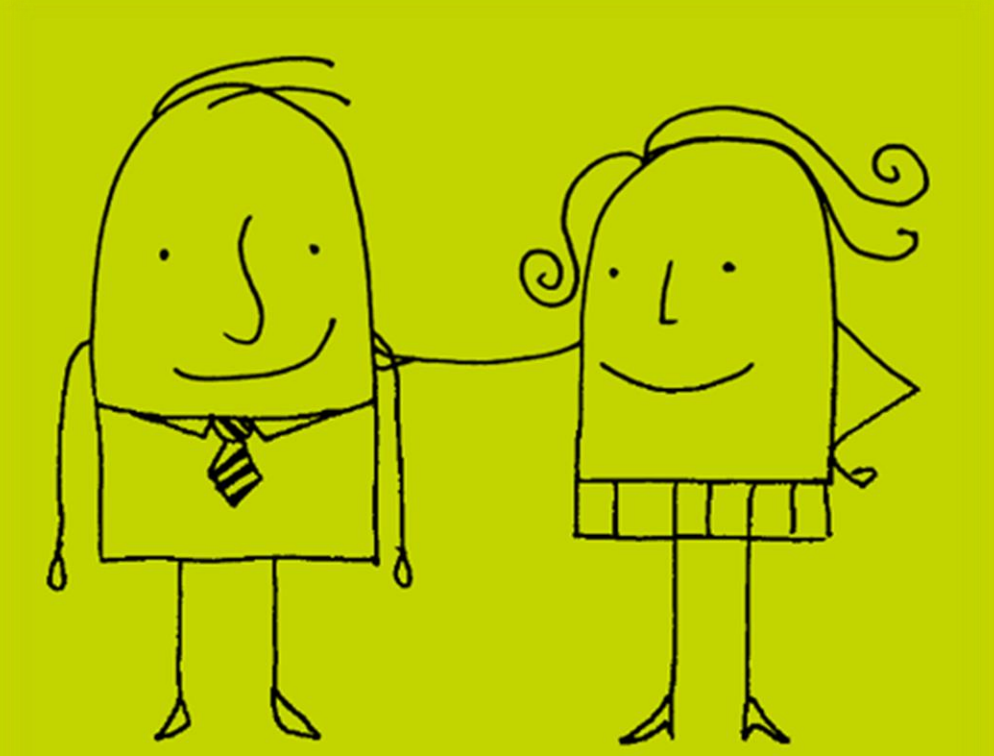
Patient and Client Council
Your voice in health and social care

Towards an action plan for health literacy in Northern Ireland

A Patient and Client Council scoping paper

January 2021



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Executive summary

What is the purpose of this document?

As a follow-up to a scoping workshop that the Patient and Client Council (PCC) co-delivered (with the Patient Information Forum) in June 2018, the PCC's Business Plan for 2019/20 included the following objective:

> **Goal 4 - Promoting the provision of information about the design, commissioning and delivery of health and social care**
>
> **4.1 Health Literacy**
>
> The Patient and Client Council will progress work to bring key stakeholders together to engage on Health Literacy and agree common understanding.
>
> - Work with Belfast Healthy Cities to facilitate discussion, with representation across HSC and relevant Bodies

The review of health literacy, policy and literature presented here is an initial step towards this objective. Its aims are to inform thinking and discussion around - and form an initial evidence base for - a health literacy 'action plan' for Northern Ireland. To this end, the study has to:

- Establish the current context of health literacy in Northern Ireland and in the wider UK;
- Collate evidence on the importance of health literacy;
- Provide evidence on the scale of the issue for different sections of the population; and
- Review specific interventions for improving health literacy.

The COVID-19 pandemic began during the development of this report. Health promotion plays a vital role in pandemics, and this has been abundantly evident in the responses to COVID-19 since the outbreak. Messaging about health and hygiene, particularly hand-washing, is one example of how health education has been delivered via mass media and social marketing campaigns. Health literacy has therefore become a key consideration as the government develops strategies to combat COVID-19. Doing this effectively requires that health messages are communicated in a concise and meaningful so that they are easy for citizens to access, understand, navigate and act upon.

Importance of health literacy

As outlined above, the COVID-19 pandemic has served to underscore the importance of health literacy and remind us of how important it is that the public is able to find, interpret, appraise and effectively use health information.

More generally, as health information and health systems have become increasingly complex, they have inevitably become more difficult to understand. While there is no baseline figure on the level of health literacy for Northern Ireland, it is closely linked to literacy in general[1]. Adult literacy statistics show that 18% of the working age population of Northern Ireland perform at the lowest literacy level[1]. This suggests that a significant proportion of adults have low individual health literacy, and may not be able to effectively exercise their choice or voice when making healthcare decisions. Low individual health literacy is associated with higher use of some health services, such as hospital emergency departments and GPs, low levels of knowledge about health care issues among patients and poorer health outcomes[2]. It has also been estimated that people with low individual health literacy are between one-and-a-half and three times more likely to experience an adverse outcome[3].

