

Making it Easy

A Health Literacy Action Plan
for Scotland



We want Scotland to be a health literate society which **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.





Foreword from the Cabinet Secretary

Alex Neil, MSP
Cabinet Secretary for Health and Wellbeing



Person-centred Health and Care Portfolio

Health literacy is about people having enough knowledge, understanding, skills and confidence to use health information, to be active partners in their care, and to navigate health and social care systems.

Health Literacy is being increasingly recognised as a significant public health concern around the world. So I am delighted that Scotland, with its ethos of innovation and collaboration, is in the vanguard of efforts to meet this global challenge.

Making it Easy sets out an ambition and the means for all of us to live well, on our own terms, and with any condition we may have, by making sure that health and social care services cater for each of us – regardless of our abilities.

Scotland’s 2020 Vision for Health and Social Care focuses on prevention, anticipation and supported self management. Addressing health literacy is at the heart of our commitment to delivering a safe, effective and person-centred healthcare system.

Closing the gap between the demands of modern healthcare and people’s abilities will help to reduce health inequalities, and strengthen the wellbeing of both individuals and communities.

Making it Easy, the National Health Literacy Action Plan for Scotland, has been developed with a national group, which has drawn on the expertise of front line practitioners, policy makers, academics and those with years of experience with NHS boards and the third sector; they in turn drew on the direct experience of those who have struggled to engage with health and care services.

Introduction

Many of us lack the knowledge, understanding, skills and confidence to take an active role in our own wellbeing, despite a strong desire to do so.

Modern health and social care can place daunting hurdles in our way – the language and processes of health and care services can be hard to understand. These hurdles can undermine our confidence in accessing and participating in our healthcare and erode our ability to sustain our health. We may be confused by the signage at the hospital, struggle to make sense of information about our health conditions, or be unable to communicate effectively with our clinical and care staff. This can be even more challenging when faced with stressful health or life circumstances. All this undermines our ability to manage our own conditions safely and effectively, and this is a cause of health inequality.

Addressing the issue of health literacy is the key purpose of **Making it Easy**. This issue affects all of us, whether we have a health problem or not, and therefore it has been written with all of us in mind. We all have a role in working together to address health literacy, whether we work in health or social care, or part of the third sector, or as teachers, employers, community workers – or indeed as relatives, carers, friends and colleagues. Strong social connections nurture good health literacy.

However, **Making it Easy** limits its scope to the responsibilities of those working in health and social care.

Making it Easy

- Highlights the hidden problem of low health literacy and the impact that this has on our ability to access, understand, engage and participate in our health and social care.
- Explains that low health literacy leads to poor health outcomes and widens health inequality.
- Calls for all of us involved in health and social care to systematically address health literacy as a priority in our efforts to improve health and reduce health inequalities.
- Sets out an ambition for all of us in Scotland to have the confidence, knowledge, understanding and skills we need to live well, with any health condition we have.
- Lays out the actions the Scottish Government and partners are taking to help all of us in health and social care collaborate and help realise this ambition.

To explore the rationale, evidence and processes that led to the development of **Making it Easy**, please visit the **Health Literacy Place** at www.healthliteracyplace.org.uk

Some facts that should get your attention

43%

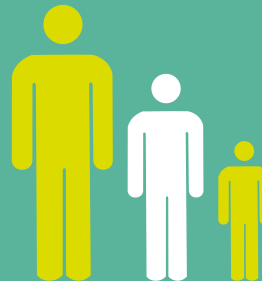
of English working age adults will struggle to understand instructions to calculate a childhood paracetamol dose

\$106 -
\$236
bn

The cost to the US economy, because of inadequate health literacy, is estimated to be in the region of \$106- \$236 billion per year



Those of us with lower levels of health literacy: have higher rates of emergency admission...



...and have difficulty managing our own health and wellbeing, that of our children, and anyone else we care for

George Bernard-Shaw

“The single biggest problem with communication is the illusion that it’s taken place”

Is health literacy really such a big issue?

The problem of poor health literacy affects a significant portion of the population.

- The proportion of the population with inadequate health literacy in a sample of eight European countries is 47% – almost half the population¹.
- 43% of English working-age adults **will struggle** to understand instructions to calculate a childhood paracetamol dose².
- The cost to the US economy, because of inadequate health literacy, is estimated to be in the region of \$106-\$236 billion per year³.
- 26.7% of people in Scotland have occasional difficulties with day-to-day reading and numeracy. 3.6% will have severe constraints⁴.

