five main tools and techniques: teach-back; chunk and check; use simple language; use pictures; and always offer help with paperwork. These are summarised below, in Box 28.2. A key principle of the awareness raising taught to staff was the importance of avoiding making assumptions about people’s abilities,
and instead to consider using these tools and techniques routinely in their practice. The extent to which these have been adopted into practice is unknown and is a challenge for future evaluation.

Box 28.2: Five simple tools and techniques

Teach-back
This is a method to check information provided is being understood. The person is asked to 'teach back' what has been discussed. The emphasis of this is to check the professional's ability to explain information and not the person's ability to understand. This avoids the person perceiving it is their intelligence that is being questioned.

Chunk and check
Rather than providing a lot of information at once, 'chunk and check' breaks down information into more manageable parts. In between each 'chunk', methods such as teach-back could be used to check understanding before moving on.

Use simple language
Practitioners are encouraged to explain things to people as they would to a friend or family member, in a more relatable way.

Use pictures
The use of diagrams or photographs alongside verbal explanations is encouraged when explaining a task or problem and can help people understand. For example, it is much simpler to see pictures of someone giving an injection or caring for a wound than just reading or hearing an explanation.

Always offer help with paperwork
Routinely offering help reduces the pressure on people who may need to ask for assistance and reduces stigma. It also means the service gathers the correct information it needs.

A national demonstrator site

‘Meeting the health literacy needs of people at transitions of care’ was the working title for the national demonstrator programme. It was set up in a single health board region, NHS Tayside (population of around 400,000), to establish and evaluate best practice in meeting the health literacy needs of people as they are looked after by different parts of the system. Implementation made use of small tests of change and quality improvement methodology to acquire knowledge on what is most effective in practice. Learning was shared initially through established Health Literacy Place networks, and later through reports and events
to inform innovation around the country. The demonstrator programme took a broad perspective on health literacy, as reflected in our working definition, which looks beyond written information and skills related to functional literacy. It focused on health service design and delivery, driven by a computer literacy analogy presented in *Making it easy*:

Thirty years ago, IBM developed the first home computer. Most people, other than the very intrepid, were reluctant to learn how to use them. The IT industry could have provided us all with more information and education to increase our “computer literacy”. Instead they set about making computers simpler and more engaging to use. Now five and 85-year-olds can do complex tasks on a tablet computer. This approach of simplifying the computer “interface” has dramatically reduced the barriers to using computers, opening them up to almost everyone. (Scottish Government, 2014, p 12)

The action plan, *Making it easy*, asserted that ‘We must likewise simplify the healthcare “interface” and make healthcare more engaging’ (Scottish Government, 2014, p 12). Our literature search of evidence presented us with many ways of addressing health literacy through the development of decision aids and health education interventions. However, these tended to be specific to particular clinical specialties or population cohorts. There is little evidence that these potentially valuable pieces of work have been disseminated beyond the academic community or implemented in a practical way. The demonstrator programme aimed to identify issues that could be scaled up. We then hoped to apply the principles and learning to broader clinical areas other than those participating in the programme and ultimately to other geographical (NHS Board) areas across Scotland. The aims of the programme were:

- to make more effective the interactions at ‘transitions’ of care such as outpatient appointments and discharge from hospital care;
- to improve methods of communication between patients/carers and their practitioners so it is tailored to their needs and circumstances; and
- to support staff to improve their practice and educational processes.

One of the key strands of the programme was a ‘health literacy walkthrough’. This placed several different people – some adult learners, a Master’s of Public Health student and the programme lead – in a hospital setting with an example appointment letter. They were then invited to find their way individually to their appointment in the paediatric neurology department, flagging any health literacy issues along the way. The exercise revealed some interesting insights, many of which were fairly simple to remedy and greatly improve people’s experience of accessing the service.
For instance, the terminology on hospital signs was often inconsistent and the job of volunteer hospital guides made unnecessarily difficult. The appointment letters failed to highlight key information, contained confusing descriptions or missed the opportunity to include pictures or diagrams and other useful information about visiting the hospital. Additionally, some existing efforts to assist people were poorly implemented and too low-profile.