A systematic review that examined the costs associated with low individual health literacy found that, at a system level, additional costs were equivalent to approximately three to five per cent of total healthcare spending. At an individual level, people with low health literacy spent between $US143 and $US 7,798 more per person per year than people with adequate health literacy[4]. Closer to home, the cost of low health literacy in England has been estimated, albeit rather crudely, to be between £2.95bn and £4.92bn per year[5].

Health literacy is important for patients and clients because it affects their capacity to make decisions and take action to manage their health and healthcare. It is also important for those providing healthcare because it affects the way that they manage their relationships with patients and clients and deliver healthcare. It is important for managers and policy makers because the complexity of the systems and services they develop can affect patients' and clients' ability to make effective use of those services. It is also important for broader society because health literacy is shown to contribute to people's overall health and consequently their capacity to participate and contribute productively to society.

Addressing health literacy can also contribute to reducing health inequalities. Partnerships with patients and clients are essential for both individual health and healthcare and for the development of better healthcare systems. Improving health literacy ensures that people can fully participate in these partnerships and that the health system and healthcare organisations are oriented to support such partnerships.

How is health literacy defined?

Health literacy is about how people understand information relating to health and healthcare, and how they apply that information to their lives, use it to make decisions and act on it. In Northern Ireland, health literacy was one of the key themes in *Making Life Better*, the Department of Health's 10-year public health framework that runs until 2023. For example, this document introduces the section on health information with the following definition:

"*Health Literacy – the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health*"[6].

It also states that:

"*Improving health literacy needs to go beyond a narrow concept of health education and individual behaviour, and address the environmental, political and social factors that determine health.*"

This local understanding of health literacy resonates with a definition adopted by the health services in Australia, which separated health literacy into two components:

- Individual health literacy - the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action;
- The health literacy environment - the infrastructure, policies, processes, materials, people and relationships that make up the health system and have an impact on the way in which people access, understand, appraise and apply health-related information and services.

Improving health literacy

While health literacy is a relatively new and evolving concept in Northern Ireland, the theory behind it is not new and many people and organisations will identify areas of their work that can improve health literacy. However, research for this paper has demonstrated that, while such activities exist, they tend to be disconnected, thus limiting opportunities for shared learning. Moreover, current systems to support improvements in health literacy at a local level are variable and largely absent at a regional level.

Addressing health literacy in a coordinated way, therefore, has potential to increase the safety, quality and sustainability of the health system. As a result, strategies are needed to build the capacity of people to understand

the choices they have, to make decisions and take action for their health and healthcare; and to build the capacity of the health system to support, encourage and allow this to occur.

Areas for action and key partners

The purpose of this paper is to stimulate discussion about actions that can be taken to increase individual health literacy and improve the health literacy environment in Northern Ireland. Based on the findings of this review, three fundamental areas for action have been identified for improving Northern Ireland's responsiveness to the issue of health literacy. A list of objectives has been developed for each action area, and these have been used to establish a compendium of proposed actions for each setting. The detail of these is set out in Section 7.

Action Area 1: Develop knowledge - Develop and maintain an extensive repository of knowledge, providing access to research and practice-based evidence on effective and proven ways to improve health literacy.

Action Area 2: Promote effective communication - Develop and implement communication strategies to influence key stakeholders by conveying the importance of health literacy. Develop and provide learning opportunities that enhance the knowledge, understanding and abilities of the public and private sector workforce, professionals and community members in their efforts to support and promote health literacy.

Action Area 3: Build infrastructure and partnerships - Allocate sufficient fiscal, human, organisational and physical resources to support and sustain a coordinated effort to build the partnerships and implement the activities outlined in the Action Plan.

Only a joint effort by multiple partners at all levels of society will ensure the best prospect for an increase in capacity for health literacy among the people of Northern Ireland. The approach developed in the report identifies the following five key partners:

- **Central and local government**;
- **Health and Social Care sector** - Healthcare providers including medical personnel, healthcare institutions and clinics;
- **Education sector** - Public and private schools, post-secondary institutions, libraries, adult literacy programs, centres for continuing education and English as a second language (ESL) education;
- **Workplaces and businesses** - small, medium and large businesses and places of employment; and
- **Community and voluntary organisations** - for example: charities, community recreation centres, religious institutions, and the media.

What are the next steps?

Transforming the actions outlined in this document into meaningful change will primarily require the sustained involvement and commitment of all those who work within the Health and Social Care system, as well as others in the education (youth and adult learning), community and business sectors, and in local and central government. With this understanding, the following tenets should be incorporated into all efforts to support the vision that has been outlined:

- A participatory approach should be strived for, so as to meaningfully engage all relevant disciplines, professions and population groups as equal partners in creating, planning, implementing and evaluating initiatives;
- The most innovative and evidence-based health literacy programmes, policies and services available must be sought out and adopted or adapted to the Northern Irish context;
- Ongoing evaluation must be incorporated into all new activities and initiatives, in order to evidence outcomes, identify areas for improvement and determine what practices should or should not be replicated or rolled out; and
- It is widely accepted that health literacy is determined by the individual *and* by the environment in which they exist and with which they interact. Any approach selected or change enacted in order to improve health literacy - including policies, physical settings and processes - must be cognisant and reflective of this.

