Making it Easier

A Health Literacy Action Plan for Scotland

NHS SCOTLAND

2017-2025

REALISTIC MEDICINE

Healthier Scotland
Scottish Government

Contents

Foreword

Health literacy is important to us all, whether as an individual, carer, family member, volunteer, teacher, employer, or health and care worker. And we all have roles to play in improving our understanding, knowledge, confidence and skills.

When the Scottish Government first looked at the evidence on the impact of health literacy, in 2009, it was clear that it was time for action. We knew that healthcare information had to more clearly tackle the challenges we all face in our day-to-day life. It was less clear **what** needed to be done.

We published our first plan of action, *Making it Easy*, in 2014. Not only did this focus on improving people's health knowledge and understanding, its actions:

❚ challenged the health and care system to remove the barriers that get in the way when we try to improve our wellbeing,
❚ raised awareness amongst the workforce of the hidden problem of health literacy and helped them respond better,
❚ built a go-to web place for health literacy news and tools,
❚ tested ideas for better designed services and more health literacy responsive organisations through a programme of work in NHS Tayside.

This was done by the many health literacy champions who are making a real change across our workplaces and communities. Together we are working hard to help Scotland to become a more health literate nation.

Our second plan, *Making it Easier,* builds on what we've learned so far. It moves us closer to removing barriers and preventing them being put there in the first place. It will improve how we design and deliver services for the future. It is a cornerstone of *Realistic Medicine's* drive to better support people's needs through shared decision-making.

Scotland has the chance to lead the way, in thought and deed, on this vital topic that sits at the heart of our person-centred aims. Here's how we plan to do it.

Dr. Catherine Calderwood
Chief Medical Officer for Scotland

A poem – This is Bad Enough

This is bad enough
So please …

Don't give me
gobbledegook.

Don't give me
pages and dense pages
and
"this leaflet aims to explain … "

Don't give me
really dodgy photocopying
and
"DO NOT REMOVE
FOR REFERENCE ONLY."

Don't give me
"drafted in collaboration with
a multi-disciplinary stakeholder partnership
consultation
short-life project working group."
I mean is this about
you guys
or me?

This is hard enough
So please:

Don't leave me
oddly none the wiser or
listening till my eyes are
glazing over.

Don't leave me
wondering what on earth that was about,
feeling like it's rude to ask
or consenting to goodness knows what.

Don't leave me
lost in another language
adrift in bad translation.

Don't leave me
chucking it in the bin.
Don't leave me
leaving in the state I'm in.

Don't leave me
feeling even more clueless
than I did before any of this
happened.

This is tough enough
So please:

Make it relevant,
understandable –
or reasonably
readable
at least.

Why not put in
pictures
or sketches,
or something to
guide me through?

I mean how hard can it be
for the people
who are steeped in this stuff
to keep it up-to-date?

And you know what I'd appreciate?
A little time to take it in
a little time to show them at home
a little time to ask "What's that?"
a little time to talk on the phone.

So give us
the clarity, right from the start
the contacts, there at the end.

Give us the info
you know we need to know.
Show us the facts,
some figures
And don't forget our feelings.

Because this is bad
and hard
and tough enough
so please speak
like a human
make it better
not worse.

Written by **Elspeth Murray** for the launch of the cancer information reference group of **SCAN**, the South East Scotland Cancer Network, 20 January 2006.

Introduction

The case for action on health literacy is set out in *Making it Easy – A Health Literacy Action Plan for Scotland*[1], published in 2014. It set out the ambition for Scotland to be a health-literate society that enables all of us to have the confidence, knowledge, understanding and skills to maintain good health.

The actions in that plan explored:

▮ how the hidden problem of low health literacy impacts on our ability to access, understand and engage with our health and social care system,
▮ how low health literacy leads to poor health outcomes,
▮ how everyone involved in health and social care should see improving health literacy as a way to reduce health inequalities, and
▮ how with joint action the Scottish Government and partners can help the integrated health and care workforce realise this ambition.

Progress was summarised in a report published[2] in July 2017. It is upon this learning, and its testing in the demonstrator programme in NHS Tayside, that this practice guidance has been built. The actions set out are designed to take the next steps in improving health literacy practice across the health and care system.

1 Scottish Government, NHSScotland. Making it Easy. A Health Literacy Action Plan for Scotland. The Scottish Government, NHS Scotland: Edinburgh; 2014. http://www.gov.scot/Publications/2014/06/9850

2 www.gov.scot/Publications/2017/07/7806

Making it Easy
A Health Literacy Action Plan for Scotland

NHS SCOTLAND

healthier scotland
SCOTTISH GOVERNMENT

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.

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

The actions

1. **Share *the learning from Making it Easy across Scotland.***

2. **Embed *ways to improve health literacy in policy and practice.***

3. **Develop *more health literacy responsive organisations and communities.***

4. **Design *supports and services to better meet people's health literacy levels.***

What can I do?

How can I contribute to making it easier?
Read about our networks of champions on page 21

Have you thought about a health literacy walkthrough of the place you work?
Find out how on page 20

How can library services support me?
More details on pages 32-35

What skills should we all have to navigate – and help others navigate – the health and care system?
Find out on page 31

How responsive to people's health literacy needs is your organisation? Maybe the Organisational Health Literacy Assessment Tool can help.
Details on page 42