How does poor health literacy affect people’s health?

- Those of us with lower levels of health literacy:^{5 6}
 - are generally 1.5 to 3 times more likely to experience a given poor outcome
 - have poorer health status and self-reported health
 - wait until we’re sicker before we go to the doctor
 - find it harder to access services appropriate to our needs
 - find it harder to understand labelling and take medication as directed
 - are less able to communicate with healthcare professionals and take part in decisions
 - are less likely to engage with health promotional activities, such as influenza vaccination and breast screening
 - are at increased risk of developing multiple health problems
 - have higher rates of avoidable and emergency admissions
 - have higher risks of hospitalisation and longer in-patient stays
 - have difficulty managing our own health and wellbeing, that of our children, and of anyone else we care for
 - have greater difficulty looking after ourselves when we have long-term conditions

Why do healthcare professionals underestimate our health literacy needs?

Healthcare professionals often underestimate our health literacy needs. This is because these needs often remain hidden and some of us actively hide them.⁷ This may be because we are too ashamed, or too polite to reveal to others that we have not understood them. While this is particularly common in those who have difficulty reading, writing or using numbers, it can affect all of us – particularly if we are overwhelmed by anxiety or worry.

Why can it be difficult for clinical and other staff to take account of health literacy needs?

People working in health and social care usually respond well to obvious difficulties. However, when health literacy needs are hidden, clinical and other staff can make false assumptions about what has been heard – and what has been understood. The concepts and language used may seem unfamiliar and strange. To avoid this, clinical and other staff should try and understand us and the difficulties we may face in understanding. Addressing health literacy is a two-way street.





Case study

Margaret is 57 and has struggled with reading and writing all her life. As a child, she was bullied and humiliated about this. Now Margaret feels ashamed and doesn't want anyone to know. She relies heavily on her husband, Tom, to help her with her medicines for several long-term conditions. Tom has some health problems too and had an emergency admission to hospital recently, but fortunately was home after two days. Tom missed a lot of school, and although he reads Margaret the information leaflets and booklets she has been given, he sometimes struggles with difficult words and phrases. When Margaret was recently diagnosed with diabetes she found it very worrying, because she didn't understand what she needed to do. However, when she goes to her appointments, the doctor or nurse asks if she understands what she has been told – she nods and says in a very convincing way that she does. She doesn't want them to think she is stupid.

Why is addressing health literacy important?

Because whenever our health literacy needs are not met, the safety, effectiveness and person-centredness of our care is undermined:

- Ineffective communication undermines our capacity to be in the driving seat of our care, which is the cornerstone of self management, and key to person-centred care.
- When our health literacy needs are met, we are better able to work with our health care professionals to safeguard our own care and live well.

Also addressing health literacy is fundamental to the following:

- The **2020 Vision for Health and Social Care**⁹ has a focus on prevention, anticipation and supported self management.
- The **Healthcare Quality Strategy for NHSScotland**⁸ sets out the ambition to deliver the highest quality health care to the people of Scotland through safe, effective and person-centred care.
- The **Patient Rights (Scotland) Act 2011** aims to improve our experience of using health services and to support us to become more involved in our

health and health care. It says that the health care we receive must consider our needs, consider what would be of optimum benefit to us, encourage us to take part in decisions about our health and wellbeing, and provide information and support for us to do so, in a way we understand.

- Health professionals are guided by **Codes of Conduct** to adapt their practices so that they communicate in ways that we can each understand. This can be hugely challenging and may require new ways of working and communicating, using a variety of formats, media and technologies.
- Addressing health literacy will help us to reduce **health inequalities**. This is because those of us with poor health literacy have the highest burden of ill health. Those of us with the lowest health literacy generally have double the rates of poor health outcomes, complications and death, compared with those who have the highest abilities¹⁰.



Case study

From talking to an adult learner

“I don’t know if it was common, but the surgeon would ask me questions and when I couldn’t remember or I couldn’t answer him, what he did was, he says, ‘I’m going to tell you what’s going on’ and it was all recorded on tape, and he gave us the tape to take home, so I could listen to everything he was saying and go over anything I wasn’t sure of. So I was able to write it down.... and ask him.”