The way forward plotted in this report identifies the importance of improving health literacy as a crucial component of the determinants of health. Its three fundamental action areas are intended to guide and encourage collective and cohesive actions at regional and local levels, aimed at enhancing the health literacy of all the citizens of Northern Ireland.

As such, the paper acts as an invitation to relevant and interested groups to review the approach set out and to discuss the application of the ideas to their own contexts and areas of health literacy work and, following this, provide feedback on how the framework could be improved to better support their efforts. Any action plan must be underpinned by a clear Executive policy that can engage all players in a sustained inter-sectoral effort to improve individual and environmental health literacy. We hope that this report can be viewed as an important step towards realising this vision within Northern Ireland.

1.0 Introduction

As a follow-up to a scoping workshop that the Patient and Client Council (PCC) co-delivered (with the Patient Information Forum) in June 2018, the PCC's Business Plan for 2019/20 included the following objective:

Goal 4 - Promoting the provision of information about the design, commissioning and delivery of health and social care

4.1 Health Literacy

The Patient and Client Council will progress work to bring key stakeholders together to engage on Health Literacy and agree common understanding.

- Work with Belfast Healthy Cities to facilitate discussion with representation across HSC and relevant Bodies

The review of health literacy, policy and literature presented here is an initial step towards this objective. Its aims are to inform thinking and discussion around - and form an initial evidence base for - a health literacy 'action plan' for Northern Ireland. To this end, the study has to:

- Establish the current context of health literacy in Northern Ireland and in the wider UK;
- Collate evidence on the importance of health literacy;
- Provide evidence on the scale of the issue for different sections of the population; and
- Review specific interventions for improving health literacy.

2.0 Background and context

Health literacy has become a priority for health and social care in the 21st century. It is vital for people's ability to manage their health and social care and to navigate the health and social care system. Health literacy is also a foundation for health organisations' capacity to serve patients and clients, and for society to ensure the health and wellbeing of its citizens.

2.1 Defining health literacy

So, what is 'health literacy'? Research for this paper found that the first systematic literature review on health literacy definitions and models was conducted in 2012[7]. A second focused on health literacy definitions and their interpretations and implications for policy initiatives[8]. A further recent study entailed an analysis of health literacy definitions with relevance for children and adolescents[9].

2.1.1 Key definitions of health literacy

Appendix 1 outlines a wide range and variety of health literacy definitions that are commonly used. The list is not intended to be exhaustive. It is perhaps most useful to note the definitions that have been applied in those countries that have developed national plans to deal with the problem of low health literacy (some of these national plans are examined in more detail in Section 6.1).

- USA (2010): "*Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*.[75]

- Wales (2010): Health literacy is "*the ability and motivation level of an individual to access, understand, communicate and evaluate both narrative and numeric information to promote, manage and improve their health status throughout their life time*".[111]

- Scotland (2014): The national action plan - *Making it easy. A Health Literacy Action Plan for Scotland (2014)* - does not include a specific definition of health literacy. Rather, it states that "*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*."[92]

- Australia (2014): "*Health literacy is about how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it*."[4]

The report then separates health literacy into two components:

- ***Individual health literacy*** - the knowledge, motivation and competencies of a consumer to access, understand, appraise and apply health information to make effective decisions and take appropriate action for their health and healthcare. This is the definition of health literacy as it was developed in the European Health Literacy Project (HLS-EU)[i]; [112] and

- The ***health literacy environment*** - the infrastructure, policies, processes, materials and relationships that exist within the health system. These elements can make it easier or more difficult for patients and clients to navigate, understand and use health information and services in order to make effective decisions and take appropriate action about health and healthcare.

2.1.2 Defining health literacy in Northern Ireland

In Northern Ireland, health literacy was one of the key themes in *Making Life Better*, the 10-year public health framework that runs until 2023[10]. For example, this document introduces the section on health information with the following definition:

"*Health Literacy – the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health*"[11].

Furthermore, it states that:

"*Improving **health literacy** aims to influence not only individual lifestyle decisions, and decisions about treatment and self-care, but also raise awareness of the determinants of health, and encourage individual and collective actions - at all levels of society - which may lead to a modification of these determinants.*

*Improving **health literacy** needs to go beyond a narrow concept of health education and individual behaviour, and address the environmental, political and social factors that determine health.*"

Appendix 2 provides further details on progress against actions and commitments on health literacy under this policy between 2013 and 2015.

This local understanding, alongside the inclusion of the 'health literacy environment' in the Australian definition above, demonstrates a shift in how health literacy is viewed. When the locus of responsibility for health literacy is simply understood to reside in individual abilities, action is limited to building individual capacity. However, focussing on the match or mismatch between individuals' skills and the demands placed on them creates additional opportunities for improvement. Building skills among the lay public as well as among those professionals responsible for communicating health information and changes to the health system can and should all be considered. Along with individual responsibility, therefore, health literacy can viewed as being embedded in a societal context, influencing the relationship and interaction between individuals and services to maintain and improve health[12].