Where can I find helpful tools and techniques?
The Health Literacy Place – **www.healthliteracyplace.org.uk** – is full of useful information
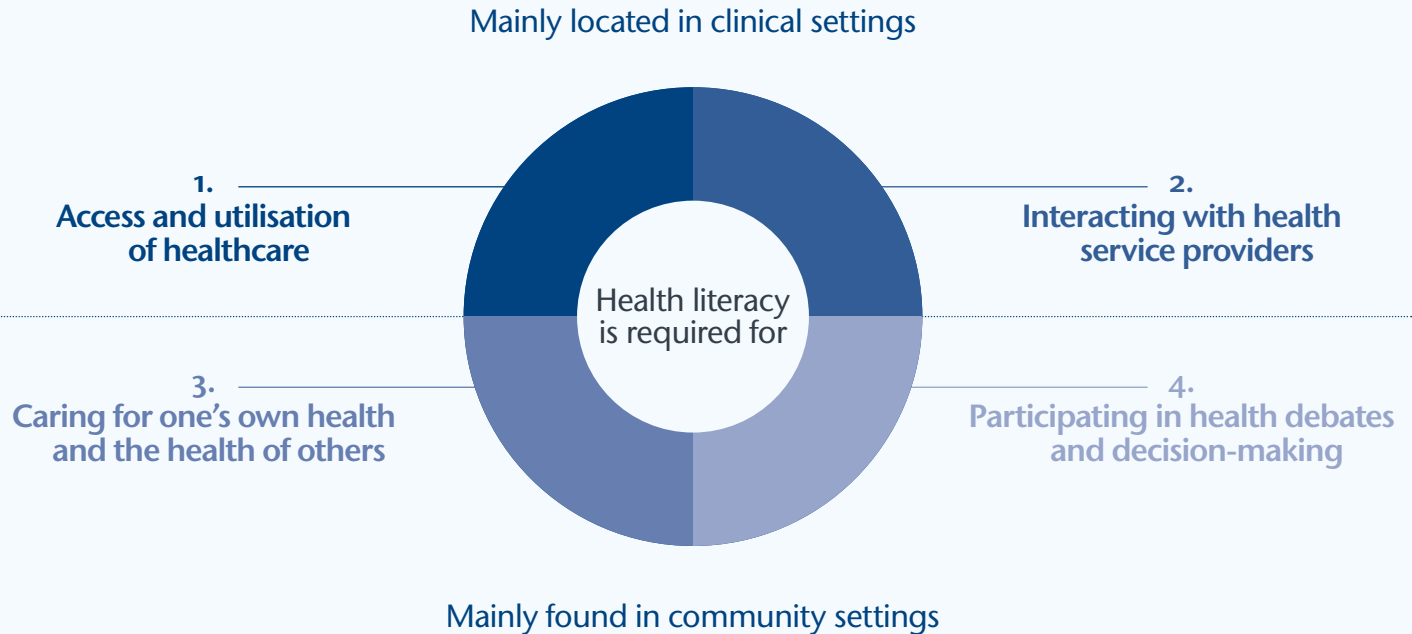
How has the context changed since *Making it Easy?*

Health literacy and the World Health Organization (WHO) sustainable development goals (SDGs)

- Improving health literacy levels is crucial for attaining the social, economic and environmental ambitions of the 2030 Agenda for Sustainable Development.

- Harnessing health literacy improves health and reduces health inequities.

Promoting health literacy, a key determinant of health

Mainly located in clinical settings

1.
Access and utilisation of healthcare

2.
Interacting with health service providers

Health literacy is required for

3.
Caring for one's own health and the health of others

4.
Participating in health debates and decision-making

Mainly found in community settings

How has the context changed since *Making it Easy?*
Continued

Worldwide

The World Health Organization (WHO) set improving health literacy as a global priority for healthcare, disease prevention and health promotion at its *2016 Global Conference on Health Promotion*[3].

Scotland

The two most recent annual reports from the Chief Medical Officer for Scotland, *Realistic Medicine*[4] and *Realising Realistic Medicine*[5], highlighted improving health literacy as a vital area for progress within health and care.

REALISING REALISTIC MEDICINE

'REALISTIC'

1. HAVING OR SHOWING A SENSIBLE AND PRACTICAL IDEA OF WHAT CAN BE ACHIEVED OR EXPECTED.
2. REPRESENTING THINGS IN A WAY THAT IS ACCURATE AND TRUE TO LIFE.
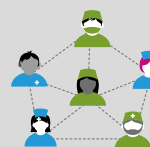
CREATING CONDITIONS

COMMUNICATE

CONNECT

COLLABORATE

CULTURE

THE VISION

BY 2025, EVERYONE WHO PROVIDES HEALTHCARE IN SCOTLAND WILL DEMONSTRATE THEIR PROFESSIONALISM THROUGH THE APPROACHES, BEHAVIOURS AND ATTITUDES OF REALISTIC MEDICINE

3 www.who.int/healthpromotion/conferences/9gchp/shanghai-declaration.pdf?ua=1

4 www.gov.scot/Publications/2016/01/3745

5 www.gov.scot/Publications/2017/02/3336

Realistic Medicine proposes a change in culture and systems to move practitioners towards 'focusing completely and relentlessly on what matters most to the people who look to them for care, support and treatment'. It marks a move further away from parental approaches, to a rebalanced connection between people and their practitioners with shared decision-making at its heart.

The Scottish Public Services Ombudsman (SPSO), in a report on consent[6], set out the role for health literacy in building a better understanding for both health and care workers and people using services. There is a key link to be made with work to support people at times when they struggle to communicate their views, for whatever reason. The SPSO report described the work to strengthen consent processes and increase people's involvement in their health decisions. It drew upon real-life experiences to show how they should inform changes to policy and practice. It offered a checklist to help health and care workers evaluate whether a consent process is clear enough.

Following the report's release, it became clear there is a need to produce equivalent supporting materials to guide patients too, and help them ask the right questions.

These need to be responsive[7] to people's health literacy needs. These will be progressed as part of this action plan, drawing upon experiences in preparing people for conversations about their health and what matters to them. We will also consider whether this information should become a core part of appointment letters.

Achieving our ambition
In Scotland the challenge remains for us all to:

▮ make things easier, by removing barriers where we find them,
▮ make our services easier to navigate,
▮ make sure that health literacy needs inform the design of new services, and
▮ make our information more engaging and responsive to people's needs, skills and preferred ways of interacting.