Case study

“I was on so many different tablets, I would get them mixed up. I didn’t want to admit I was struggling but then I got ill and ended up in hospital. When I came out of hospital, the nurse had given me a chart of what and when to take, and she also checked that I had understood it all. It gave me a lot of confidence.”

Achieving our ambition... shifting the focus

The traditional approach to helping us understand health and healthcare, is to provide us with high quality information. Scotland has many great examples of quality education and innovative information resources, such as NHS Inform.

Those of us who are healthcare providers need to go further and adapt services to meet everyone's health literacy needs. As users of services, we need the people providing those services to routinely ensure that we understand and have been understood.

This approach locates the task of dealing with the 'problem' of health literacy, not just with those of us who have difficulty understanding and using services, but also with those of us who are delivering them.

In Scotland our challenge is to those providing services **to make things easier**, by more engaging and effective communication.

An analogy

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 5 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.



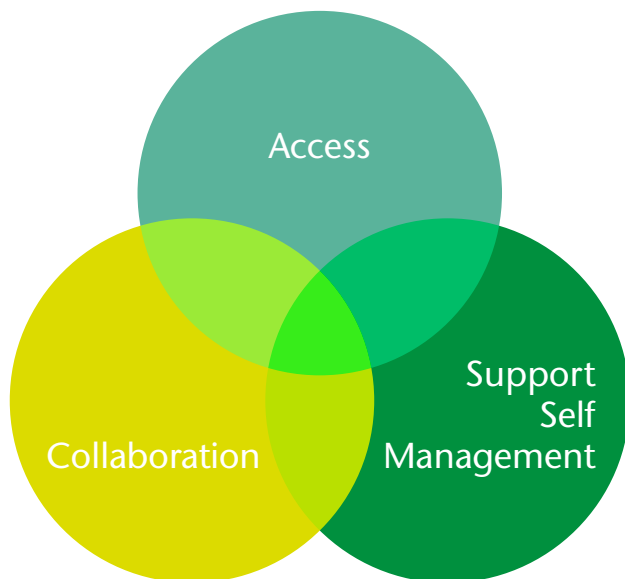
We must likewise simplify the healthcare 'interface' and make health care more engaging.

Actions

The outcome that is being sought from this health literacy plan is a culture and practice which supports:

- equal access
- collaborative working
- self management

This means making it easy for us to access services, have better conversations with our professionals, and be in the driving seat of our health and healthcare.



The specific actions highlighted below will help all of us working in health and social care to cater for the health literacy needs of those we are trying to support. They have been selected for promoting the required change in practice and culture by:

- **Raising awareness and the capabilities of professionals** to address health literacy.
- Promoting the development and **spread** of existing and new health literacy tools, **innovations and technologies**.
- Improving **access** to these useful enabling **health literacy tools** and resources.
- Enhancing health literacy at **transitions of care**, which are key learning and patient safety points in health and social care.

More detail on these actions can be found at www.healthliteracyplace.org.uk

Actions (continued)

1. Workforce awareness and capabilities activity.

This activity will enable people who work in health and social care services to be aware of the challenge of health literacy, to commit to responding to it, and to have the skills, knowledge and capability to do so.

The full strategic context of the workforce-focused work and specific actions are available at the **Health Literacy Place**, but call for action on the following:

Leadership, management and team leaders to:

- Address health literacy in order to reduce health inequalities, to uphold people's human rights, as well as safeguarding the achievement of NHSScotland's effective, safe and person-centred ambitions.
- Take responsibility for staff to be aware of health literacy tools, and have access to them.
- Address staff capability to support peoples' health literacy needs (addressing the personal health literacy needs of people working in health and care services is vital, but this is beyond the immediate scope of this plan).
- Develop an organisational culture that promotes health literacy.

Individual clinical staff to:

- recognise people's health literacy needs
- be aware of appropriate resources
- employ a range of communication tools

The workforce-related actions in this health literacy action plan are aimed at establishing a healthy organisational culture, effective leadership and management and most particularly to having a capable workforce. This is in line with **Everyone Matters: 2020 Workforce Vision** which sets out the shared values of:

- care and compassion
- dignity and respect
- openness, honesty and responsibility
- quality and teamwork.