2.2 Why is health literacy important?

Under ideal circumstances, high levels of individual health literacy and a supportive health literacy environment support people to access understandable, useable and evidence-based information about their health and healthcare. Through this, they are enabled to understand:

- How to maintain or improve their health and wellbeing;
- How to access and interact with the health system;
- Their condition and treatment options;
- The processes and likely outcomes of possible tests and treatments;
- How to manage their condition(s); and
- How to prevent further illness.

However, the benefits of health literacy are perhaps best viewed through the lens of what happens in its *absence*. The negative effects of low individual

health literacy and of structures that fail to effectively provide and empower people with information about their health are well documented. It has been estimated that people with low individual health literacy are between one-and-a-half and three times more likely to experience an adverse health outcome[13]. Lower health literacy has also been linked to a lack of social empowerment and efficacy[14]. In addition, a report by the World Health Organization (WHO) suggested that low health literacy *"significantly drain[s] human and financial resources in the health system"*[15].

2.2.1 Linking health literacy and health outcomes

Low levels of health knowledge and low levels of individual health literacy in the population, along with the increasing demands of a complex health system[16] have had a significant impact on health. In general, low individual health literacy has been found to be associated with[17]:

- Increased rates of hospitalisation and greater use of emergency care;
- Lower use of mammography and lower uptake of the influenza vaccine;
- Poorer ability to take medications safely and appropriately;
- Poorer ability to interpret labels and health messages;
- Poorer knowledge among consumers about their own disease or condition;
- Poorer overall health status among older people; and
- Higher risk of death among older people.

However, it should be noted that the influence of health literacy on many other health outcomes, such as oral health, can be unclear or insignificant[18].

It has been recognised for some time that the complexity of the health system is challenging for consumers and healthcare providers[19] and that this complexity contributes to poor quality and unsafe care[20]. However, compared to *individual health literacy*, there has been far less research about the impact of the *health literacy environment* on health outcomes.

Consumers report that their health information needs are not always met. For example, research about the readability of written health information has found that documents contain language and complex concepts that would be difficult for most people to comprehend[21]. Other studies looking at the information provided to patients about their condition and treatment, particularly for specific conditions such as cancer, suggest that healthcare providers may need to pay more attention to providing person-centred information[22]. Assessments of the health literacy environment of health centres/hospitals meanwhile identify issues such as difficulties in 'wayfinding' and written information that is too complex, particularly on consent forms[23].

It is known that people who are provided with appropriate information (based on satisfaction with received information, fulfilled information needs, high quality and clear information) report better health-related quality of life and lower levels of anxiety and depression[24]. This suggests a link between the

health literacy environment and health outcomes, albeit mediated by individual health literacy.

2.2.2 How can health literacy affect health outcomes?

A number of models have been proposed to explain the links between health literacy and health outcomes[25]. Generally, the data to support these models are limited, and the models may underestimate the complexity of relevant factors, relationships and interactions[26]. Nonetheless, it is important to understand the models, as they may suggest areas where action can be taken for improvement.

The key causal pathways that have been described relate to the way in which individual health literacy, the health literacy environment and contextual factors (e.g. age, education, socio-economic status, cultural background, social support and the media) interact to influence the following[27]:

How people access and use healthcare services: For example, people with higher individual health literacy may have a greater understanding of when and how to seek treatment and preventive care, reducing use of acute health services. The design of healthcare facilities may make it more difficult for people with lower individual health literacy to find the information and services that they need.

Textbox 1: Anti-vax - The link between health literacy context and outcomes

An important example of how health literacy can affect people's use of healthcare services comes from the growth of the anti-vaccination movement. Vaccines have proven to be an important and effective preventative measure against infections and diseases. However, many parents now refuse to vaccinate their children on the grounds that this may do more harm than good[28]. Measles outbreaks have increased in recent years. In the first half of 2018, over 41,000 measles cases were reported in Europe, an increase relative to the preceding decade. In France, Greece and Italy, more than 1,000 cases were registered in each country, and deaths confirmed[29]. As a consequence, the European Commission has called for stronger efforts and cooperation to improve vaccination coverage and develop sustainable vaccination policies in the European Union[30].

Interactions between service users and healthcare providers: Healthcare providers may have limited awareness of their patients' health literacy levels and may not tailor the information that they provide appropriately, affecting the likelihood that consumers will follow the recommended treatment. A study in the Netherlands, for instance, has shown that 40 to 50% of health care providers do not consider individuals' understanding of health information when communicating or providing information or advice[31]. Reasons for this include not recognising limited health skills, not being aware of a problem, lack of knowledge of available methods or having limited time for interaction, for instance, during consultation times.

On the patient side, people with lower individual health literacy may be less likely to ask questions of their healthcare professional, or to ask for clarification or more information if they do not understand. Empowered individuals are more comfortable engaging in dialogue with health professionals, whereas people with low health literacy can experience difficulties in speaking during consultations and may hide these difficulties due to stigma[32]. In clinical settings, good patient-provider communication is found to be important for patient safety and patient satisfaction[33]. When health information is wrong or misused it can compromise health outcomes, for example, in the case of medication adherence. When medical instructions are not clear or individuals are excluded from health decisions, they may reject treatment decisions or lack the motivation to follow therapy. Estimates show that poor medication adherence - which can be driven by numerous factors, including patients' health literacy - may contribute to nearly 200,000 premature deaths in Europe annually[34].