6 www.spso.org.uk/sites/spso/files/communications_material/research/Informed%20Consent%20SPSO%20March%202017%20%28PDF%2C%20246KB%29.pdf

7 Trezona A, Dodson S, Osborne RH. Development of the organisational health literacy responsiveness (Org-HLR) framework in collaboration with health and social services professionals. BMC Health Services Research: London; 2017. https://www.ncbi.nlm.nih.gov/pubmed/28764699

How has the context changed since *Making it Easy?*
Continued

To achieve this we need to engage better with people no matter what skills they currently have. For any of us to be a lead partner in our care, we do not want to be held back by systems or words that are confusing or unclear. All health and care workers can help.

Some of the changes needed may be small but make a big impact; others need a longer-term shift in approach and mind-set. This plan will strengthen culture and practice based on a human rights approach founded on:

▪ equal access,
▪ shared decision-making, and
▪ people supported to live and die well on their own terms with the health conditions they have.

Supporting people to be in the driving seat of their health and care is widely known as self-management. A key element of support for self-management is ensuring that people have the skills to access, understand and engage with the systems and sources of support that keep them well. This challenge will be met through three action areas:

▪ Share the learning from *Making it Easy*.
▪ Embed ways to improve health literacy in policy and practice.
▪ Shift the culture by developing more health literacy responsive organisations and communities.

This will ensure we design supports and services that better meet people's health literacy levels.
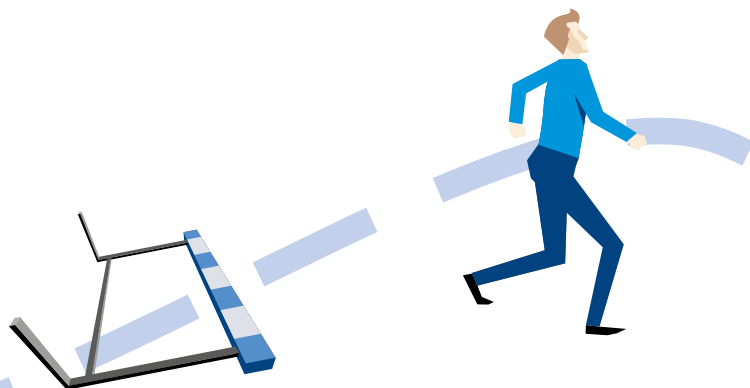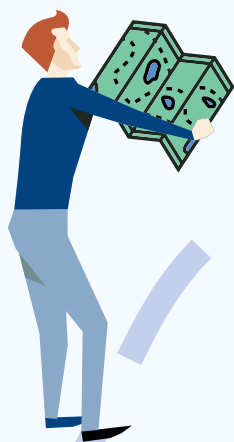
Action area 1

Share the learning from Making it Easy

Headlines from this section

❚ Organisations should embed the key learning points from *Making it Easy* to support safe, effective, person-centred care.
❚ Tools and techniques tested through our work in NHS Tayside should be used to support spread and adoption of the learning points.
❚ Our network of health literacy champions will continue to promote progress against actions locally and nationally.

Based on the work reported in *Making it Easy – Progress Against Actions*[8], our key learning areas to share across the system are:

❚ health literacy tools and techniques[9] for professionals to use, such as Teachback,
❚ clearer information shared with people before they attend and leave hospital. This includes improved appointment letters, making them more considerate of people's communication needs, and
❚ improved safety and support for people on high-risk treatments, promoting the involvement of pharmacists and their support staff.

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8 www.gov.scot/Publications/2017/07/7806
9 www.healthliteracyplace.org.uk/tools-and-techniques/techniques/

Action area 1
Continued

These align with the quality aims of [effective, person-centred and safe][10] healthcare set out in the Healthcare Quality Strategy for NHSScotland.

Videos to raise awareness of the hospital experience

What? Why? Children in Hospital is a charity that makes videos to help children and parents prepare for hospital and answer some of their questions starting with What? and Why?

These films have been helpful in reducing anxiety both for children and parents ahead of hospital treatment.

One of their recent videos shows what happens when your child is admitted to the Cancer Centre in Glasgow – **https://www.whatwhychildreninhospital.org.uk/glasgowcancercentre**

The next phase will move these actions on from ones that improve communication to responses that better support people to self manage their health and wellbeing:

- We will further embed Teachback to check that people have received information clearly from their practitioners. NHS Tayside will take the lead in this work, with learning spread to other sites across Scotland.
- We will promote the What Matters to You?[11] approach to support people to ensure that their practitioners have understood what matters to them.
- We will promote walkthrough and wayfinding approaches. These will enable people to access health and care more easily by removing barriers such as inconsistent signs and confusing pre-visit information.
- We will work with the Living Well in Communities workstream on Anticipatory Care Planning and Scotland's House of Care[12] programmes to develop and test more health literacy sensitive approaches to care and support planning.

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[10] www.gov.scot/Resource/Doc/311667/0098354.pdf

[11] www.whatmatterstoyou.scot/

[12] www.alliance-scotland.org.uk/what-we-do/our-work/primary-care/scotlands-house-of-care/

- We will continue to contribute to development of the Scottish Social Services Council (SSSC) outcomes focused support planning resource which is being developed in the context of the Carers (Scotland) Act 2016.
- We will promote a universal precautions[13] approach in all decision-making steps, with appropriate use of decision aids and scenario thinking to trace the best options for people. NHS Lothian will lead on work to improve the appointment process, including improvements to appointment letters, with learning spread to other sites across Scotland.

Awareness

We will increase the public awareness of health literacy issues. This will include use of the Health Literacy Place[14] website and social media. Part of this will include continued involvement with the global Health Literacy Month[15] campaign, which takes place in October each year. Wider strands such as the 'What Matters to You?'[16] movement and Our Voice[17] framework will have a useful role in both enabling members of the public to speak out and raise issues around health literacy with staff, and provide new ideas to improve the current design and re-design of services.