These findings were spread to other departments in the test area and, at the time of writing, work is ongoing to simplify and improve consistency in signage and direction information in departments. New information and appointment letters are being written in partnership with people accessing services to ensure they are easy to understand (see www.healthliteracyplace.org.uk).

Another strand of the programme focused on the need to be clear in communication before medical procedures. In some cases, the successful and safe completion of a procedure requires the person to follow very particular instructions. The quality and accessibility of relevant written information is therefore an important consideration in ensuring that people are appropriately supported to carry out any necessary preparation.

The demonstrator programme looked at endoscopy procedures as an example. It reviewed the suitability of materials relating to bowel preparation using both adult learners to test for comprehension, and specialist software to test for readability scores. The exercise highlighted that much of the mainstream language, not only the medical language, was needlessly complex. Adult learners involved in the exercise stated that they “would have signed the consent form but would have lied about understanding the information given.”

This project also highlighted that relying solely on specialist software that estimates necessary reading ability levels is inadequate. The algorithms used do not assess comprehension or how information may be interpreted by different people. It was clear that, although there are several guidelines relating to the production of patient information, testing the final product must again involve real people from various backgrounds to ensure that instructions are clear and appropriate (see www.healthliteracyplace.org.uk).

Other projects in the demonstrator site explored the use of new technology, using tablet computers to share videos explaining how to self-manage some conditions, and reviewing people’s understanding of their medication, prior to discharge from hospital. Work continues to further improve services and promote person-centred care through partnerships between academics and health service staff. While the findings of the demonstrator programme are not necessarily prescriptive or universally valid, they aim to give examples of common health literacy challenges and tips for local implementation. So, for example, the walkthrough can be replicated in any healthcare environment; many of the findings are likely to be the same but local issues can also be identified (see www.healthliteracyplace.org.uk).
Embedding health literacy into the shifting policy landscape

When the *Making it easy* action plan was published (Scottish Government, 2014), it was welcomed as a fresh approach. Since then, however, there have been further shifts in strategic policy for health and social care. The national action plan has been helpful in embedding the principles of health literacy into these policies, which, in turn, are giving energy and movement to addressing health literacy.

In January 2016 the Chief Medical Officer for Scotland published a novel annual report, *Realistic medicine* (Scottish Government, 2016a). In its chapter ‘Sharing decision-making and informing consent: People and professionals combining their expertise’ (2016a, p 16), it explored the case for change from the out-dated ‘doctor knows best’ culture to one where both parties can combine their expertise and be more comfortable in sharing the power and responsibility of decision-making. A key component of this is rebalancing the conversations and interactions between people and their practitioners that sit at the heart of our health and care system. The chapter identifies the need for system and organisational change to promote the required attitudes, roles and skills.

Scotland’s Chief Medical Officer’s next annual report, *Realising realistic medicine* (Scottish Government, 2017b), also looked to initiatives in health literacy as a specific means to implement the well-received approach outlined in *Realistic medicine* (Scottish Government, 2016a). *Realistic medicine* has therefore provided an important strategic context for progress on our actions to address health literacy.

In addition to the impact of *Realistic medicine*, 2016 also saw the integration of funding and commissioning for health and social care services at the level of local council authorities. This service restructure was to put people and not services at the centre of decisions, aiming to improve services, and to make them seamless and more responsive to the people who use them (Scottish Government, 2017c). Over the following 18 months, momentum in Scotland built further. Scotland’s *Health and social care delivery plan* (Scottish Government, 2016b) specifically called for an updated health literacy action plan to extend the progress achieved since 2014.

Improving health literacy was also noted by other organisations reviewing what improvements services require, as expressed in the Scottish Public Services Ombudsman’s report *Informed consent: Learning from complaints* (2017). The challenge had now become to capitalise on this momentum to encourage further innovations that would improve care and patient experience across the country. These helped develop the conversation around what the next steps and collaborations to meet this challenge should be.