How people manage their own health: People with higher levels of health literacy tend to be more engaged in self-care practices, such as, those who self-administer insulin to treat their diabetes. Health literacy can strengthen individuals' capacity to understand long-term conditions (which require continuous management) and to learn about treatment, risks and self-care[35].

How people exert control over the factors that shape health: While coming from a more socially advantaged background is no guarantee of good health literacy, many of the social determinants of health have been found to strongly correlate with health literacy. In the US, for example, lower educational attainment, income and minority race/ethnicity have all been linked with lower levels of health literacy[36]. Results from Europe also show that those reporting lower education and lower income or financial deprivation tend to have lower health literacy levels[37]. This has also been partially confirmed in countries across Asia and the Middle East[38], and evidence from Australia suggests that people from vulnerable or disadvantaged groups can be at higher risk of having low individual health literacy[39].

On the other hand, people with higher individual health literacy may have a greater understanding of these social determinants of health, and may use this knowledge to take greater responsibility for their own health and to influence others to do the same. Such efforts can be supported by a health literacy environment which provides health education that is focused on the development of interpersonal and social skills, as well as knowledge about specific health-related issues.

2.2.4 The financial cost of low health literacy

As mentioned, people with lower health literacy may experience difficulties in understanding which services they should use when they become ill or which preventive behaviours they should engage in. A study conducted in Belgium

found that individuals with low health literacy made more use of specialised health services, which also tend to be more expensive[40]. A systematic review also found low health literacy to be moderately associated with increased hospitalisation and use of emergency care[41].

It is difficult to accurately determine the financial cost of lower individual health literacy to the person, healthcare organisations and the system as a whole. This is partly due to the difficulty in separating individual health literacy from other related concepts that influence behaviour. However, where efforts have been made to estimate costs, they have been substantial. One systematic review in the United States examined the costs associated with lower individual health literacy and found that, at a system level, additional costs corresponded to approximately three to five percent of total healthcare spending[42]. At the individual patient level, the amount of additional healthcare expenditure incurred by those with limited health literacy (e.g. older people and those on low incomes compared to reference groups with adequate health literacy) may vary between $143 and $7,798 per person annually[43]. The cost of poor health literacy in England has been estimated, albeit rather crudely, to be between £2.95bn and £4.92bn per year[44].

3.0 Health literacy as a public health policy issue

Given its influence on people's health, and on the safety, quality and cost of healthcare, it is perhaps unsurprising that health literacy has become a highly debated policy issue[45] and received increasing recognition as an important public health goal[46]. Increasing numbers of people living longer with multiple long-term conditions creates more and heavier users of health and social care services. Moreover, the growing demands and expectations that modern medicine places on individuals - in terms of taking more responsibility for their own health - often overwhelm their abilities and may undermine the safety and effectiveness of healthcare.

In this context, health literacy has become a higher policy priority and an increasing policy challenge. Public policy calls to improve health literacy are based on the idea that those with higher levels of health literacy are better equipped to make decisions that help maintain or improve their health and quality of life, and to navigate the health system in case of illness.

3.1 Global health literacy policy

The WHO and the Institute of Medicine (IOM) have led on raising international awareness of the political relevance of health literacy via several dedicated programmes, publications and workshops, as well as explicit calls to address the problem of limited health literacy[47].

The WHO, for example, published a report in 2013 titled '*Health Literacy: The Solid Facts*' - which identifies effective ways to strengthen health literacy in a variety of settings - and the *2016 Shanghai Declaration* on promoting

health in the '*2030 Agenda for Sustainable Development*', which stresses the importance of health literacy for reducing health inequalities[48]. While policy debates on health literacy first became prominent in English speaking countries like the US, Canada, and Australia[49], they have now spread across most of Europe[50]. Policy debates in Europe are fuelled by international developments as well as by a benchmark based on a survey that measured health literacy in eight European Union member states[51] (see Section 4.1).

In September 2019, the WHO published a draft European roadmap for implementation of health literacy initiatives, to guide WHO Member States and the WHO Regional Office for Europe in their efforts to enhance health literacy in the WHO European Region. The roadmap builds on ongoing health literacy-oriented regional initiatives and charts possible ways of achieving more closely integrated, purpose-oriented and evidence-based health literacy action.

It is aimed at supporting health literacy development over the life course, through five strategic directions:

- Increasing capacity building on health literacy;
- Advocating and facilitating cross-sectoral integration of health literacy;
- Advancing development and implementation of health literacy initiatives;
- Improving digital health literacy; and
- Strengthening the measurement, monitoring and evaluation of health literacy.

3.2 National policies in EU member states

Currently, it seems to be uncontested that political action can play a crucial role in addressing health literacy and implementing sustainable health literacy initiatives[52]. To this end, the draft WHO Roadmap for health literacy calls on all 53 member states to develop health literacy at the policy, organisational, community and individual levels. Several European governments are currently developing or implementing national strategies in order to improve the health literacy of their citizens[53] (**Textbox 2**).