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[13] https://health.gov/communication/interactiveHLCM/content/heading2.html

[14] www.healthliteracyplace.org.uk/
[15] www.healthliteracymonth.org/
[16] www.whatmatterstoyou.scot/
[17] www.ourvoice.scot/

Action area 1
Continued

Links to the Our Voice approach

The Our Voice citizens' panel[18] asked panel members (who are a broadly representative sample of the Scottish population) what they think makes for a good doctor, and what things combine to make for a good consultation.

59% of panel members said a good doctor needs to be a good listener. In the words of one panel member, a good consultation takes place "when both patient and doctor are satisfied they have been heard and are in agreement with prognosis or way forward".

Over 91% of panel members felt comfortable asking a nurse about their treatment or care options. One said: "they are professionals and are sometimes easier to contact than a doctor." Another: "these other care professionals tend to be more willing to listen and be more supportive to your decision." Also: "practice nurses are part of the normal routine so easy to communicate with."

An Our Voice citizens' jury[19] will explore how we further strengthen relationships between healthcare professionals and individuals – a key theme of the Chief Medical Officer's report *Realising Realistic Medicine*[20]. Findings will shape how we progress this action plan.

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18 www.ourvoice.scot/citizens-panel
19 www.ourvoice.scot/citizens-jury
20 www.gov.scot/Publications/2017/02/3336

Expand on successes and deepen the work in Tayside

The work in Tayside[21] started under *Making it Easy* will continue. The learning will be broadened to new areas that place barriers to improved health literacy. It will be helpful for other sites across Scotland to:

▮ learn from Tayside's journey,
▮ learn from Tayside's plans for 'what to do next', and
▮ see an illustration of what the 'next phase' looks like.

21 www.healthliteracyplace.org.uk/blog/2017/news/presentations-from-health-literacy-demonstrator-event/

Action area 1
Continued

Hospital walkthroughs in NHS Tayside

A range of people – adult learners, students, healthcare workers – walked through Ninewells Hospital in Dundee to see what the journey was like from the front door to their clinic location.

They found the information on the appointment letter and on signs was different. For example it read "Children's Outpatient Department" on the letter, and "Tayside Children's Hospital" on the signs. The signs on the way to the clinic also used different terms for the same place.

Volunteers at the hospital were helpful but the directions they offered were too complex.

There were few details on how to travel to the hospital. It would be helpful to know that parking at the hospital may be some distance away from the front door. The appointment letter could also include some indication of the time it takes to reach the clinic from the car park or the front door.

It is a core action for other parts of the health and care system to undertake walkthroughs to inform their drive to better health literacy responsiveness.

Building networks of health literacy champions

As part of *Making it Easy*, we trained more than 90 trainers across the health and care system to promote skills for better health literacy practice. We have also worked with groups such as the ALLIANCE's Self Management Network Scotland[22] and the Scottish Public Health Network[23]. Through the NHS Education for Scotland (NES) practice nurse and practice manager networks, we have promoted health literacy tools and techniques, in particular the idea of walkthroughs and wayfinding.

We have the chance to align with work on accessible information and inclusive communications through the Royal College of Speech and Language Therapists[24], as well as pharmacist networks through the Royal Pharmaceutical Society[25] to embed health literacy responsiveness in many key parts of the system.

We will develop this set of networks to sustain positive health literacy attitudes and behaviours across all health and care workers. The networks will have clear tasks to spread good health literacy practice across Scotland.

In addition, there is a global community of practice[26] through the World Health Organization (WHO) that we will play an active role in.

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22 http://smns.alliance-scotland.org.uk/

23 www.scotphn.net/

24 www.rcslt.org/governments/scotland

25 www.rpharms.com/making-a-difference/scotland

26 https://communities.gcmportal.org/ncd-health-literacy

Action area 2

Embed ways to improve health literacy in policy and practice

- We will embed health literacy improvements into policy and programme developments across sectors throughout the lifetime of the action plan.
- We will have a specific focus on building the common skills of connectors across all sectors.
- Library and information services have a key role to play.

We have made many useful links across the health and care system during the development of *Making it Easy*. Many of these links benefitted from being quick, simple and agile, but there's an opportunity to better target our efforts in the next phase. This section sets out a range of policy and practice areas we'll work with to embed our learning.

Primary care

Primary care is where many people first seek advice when they have a health issue. It's a good place to get things right from the start. There is much work underway to ensure people are better informed, with access to the right person at the right time so they receive the best care in the most appropriate setting.

All members of the team have a role to play. Through primary care's developing skills and roles of non-clinical staff improvement programme, we will include health literacy skills within training. In addition, we will work with the Royal College of General Practitioners (RCGP) Scotland's Patient Partnership in Practice (P3) network to promote and develop greater health literacy responsiveness in general practice.

Dentists have long made efforts to create positive environments in their surgeries, particularly to reduce anxiety for young children and parents. There is much to learn from this work.

Childsmile programme

The Childsmile toothbrushing programme aims to provide very young children with knowledge and skills which should stand them in good stead for looking after their teeth for life, saving them from unnecessary pain and suffering. It relies on bespoke resources which have been developed with, and for children and their carers and involves the children in the practical process of brushing their teeth in nursery school every day.

The combination of involving the children and their carers in the project and ensuring resources are accessible and appropriate has significantly improved child oral health over the last 10 years.

A recent Our Voice citizens' panel report showed where we should target our efforts to support people in understanding more about pharmacy services. It also showed how we can help pharmacists meet people's information needs. We will work with a variety of patient interest groups to progress this work.

We will work through the Modern Outpatient Programme[27] to give people at all levels of health literacy confidence to access the system whenever necessary, and ensure they have the skills and support to self manage their conditions when clinically appropriate. This will help to reduce health inequalities and minimise unnecessary demands on current services.