The growing evidence base and future policy development

As we broaden our health literacy developments in Scotland in pursuit of our ambition, the evidence base supporting specific initiatives is growing. It is important to use this evidence to inform future policy development. For instance, studies are starting to demonstrate that interventions to improve how people think
about their health and wellbeing needs to begin at an early stage. A recent paper has suggested that young people can be better supported to interpret health information (see Nsangi et al., 2017).

The Health Foundation in England, on their Making Good Decisions in Collaboration (MAGIC) programme (2017), provided lessons in respect to shared decision-making. This emphasised that shared decision-making is not confined to a single one-to-one interaction between a patient and clinician. Rather, it must be embedded across the whole healthcare team, between people and their families or carers, and their wider community. All these people will influence the process, especially for people living with long-term conditions. Approaches such as the Ten attributes of health literate health care organizations (Brach et al., 2012) or the work from Deakin University on the organisational health literacy assessment tool (Trezona et al., 2017) summarise this well.

The development of the Ophelia approach (OPtimising HEalth LIteracy and Access) uses health literacy needs and responsiveness to help design health and care services (Deakin University, 2017) and shows much promise. Importantly these approaches make it clear that identifying problems and implementing change in specific organisations or service areas requires the involvement of those trying to access and use the service.

Considering recent policy developments and emerging evidence, the Scottish Government has developed a second action plan on health literacy, Making it easier. This was published in November 2017 (Scottish Government, 2017d). It outlines three concurrent approaches to improve people’s confidence, knowledge, understanding and skills in their health and healthcare. It intends to involve a public response on health literacy through Scotland’s ‘Our Voice’ programmes, to include a citizens’ jury focused on shared decision-making (Scottishhealthcouncil.org, 2017). The three areas of focus for the action plan are to:

- Spread the lessons and progress already made in Making it easy across the country, aiming to engage with all ages and abilities to reduce variation and unnecessary inequality.
- Support the development of new work and collaborations in areas beyond secondary healthcare, such as library services. Its focus is on embedding improved health literacy responsiveness across the full range of Scottish public policy.
- Shift the culture of organisations and communities towards ‘health literacy by design’. Any planned strategic change or service development should consider the consequences for health literacy and what opportunity is present to respond and improve it. The aim should be to avoid barriers to health literacy being created in the first place.

We hope to expand beyond Making it easy’s initial focus, and support activity across the whole health and social care landscape, and associated services. Specific areas highlighted for attention are:
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- primary care
- urgent care services
- mental health
- information about medicines
- supporting people with augmentative and alternative communication needs
- care and support planning
- community links worker relationships
- the role of librarians
- the integrated health and social care workforce.

There is also a need to specifically consider people with few social connections, as well as refugees and asylum-seekers.

Conclusion

Making it easy has given encouragement and inspiration to many health literacy champions who are making a real difference and working hard to help achieve our ambition in Scotland. Internationally it is contributing to the case for action on health literacy and helping other countries to follow suit.

Health literacy is now a global health promotion priority (Quaglio et al, 2017; WHO, 2017). At home, it now resides firmly at the heart of our person-centred care ambitions, Realistic medicine, and the transformation towards more enabling integrated health, social and community care services.

As we move towards achieving our ambition to become a health-literate society, assessing the impact and progress will always be a challenge. However, Scotland, with its spirit of innovation, community and commitment to rights and equity, is well placed to remain at the vanguard of this important agenda.

References

ALISS (2017) Homepage (www.aliss.org/).


Deakin University (2017) *OpHeLiA stands for Optimising Health Literacy and Access to health information and services* (www.ophelia.net.au/).


WHO (World Health Organization) (1998) Health promotion glossary, Division of Health Promotion, Education and Communications, Health Education and Health Promotion Unit (www.who.int/healthpromotion/about/HPG/en/).