Textbox 2: HEALIT4EU Study - Reviewing health literacy policy across EU nations

In 2014, the European Commission financed the HEALIT4EU study to review policies and activities around health literacy across EU member states. The study showed that:

- *Six EU member states had already included health literacy in national policies – Austria, Italy, Spain, Portugal, Republic of Ireland and UK. Most of the other EU member states do not have a national policy or plans to develop national policies on health literacy;*
- *The target groups of the policies in the six EU states were varied, and included the general population or specific groups such as children, minority ethnic groups, older people, people with diabetes or people with mental health problems;*
- *The ways policies sought to improve health literacy also varied and included, for instance, providing tailored health information, educating professionals and developing health education programmes or materials for people with lower levels of health literacy. Efforts to improve health literacy at a population level included better prevention, stimulating research and intervention development.*

The conclusions of the study were as follows:

- *Health literacy had definitely gained attention in several EU member states in recent years;*
- *Efforts to address health literacy through policies or activities were just beginning in most countries;*
- *Evidence at the time did not support firm statements about the effectiveness of interventions, policies and programmes;*
- *Nevertheless, two best practices stemmed from promising interventions:*
    1. *Interventions should be tailored to the needs of the patients or groups with inadequate health literacy;*
    2. *Interventions should target critical and/or interactive skills and competencies (and not only knowledge).*

Section 6.1 looks in detail at some examples of such policies. Other nations have embedded action on health literacy within broader strategic programmes and policies.

3.2.1 Republic of Ireland

In the Republic of Ireland (RoI), health literacy has gained attention in the country's health debate during the last decade. The policy conversation began with '*Health literacy, policy and strategy*', a 2002 research report produced by the National Adult Literacy Agency (NALA) [113]. In 2007, NALA published a policy paper on the issue of health literacy [114]. This included a strategic plan for 2007-10 that stressed the importance of addressing the issue of health literacy through research, awareness and integration of health literacy in the RoI health system. In 2013, the Irish Department of Health published their new policy, *Healthy Ireland: A framework for improved health and wellbeing 2013-2025* (see **Textbox 3**).

Textbox 3: Republic of Ireland: Example of a national health literacy policy

The policy 'Healthy Ireland: A framework for improved health and wellbeing 2013-2025' includes a theme entitled 'Empowering people and communities', the goal of which is to foster the implementation of mutually reinforcing and integrated strategies and actions to encourage, support and enable people to make better choices for themselves and their families (DH, 2013). Recommendations under this theme include actions to:

- *"Address and prioritize health literacy in developing future policy, educational and information interventions"; and to*
- *"Support and link existing partnerships, strategies and initiatives that aim to improve the decision-making capacity of children and young people through strengthening self-esteem, resilience, responses to social and interpersonal pressure, health and media literacy (including social media literacy)".*

The partners involved in these proposed actions to enhance health literacy include the Department of Health, Department of Children and Youth Affairs, Department of Education and Skills, HSE directorates, statutory agencies, community and voluntary bodies and the private sector.

3.2.2 Great Britain

Although there is no UK-wide policy on health literacy, there has been some steps from the devolved governments across Great Britain to make health information more accessible to people and easier to understand. In England, health literacy was mentioned in the NHS long-term plan[115], while Scotland has '*Making it easier, a health literacy plan for 2017 to 2025*'[116] (see Section 6.1.2). In Wales, the '*Fairer health outcomes for all*' document to tackle health inequalities included improving poor health literacy[117] and a review in 2018 suggested that new public health plans should include health literacy targets (Review of Health and Social Care, 2018).[118] This does not appear to have happened, but the Public Health Wales long-term strategy for 2018-30, pledged to tackle health inequalities and the wider determinants of ill health (Public Health Wales, 2018).[119]

3.2.3 Northern Ireland

Health literacy was a key element within '*Making Life Better*', the 10-year public health framework for Northern Ireland that runs until 2023[54].

In recognition that much of the work being carried out on health literacy has not been consistently known or applied across sectors, settings, professions, agencies or healthcare settings, a Regional Health Literacy Forum was established in 2019 to explore opportunities to tackle health inequalities by improving health literacy on a regional basis. The Forum is a grouping of key partners drawn from across the health and social care sector.

The objectives of the Forum are to:

- Work in partnership across the region to promote and improve health literacy rates in the population.
- Work in partnership across the region to reduce the impact of health inequalities.
- Have specific regard to those communities with poorest health literacy – areas of deprivation, older people etc.
- Work in partnership to develop an evaluation framework to monitor the impact of the work of the Regional Health Literacy Forum.