Urgent care services

In line with recommendation 25 of the National Review of Primary Care Out-of-Hours Services[28], there is an opportunity to develop out-of-hours and urgent care services that respond better to people's health literacy needs. Many of the challenges are the same in all care settings, but we will explore the best way to make changes in this particular area that meet the needs of people and their practitioners.

27 www.gov.scot/Publications/2016/12/2376
28 www.gov.scot/Topics/Health/Services/Primary-Care/nrpcooh

The role of NHS inform as 'go-to' source of online information

NHS inform is Scotland's national health information service.

Its aim is to provide people with accurate information to help them make informed decisions about their own health and the health of the people they care for.

Inform has engaged with people on the development of information and resources to support self-care. A good example is the Musculoskeletal (MSK) Help app – **www.nhsinform.scot/ care-support-and-rights/tools-and-apps**

It has also produced self-help guides. These allow people to access information about common conditions and provide suggested outcomes based on the answers given, for example 'contact a pharmacist'. The self-help guides can be accessed at **www.nhsinform.scot/self-help-guides**

Work is underway under action 14 of the Mental Health Strategy for Scotland 2017-2027[29] to improve NHS inform's online material for people with urgent mental health care needs.

29 www.gov.scot/Resource/0051/00516047.pdf

Mental Health

The new Mental Health Strategy for Scotland 2017–2027[30] (action 11) reaffirms the Scottish Government's commitment to improve the response for people presenting in distress in Scotland, through the implementation of the Distress Brief Intervention[31] (DBI) programme. This aims to build a framework for connected, compassionate support.

A DBI is a time limited and supportive problem-solving contact with someone in distress. It is a two-level approach:

- DBI level 1 is provided by front line staff and involves a compassionate response, signposting and offer of referral to a DBI level 2 service.
- DBI level 2 is provided by trained third sector staff who will contact the person within 24 hours of referral and provide compassionate community-based problem-solving support. This will include wellness and distress management planning, supported connections and signposting for a period of up to 14 days.

We will embed health literacy learning into practice through the DBI programme[32] by supporting the associated training programmes, building knowledge and skills, supporting the use and testing of the available tools, and influencing the evaluation framework.

Supported decision-making at times of impaired capacity

Supported decision-making is the term used to describe the process of assisting a person with cognitive disability to make decisions for themselves. Anyone may need support in decision-making but people with a learning disability, dementia, or mental ill health, face particular challenges while having the same rights as anyone else. Support is needed to ensure that they can make decisions about their lives, while recognising barriers in society such as stigma, paternalistic attitudes, and discriminatory systems.

30 www.gov.scot/Resource/0051/00516047.pdf

31 www.dbi.scot/

32 www.dbi.scot/general/distress-brief-intervention-programme-overview/

Action area 2
Continued

There are many examples of good current practice across the health and social care sector in Scotland. We should build upon this to create the right environment for the types of good conversations that are the basis of supported decision-making. This will ensure that everyone in Scotland who needs support to make important decisions can access it, or be given the opportunity to have their wishes heard.

Information about medicines

Some of the most common interactions that people have with health and care services relate to medicines information. One of the key statistics from *Making it Easy* was the high proportion of people (43%) who lack the skills to calculate a dose of childhood paracetamol.

Not sure? Just ask!

To help people understand their medicines the Scottish Patient Safety Programme promotes **Not Sure? Just Ask!** cards. The cards were originally developed by NHS Tayside with input from patients, carers and members of the healthcare team.

Not Sure? Just Ask!

Starting a new medicine?
Make sure you can answer the following:

- What is the medicine for?
- How do I take it and for how long?
- Are there any side effects?
- Are there any check-ups required?
- Can I stop any other medicines?

SCOTTISH PATIENT SAFETY PROGRAMME   NHS SCOTLAND   Initially produced by NHS Tayside

Not Sure? Just Ask!

Your current medicines
Make sure you can answer the following:

- Do you take all your medicines as prescribed?
- Do you understand what your medicines are for?
- Do you understand how and when to take your medicines?
- Do you know the possible side effects and what to do if you have concerns?

If you are not sure of the answer to any of the questions you should refer to the patient information leaflet, speak to your doctor, pharmacist or health professional, or go to: www.medicines.org.uk

There is an excellent opportunity to improve support for people who are taking complex medications by using clearer medicines information. At a Europe-wide level we can link to the SIMPATHY[33] programme to improve people's knowledge and skills in managing their medicines.

At points where people are having their medicines reviewed, there's a good opportunity to check understanding and be clear in communication. This video[34] offers an example of what good practice can look like.

33 www.simpathy.eu/
34 https://vimeo.com/235875955

Workshop with the Scottish Commission for Learning Disability's (SCLD) expert group

A key theme about the need for clearer information about medicines emerged during a workshop with SCLD's expert group.

People like information in picture format, with easy words and clear explanations of "what it's for". What are the differences between capsules, tablets and caplets? What does that mean for how we take the medicine? Clearer packaging with no smallprint is vital. Reminders of when to take medicines would be helpful.

Pharmacists can help by giving more clear information about taking our medicines. Including a person with lived experience of learning disability in pharmacists' training may be a good idea. This might also be helpful for GP receptionists' training as there are some barriers to phoning for appointments.

Action area 2
Continued

Promoting Inclusive Communication
The [Royal College of Speech and Language Therapists](#)[35] promote improved inclusive communication. This approach recognises that people communicate in many different ways and that the environment must support this. There is a large body of work to draw upon and align with. Scotland's [Inclusive Communication Hub](#)[36] is a key resource.

Significant work is underway to better support people with [Augmentative and Alternative Communication](#)[37] (AAC) needs. Links need to be made between this work and improvements to health literacy to ensure that systems are more responsive to the needs of people with very complex communication needs. The same principle applies to the new framework for improvement on British Sign Language (BSL).