2. Test and spread health literacy innovations

The Person-Centred Health and Care Collaborative is supporting teams across NHSScotland to use improvement methodology to test, implement and sustain changes to the way care is provided, so that it is reliably person-centred for every person, every time.

This ‘Collaborative’ approach has been successfully used to improve patient safety.

Effective communication – which takes account of people’s health literacy needs – underpins person-centred care. This is particularly important at key healthcare interactions and transitions. These include:

- hospital discharge and clinic visits;
- shared decision making and consent for treatments and procedures
- changes in people’s medication.

There are several evidence-based health literacy interventions, that will be promoted within the Collaborative, to support teams to test and implement new ways of working. These include:

- Checking understanding using ‘Teach Back’, a simple technique for confirming that people have understood what has been said
- Sharing jargon-free copies of clinic and discharge correspondence, which use language that the person can understand
- Providing test results in meaningful and accessible formats
- Using clear jargon-free oral communication
- Tailoring information to people’s needs

Focusing on these elements is likely to provide big gains in highlighting the health literacy needs of service users to practitioners.

Crucially, it will improve people’s understanding and confidence, helping them to sustain their health and to contribute to their own healthcare safely.

3. A National Health Literacy Resource for Scotland, “The Health Literacy Place”

The National **Health Literacy Place** has been established to:

- provide desktop access to examples of *existing* good practice, techniques and tools
- generate and disseminate practice-based evidence of *emerging* effective health literacy innovations, resources and technologies
- provide references and articles that expand on the themes of **Making it Easy**, including improving access, collaboration and support for self management

and

- create access to a community of practice, providing support and connection between those engaged with health literacy developments



Case example

Ward 19, Royal Alexandra Hospital, NHS Greater Glasgow and Clyde

In feedback, patients in the ward said that they often forgot the questions they had meant to ask their consultant during ward rounds. As a proactive way of dealing with this, patients were given white boards and marker pens, to write down any questions or concerns they had beforehand.

One patient just drew pictures on the white board. The patient disclosed to the hospital chaplain that he could not write. This information came as a surprise to the staff on the ward.

Issues of health literacy had not emerged through the admission assessment. The staff realised that no account was taken of health literacy in their routine enquiry arrangements, and yet they often provided information about treatment and procedures in writing only. This awareness has led to a change of approach within the ward, where staff now always offer assistance in writing questions down on the white board prior to ward rounds.

Staff now have a raised awareness of the issue of health literacy. They routinely make subtle enquires with patients, to check their understanding, particularly when written information is being shared.

This situation has served as an important reminder that we should not expect people to be health literate and able to read and write – and that we need to behave in ways that more effectively meets people's health literacy needs.

A quick guide to ‘Making It Easy’ has also been produced – it highlights the following ways to make it easy;

- Use the ‘**Teach-back**’ type techniques: check that you have explained everything in ways people understand, by asking them to explain in their own words the information you have given.
- **Chunk and check:** break what you need to discuss into small chunks, and check understanding using teach-back before continuing.
- **Use pictures:** draw or show a picture to help convey a complex concept or body part.
- **Use simple language:** avoid jargon and use language that is easy for the person in front of you to understand, both when you speak to them and in any written information you provide.
- Literacy awareness: **routinely ask people** if they would like help in filling out forms.



Bill Gates

“I’m a great believer that any tool that enhances communication has a profound effect in terms of how people can learn from each other...”

4. Establish a national demonstrator site

The route map for the delivery of the quality strategy includes the deliverable ‘Information and Support to enable people at home and during times of transition’.

A national demonstrator site will develop and display an integrated way of working with people, making successful communication at transitions of care a routine experience.

Health Boards will be offered the opportunity to host the national demonstrator site. The aim is to meet the health literacy needs of people at transitions of care in specific settings over the next 18 months. This work will include an evaluation of the effectiveness of the approach to enabling people to stay well and to self manage. It will also assess the impact this has on service delivery. This will be taken forward using the Person-Centred Health and Care Collaborative approach, to take the learning and improvement forward reliably across the country.

Workforce awareness and capabilities activity

Effective communication (within the Person-Centred Health and Care Collaborative)

Confidence, knowledge, understanding and skills

The Health Literacy Place

National demonstrator and evaluation site

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