Health literacy was also identified by stakeholders as a core theme in Belfast's successful application for designation as a member of the WHO's European Healthy Cities Network Phases VI and VII (2014-2018 and 2019-2024). In preparation for taking forward a programme of work on health literacy, a working group was established by Belfast Healthy Cities with key stakeholders to identify priorities for health literacy in Belfast. To date, this group has delivered:

- A background paper outlining the evidence on the link between health literacy and health outcomes and describing existing tools for measuring health literacy;
- A template for evaluating and recording case studies on health literacy to support the development of health literacy in policy and practice;
- A number of case studies for reference and for use in shaping future practice in health literacy;
- A workshop (in 2014) to explore and develop a common understanding of health literacy in the Belfast context. The workshop presented models of practice locally and from across the UK and Ireland. Through small group discussion, participants proposed suggestions for a way forward with partners and stakeholders in Belfast (see Appendix 3 for more details on the workshop);
- Health Literacy Focused Communication Training (**Textbox 10**), which was delivered to health professionals in Belfast as part of a research project led by University Medical Centre Groningen, Netherlands. The objectives of this training are to promote a person-centred approach to enhance three key elements of health literacy skills of patients and, ultimately, to promote effective self-management:

  Functional health literacy: Basic health literacy skills that are sufficient for individuals to obtain relevant health information and apply that knowledge to a limited range of prescribed activities;

  Interactive health literacy: More advanced literacy skills that enable individuals to extract information and derive meaning from different forms of communication, to apply new information to changing circumstances and to interact with greater confidence with information providers such as healthcare professionals;

  Critical health literacy: Most advanced cognitive skills which, together with social skills, can be applied to critically analyse information and to use this information to exert greater control over life events and situations.

These discussions around health literacy in Belfast reflect many of the health literacy challenges and required actions highlighted in this paper. As such, the approach to health literacy outlined here should resonate with and be familiar to many of the partners connected with the Belfast Healthy Cities initiative, as well as the Regional Health Literacy Forum.

4.0 The scale and measurement of limited health literacy

Measuring health literacy is important. Health literacy data help policymakers to identify the scale and severity of people's difficulties and needs with respect to health information, to benchmark against other populations or areas, and to develop guidance and plan interventions in an effective way. Evidence-based and practice-based decision-making uses the best available evidence on health literacy (as well as general literacy), on the determinants of health and on the effectiveness of interventions to identify priorities and develop strategies for improving health literacy[55].

4.1 Health literacy levels in OECD countries

Health literacy has been measured in eighteen OECD countries using general skills surveys or health literacy-specific surveys (e.g. the European Health Literacy Survey)[56]. A majority of OECD populations showed low levels of health literacy. In twelve out of the eighteen countries where data are available, more than half of individuals showed poor levels of health literacy:

- The 2012 European Health Literacy Survey (HLS-EU) suggested that between 29% (Netherlands) and 58% (Spain) of populations have inadequate levels of health literacy, with a figure of 40% in the Republic of Ireland;
- Adjusted forms of the original HLS-EU suggested that, for the majority of countries examined (Japan, Slovenia, Turkey, Portugal, Czech Republic, Switzerland, Italy and Germany), more than 50% of their populations may have inadequate health literacy. In Israel, the proportion is lower at 31%;
- The general adult skills surveys (Australia, Canada, United States) showed between 36% and 60% of the adult population may have low health literacy levels.
-

4.2 Health literacy levels in the UK

A 2015 study[57] on functional health literacy levels (see paragraph 3.2.3) across England reported that 42% of working age adults (aged 16-65 years) in England are unable to understand and make use of everyday health information, rising to 61% in situations where numeracy skills are also

required for comprehension. Furthermore, 43% of working-age adults will struggle to understand instructions to calculate a childhood paracetamol dose.

The Community Health and Learning Foundation[58] estimated that 15–21 million people in the UK might not have the level of skills needed to live a healthy life. These estimates do not factor in the number of people who have low interactive and critical health literacy skills (see paragraph 3.2.3) as this is not yet known, so overall numbers are likely to be even higher[59].

There are no health literacy statistics for Northern Ireland but, based on statistics in other regions of the UK, it can be seen that up to half the population could be expected to have limited health literacy.

4.3 How is health literacy measured?

The majority of measurement efforts have focused on measuring the health literacy of individuals rather than evaluating the health literacy environment. Different tools have been developed to measure individual health literacy (**Textbox 4**). The tool or method that should be used depends on the reason(s) for measuring individual health literacy and the intended use of the results. For example:

- Healthcare providers can use short form tools (such as the Newest Vital Sign) to measure a person's individual health literacy within a consultation in order to quickly identify barriers to understanding and to allow staff to communicate with the individual consumer in the best possible way;
- Healthcare organisations can use more detailed tools (such as the Rapid Estimate of Adult Literacy in Medicine) to assess the individual health literacy of the people to whom they provide services to identify common barriers to understanding and to target groups of service users with appropriate education and support programs;
- Governments, policy makers and planners can use population-based measurement tools (such as the Adult Literacy and Life Skills Survey) to measure individual health literacy across the population to identify trends and to measure the impact of population-based strategies for health literacy[60].

None of the commonly used tools for measuring individual health literacy provide the 'whole picture' of an individual's capacities; they measure selected domains, which are treated as proxies for an individual's overall capacity.

Textbox 4: Commonly used tools for measuring individual health literacy

The most commonly used tools for measuring individual health literacy are the Test of Functional Health Literacy in Adults (TOFHLA), the Rapid Estimate of Adult Literacy in Medicine (REALM), the Newest Vital Sign (NVS), the Adult Literacy and Life Skills Survey (ALL) and the National Assessment of Adult Literacy (NAAL).