Care and Support Planning conversations
New models of care, such as [care and support planning](#)[38], place a strong focus on preparing people and their practitioners to make best use of precious face-to-face time. The theme of ['good conversations'](#)[39] links policy and practice including Adults with Incapacity, Palliative and End of Life Care, Self-directed Support, Adult Carer Support Plans and Young Carer Statements, 'thinking ahead' in Anticipatory Care Planning, when discussing emergency care and treatment plans using processes like [ReSPECT](#)[40], or any conversation about *What Matters to You*.

It is vital that these care and support planning conversations consider the range of health literacy needs that people are likely to have, including:

▮ creating more relaxed settings for conversations,
▮ how best to present test results in helpful formats,
▮ tools and techniques that can best support people to more actively participate, and
▮ supporting the skills and confidence of health and care staff at all levels to start these conversations, listen closely, and respond to people.

35 www.rcslt.org/governments/scotland
36 http://includeusall.org.uk/
37 www.aacscotland.org.uk/Home/
38 www.alliance-scotland.org.uk/what-we-do/our-work/primary-care/scotlands-house-of-care/
39 www.evaluationsupportscotland.org.uk/news/2016/Dec/05/blog-good-conversations-matter-and-recording-them-/
40 www.resus.org.uk/respect/

We need to avoid having prepared people but unprepared practitioners, though, by addressing and improving clinical consultation skills. In particular, we need to improve how we approach shared decision-making, setting priorities and action-planning. Examples of how we might do this include model examples of what good conversations, which promote people's rights[41], might look like, and building training on return consultations into training. We need to highlight the importance of practitioners having the time and space to allow the essential health literacy aspects of consultations to take place.

There is a need to promote the importance of good palliative and end of life care across all settings. The Strategic Framework for Action on Palliative and End of Life Care[42] sets out a vision that everyone in Scotland who needs palliative care will have access to it. We need to support people to have conversations that meet their needs and preferences. It should better explore people's understanding about their condition, their preferences, as well as what is unacceptable to them, to achieve a clear picture of the extent they wish medical treatment. The focus is on listening firstly, and making sure that any information is in a form the person can engage with. These sorts of conversations should happen early, where people still have sufficient capacity, and must always involve those closest to the person where that capacity is limited.

In a number of locations in Scotland, public health approaches are being used to improve people's experiences of death, dying and loss. These involve:

▮ creating supportive environments to promote open discussion,
▮ building individual skills and capacities such as how to listen to someone who is bereaved, and
▮ strengthening community action including developing informal networks of support[43].

41 www.nhsinform.scot/care-support-and-rights/health-rights
42 www.gov.scot/Topics/Health/Quality-Improvement-Performance/peolc/SFA
43 http://smns.alliance-scotland.org.uk/2017/10/living-well-to-the-end/

The integrated health and care workforce

Integration authorities across Scotland[44] are planning, innovating and working with health and social care staff, communities and the third and independent sectors to ensure person-centred approaches in the design of care and support locally.

The integrated workforce is supported by bodies such as NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC). They work together to support the education and training of health and social care workers. Their programmes of work are a good opportunity to develop and share what we have learned to date.

Three potential areas for mutual action across the Scottish Government, NES and SSSC have been identified:

- Systems work – to better understand how the healthcare system works and can be more easily navigated.
- Forum theatre – this is a way of co-produced working to bridge the interaction between people and their practitioners.
- Outcomes focused support planning – a co-design group is developing a resource to support outcomes focused support planning[45] at individual, organisational and local level in the context of implementing the Carers (Scotland) Act 2016.

There is also a chance to build on the examples, tools and conversation aids[46] that have been developed to help anyone who wishes to discuss funding support for their social care.

Creating common skills across the system

Strathclyde University, funded by the Economic and Social Research Council, has undertaken research[47] on the role that human information intermediaries, for example family nurses, support group leaders, and social workers, can have in improving information skills and understanding for the most disadvantaged people. They identify an important human intermediary role that can:

1. help to **recognise** where information needs exist and take measured, purposeful action that takes account of the context,

2. be a key **source of information** in themselves, and a key connection to other sources of information not otherwise accessed, and

3. **tailor and personalise** information for relevance, and communicate in ways that take into account individual digital and health literacy and learning levels.

Working through our networks of champions, these common skills of connectors competencies can be widely promoted across sectors, situations and contexts to build a more skilled workforce and health literate society. In particular, we will work with the Care Inspectorate to support social care services and staff to understand the role they can play in supporting health literacy.

CONNECT

47 Buchanan S, Jardine C, & Ruthven I: Information behaviours in disadvantaged and dependent circumstances and the role of information intermediaries. Forthcoming (2017)

Action area 2
Continued

Community Link Workers

Community link working[48] is a way to connect people to sources of support or resources in the community that are likely to help with their health problems and improve wellbeing. A link worker also maps local sources of support, and develops relationships with the third sector, keeping updated on the status of existing and new services. The link worker offers a key gateway to promote health literacy with people, their health and care workers, and the third sector. It is vital that health literacy is included in the range of skills and knowledge that link workers have.

Social welfare literacy

There's an opportunity to spread learning from our health literacy work through the emerging welfare reform programme. In particular the agency established to deliver Scotland's new social security system could incorporate many health literacy tools and techniques. This will ensure people are treated with fairness, dignity and respect by taking into account their communication needs and preferences. This will support people to navigate the new system from the outset and use the information they receive to make informed decisions, regardless of their situation or circumstances.

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[48] www.vhscotland.org.uk/gold-star-exemplars-third-sector-approaches-to-community-link-working-across-scotland/

Common skills of connectors in the InS:PIRE programme

InS:PIRE (Intensive Care Syndrome: Promoting Independence and/or Return to Employment) is a Health Foundation funded project which aims to improve the health and wellbeing of Intensive Care Unit (ICU) patients after discharge from hospital, measured through return to work levels, GP visits and quality of life.

It was a case study in *Realising Realistic Medicine.*

A key part of the project is linking people to sources of support in their communities, so we will work with InS:PIRE to embed the 'common skills of connectors' into their roles and responsibilities. This will provide a good chance to refine and develop how we describe the skills needed.

The role of librarians

The National Strategy for Public Libraries 2015-2020[49] has a strand that relates to the promotion of social wellbeing:

'Libraries can be key partners in tackling the problems of social isolation, inequality, disadvantage, fractured communities and ill health. Libraries provide an important space and resource for many disadvantaged people in a non-judgmental, public space, open to all.'

There is an appetite for librarians to play a more active role in linking people to useful sources of health and care information. There is work already underway. We will work with them to develop resources that better meet people's needs by building upon the common skills identified by the Strathclyde University research. This will include drawing upon sources of support for improved digital literacy skills such as the SCVO's digital participation programme[50].

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49 https://scottishlibraries.org/advice-guidance/the-national-strategy-for-public-libraries/

50 https://digital.scvo.org.uk/participation/

The role of public librarians

Helping people improve sense of belonging to a community

Improved attitudes to reading

Helping people improve education & employment prospects

Public librarians contribute to

A good return on investment

Helping people improve their health

Reference: CILIP and University of Salford

Digital transformation

Health literacy is an important consideration for organisations as they develop digital solutions to support more aspects of service delivery. As well as building capacity in the use of digital tools for self-management, there is a need to further explore how digital tools can effectively support the shared decision-making interaction between people and their practitioners. These digital health literacy challenges will be an area of focus for the new Digital Health and Care Strategy.

Digital services that suit individual needs

Access to digital services that work

Motivated to engage with digital services

Feel safe and in control

Ability to actively engage with digital services.

Engagement in own health

Ability to process information
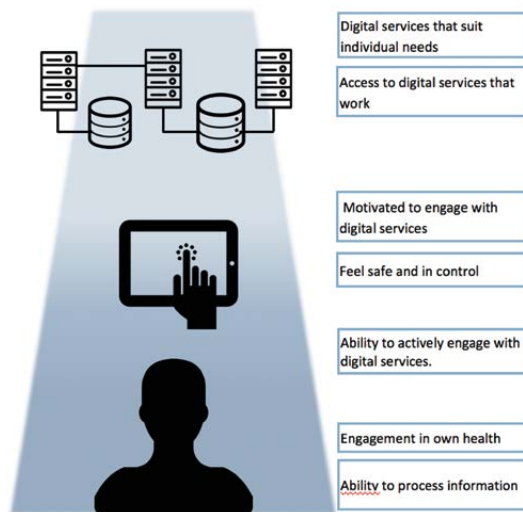
Image reference: Kayser L, Karnoe A, et al. The e-Health Literacy Questionnaire (eHLQ): *Development and initial validity testing of a multi-dimensional tool based on the e-Health Literacy Framework. JMIR (submitted)*

Macmillan information support services in Scotland's public libraries

The Macmillan @ Glasgow Libraries service offers cancer information and emotional support in libraries across the city.

This ambitious and innovative service design allows people affected by cancer to improve their quality of life by ensuring they receive easy access to understandable information and support at the right time, regardless of where they are on their cancer journey or where they live. This includes those who have had a cancer diagnosis and also their carers, family, friends and those who are worried about cancer and would like to find out more.

People can drop in without referral or appointment. Within the centres they will find information zones stocked with free easy to read booklets, leaflets, audio-visual and electronic resources. Trained volunteers offer emotional support and tailored information on living with and beyond cancer, helping people understand complex information and think of questions they might wish to ask their doctors or nurses.

Access to practical support is also on offer, including benefits advice and counselling, which can all take place in libraries across the city. Volunteers also signpost to a wide range of local services from physical activity and leisure classes to carers support and befriending services.

The Right Decision – what NHS librarians do

The Right Decision campaign encourages people to make full use of the expert evidence services provided by NHS librarians.

In addition, Going in the Right Direction – Health Information for Health and Wellbeing is a resource jointly produced by the NHS and the ALLIANCE to support library and information services across sectors.

Collaborative action with NHS England

We've made links with work across the UK through the UK Literacy Group[51]. Building on that, we will work with the NHS England National Health Literacy Collaborative to explore areas of common interest to derive clear actions for mutual benefit. An initial focus will be on medications information, but there will be opportunities to look at other topics throughout the lifetime of the action plan.

Harvey's Gang – an example from NHS England

This story starts with Harvey Baldwin, a 7-year-old boy with leukaemia who was being treated at Worthing Hospital. Could Harvey visit the labs that processed his many blood samples? Chief biomedical scientist Malcolm Robinson agreed. Harvey sat there, transfixed, watching his own blood going through the machine. The lab coat he wore swamped him so overnight, the chief of service ran up a mini lab coat from discarded NHS sheets.

Then Malcolm got the idea of bringing these young patients who endure frequent blood tests into the labs on a more regular basis. Sadly Harvey – who would have made a great biomedical scientist – died, but Harvey's Gang is his legacy.

Youngsters come into the labs, they get a special lab coat (not run up by the chief of service) and other goodies. Having been there, youngsters are less frightened about giving samples, and having explained how the lab works, parents are more reassured.

For the healthcare scientists involved, the experience of Harvey's Gang has been transformative. 'It reconnects us with our patients,' says Malcolm, 'and it's also meant that we've made changes to our services which ensure better care for our patients'. Harvey's Gang is now being rolled out not just in other UK units but across the world with places as diverse as the United Arab Emirates and Tennessee wanting to emulate it.

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51 www.healthliteracy.org.uk/

Action area 3

Shifting the culture by developing more health literacy responsive organisations and communities

Headlines from this section

- We will support the drive to a culture of shared decision-making.
- We will promote approaches that help organisations to be responsive to health literacy needs.
- We will work to embed health literacy concepts within school age education.

Shared decision-making

Health literacy has a vital role in supporting *Realistic Medicine's* culture change work towards shared decision-making. Supported shared decision-making has emerged as one of the key areas of focus in the feedback on *Realistic Medicine* and *Realising Realistic Medicine*. Wherever possible, we need to enhance people's ability to be in the driving seat of their own health and care through improving their health literacy. We need to support health organisations to understand health literacy diversity in communities and then be responsive to the community's needs.

Shared decision-making is not a one-way transmission of information about options and risks from the professional to their patient. It is a two-way relational process of helping people to reflect on, and express, their preferences based on their circumstances, expectations, beliefs, and values.

There is useful learning to draw upon from the [MAGIC Programme][52]. It found that shared decision-making is not confined to one patient and one clinician during one consultation. The process needs embedded across healthcare teams, and between people and their communities, all of whom will influence the process, especially for people living with long-term conditions.

EM**POWERING**

CHANGE OUR STYLE TO
SHARED DECISION-MAKING

We will examine aspects of Realistic Medicine including shared decision-making through an Our Voice citizens' jury. It is likely that some of the major findings from this process will fall under the remit of health literacy so this action plan will provide a place to address them.

Scotland's updated [health and social care standards][53] were published in July 2017. They set out what everyone experiencing care should expect, and are common across all of health and care.

One of the standards is that:

❚ I am supported to make informed lifestyle choices affecting my health and wellbeing, and I am helped to use relevant screening and healthcare services.

This means that everyone involved in the delivery of health and social care services needs to reflect on how they can make this a reality for everyone they work with.

52 www.bmj.com/content/357/bmj.j1744

53 www.newcarestandards.scot/

'Health literacy by design'

We will explore health literacy development approaches that use active community engagement and co-design, such as Deakin University's Ophelia[54] (OPtimising HEalth LIteracy and Access) approach to health literacy. Proactive health literacy-informed co-design will stop the creation of barriers that we've been working to remove. Using the local wisdom from the community, we need to work together to develop practitioners and design services that are responsive to people's health literacy needs from the outset. There is useful learning to draw upon from projects funded by the Self Management Fund for Scotland.

We need to understand the landscape of service change across the health and social care sector in Scotland to develop specific actions and key points to influence system thinking. Of particular relevance is work being progressed under the Our Voice banner.

Creating health literate organisations and communities

At its core, the NHS Tayside's work under *Making it Easy* was about creating a focus on improved health literacy within one locality from which we could then spread and share the learning to many. Through this work we now have more confidence in what a health literate organisation looks like. Approaches such as the Ten attributes of a health literate healthcare organisation[55] and the work from Deakin University on the Ten Focus Areas for Health Literacy summarise this well.

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54 www.ophelia.net.au/

55 www.dhhs.tas.gov.au/publichealth/about_us/health_literacy/health_literacy_toolkit/ten_attributes_of_a_health_literate_healthcare_organisation

Belfast Healthy Cities work

Belfast Healthy Cities[56], established in 1988, was among the initial 15 cities to be formally designated as World Health Organization (WHO) Healthy Cities.

At the time, it introduced an entirely new approach to addressing health inequalities. Its appeal was its focus on health being the responsibility of all sectors, which was considered key to addressing the social determinants of health and inequalities in health.

Belfast Healthy Cities has had significant influence on policy and action in working with other sectors and departments in the areas of health, inequities and wellbeing. It has provided strong evidence and research on how the health of a city can be improved.

With a small, but very effective team, their work together with city stakeholders over the past decades has had far reaching influence on the shaping of health and wellbeing strategy in Belfast and beyond.

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56 https://www.belfasthealthycities.com/

Action area 3
Continued

Emerging work from Deakin looks at an Organisational Health Literacy Assessment Tool[57]. This tool can help organisations find their priority areas for action on health literacy, building on their strengths and assets, while targeting their weaknesses. We will promote this approach to spread our learning to organisations across all sectors.

Likewise, we need to support the building of health literate communities. People should be supported to tap into local networks and resources. Knowledge and skills exist across communities, such as within library services, and offer opportunities to improve health literacy. We need to consider the needs of people who are isolated or have few social connections, by linking with emerging national work to tackle social isolation and loneliness. In addition, the case for asylum seeker and refugee populations is covered by our New Scots[58] work.

There are strong examples that we can draw upon of how services have worked to make it easier for people to understand how health and care works in Scotland because they come from different cultures and countries. Explaining basic concepts, often for those with language barriers, such as that the NHS is free to access or how to register with a GP or dentist, can be vital in welcoming people into our communities. New Scots offers a fresh chance to work with migrant populations to improve how their access needs inform our overall approach.

Ideas to improve how people think about their health and wellbeing need to be embedded at as early a stage as possible in their lives. We will consider approaches that have been tried with some success in other countries which have begun to show that young people can be better supported to interpret health information[59]. We will work with the Royal Pharmaceutical Society to further their ambition to embed health literacy within school age education.

57 https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2465-z
58 https://beta.gov.scot/policies/refugees-and-asylum-seekers/new-scots/

59 Allen N, Semakula, D et al. *Effects of the Informed Health Choices primary school intervention on the ability of children in Uganda to assess the reliability of claims about treatment effects: a cluster-randomised controlled trial.* www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31225-4/fulltext

How we evaluate impact

Through this phase of work, the emphasis will be on improving the quality of people's experience with the health and care system. Simple measures such as confidence scales can show improvements in awareness, understanding and confidence, all of which are key markers of improved health literacy responsiveness.

The Organisational Health Literacy Assessment Tool provides a clear way of tracking strengths, weaknesses and systematically building health literacy into quality improvement processes across a wide range of organisations.

Stories are a key form of evidence for improved health literacy impact. We will use tools such as Care Opinion[60] to capture experiences, innovation and feedback.

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60 www.careopinion.org.uk/

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