- *TOFHL[611] measures reading fluency. It consists of a 50-item reading comprehension section to measure prose literacy and a 17-item numeracy section to assess an individual's capacity to read and understand actual hospital documents and labelled prescription vials.*
- *REAL[622] is a 66-item word recognition and pronunciation test that measures vocabulary.*

Although these two tests measure different capacities, they are highly correlated with each other and with general vocabulary tests.

- *NVS[63] is a short practical questionnaire that requires the interpretation of health information from a nutritional label.*
- *The Canadian model of the ALL is used by the Australian Bureau of Statistics to assess knowledge and skills at a population level in five domains: prose literacy, document literacy, numeracy, problem solving and health literacy.*

The NAAL is used in the US, and includes a component designed to measure health literacy, consisting of 28 tasks grouped into navigation, clinical and preventive tasks.

In addition to literacy and numeracy skills, a person's baseline knowledge of health and healthcare will influence their individual health literacy. There is currently no commonly used tool for measuring this knowledge.

To date, there has been much less focus on measuring the health literacy environment - that is, how easy or difficult health services are for people to navigate, understand and use. Tools are now being developed that can be used to assess the health literacy environment of individual healthcare organisations. An Australian example of this is the Enliven Organisational Health Literacy Self-Assessment Resource, which was based on the Institute of Medicine's ten attributes of a health-literate organisation (**Textbox 11**, paragraph 6.2.1). An organisational health literacy audit currently being developed by Belfast Healthy Cities is a further example of recent efforts to monitor and benchmark the health literacy environment.

5.0 Where does health literacy fit in?

It can be confusing and difficult to determine where health literacy 'sits' within the policy and practice landscape, due to:

- The breadth of health literacy as a concept;
- The wide variety of policies, practices, concepts and research initiatives that relate to or influence health literacy; and

- The range of potential tools and strategies to measure or address health literacy.

This section provides an overview of the main contextual and conceptual factors that may have an influence on health literacy in Northern Ireland, on what approach should be considered to address health literacy here and on how effective any interventions are likely to be.

5.1 The Health and Social Care context

Recognition that health literacy is fundamental to good health and high quality healthcare is not new in Northern Ireland. Since the turn of the century, a series of local reviews[64] reached similar conclusions about the problems the Health and Social Care system faces, and the range of solutions needed to improve things. Effective partnership working between providers and users of healthcare across the Health and Social Care system is fundamental to these reforms; such partnerships have been identified as one of the key factors for success in large-scale transformation of healthcare. A focus on health literacy is one way of ensuring that consumers are sufficiently informed, equipped and supported to participate in these partnerships. It can also contribute to reducing inequalities in healthcare access and outcomes.

5.2 The education context

The links between school education and health have been of interest to researchers for several decades, and health literacy in particular has been associated with the health-promoting school approach for almost 20 years.[65] From an educational perspective, this is not surprising because there is little doubt that health literacy is a competence that contributes to health skill development and can be facilitated through educational practices.

Many of the core capabilities underpinning school curricula in Northern Ireland (and elsewhere) - literacy, numeracy, critical and creative thinking, and personal and social responsibility - are relevant and related to building health literacy skills. In particular, health literacy and literacy are very closely related. Literacy determines a person's knowledge and abilities to perform in all different domains of society (home, work, communities, politics, etc.) and is recognised as an *"important predictor of community participation, employment, and health status"*[66]. Moreover, according to some researchers[67], *"Literacy skills predict health status even more accurately than education level, income, ethnic background, or any other socio-demographic variable"*. The latest statistics available for Northern Ireland suggests that as many as 1 in 5 of the adult population here have very poor literacy skills[68].

In recent years, the Northern Ireland Executive has implemented initiatives aimed at improving the literacy and numeracy of local children, including the

Delivering Social Change Signature Programme. Under this, an additional 230 recent graduate teachers were to be employed to deliver tuition, where appropriate, for children in primary and post-primary schools who were currently struggling to achieve even basic educational standards.

However, while general literacy is an important determinant of health[69], the concept of health literacy was introduced because it was recognised that people need more than general literacy skills to be able to manage some of the complex health and health system issues that they face[70].

5.3 Social, personal and cultural factors

As noted previously, health literacy can be influenced by a range of personal, social, environmental and cultural factors. Although low individual health literacy can be found across the socio-economic spectrum, people from vulnerable or disadvantaged groups are more likely to have low individual health literacy[71]. Furthermore, having low individual health literacy can exacerbate access and equity issues which people are already experiencing.

Groups at higher risk of low individual health literacy include people from lower socio-economic backgrounds; people with lived experience of mental health problems; older people; people living with disabilities; people from minority ethnic, cultural and linguistic backgrounds; people with drug and alcohol dependencies; people experiencing chronic or complex illness; and people who are homeless, socially isolated or geographically isolated. Personal factors, like a person's previous experience of health and illness and knowledge of their own health condition, will also affect individual health literacy[7].

Individual health literacy may also vary depending on timing and context; for example, if someone is in an unfamiliar place, unwell, stressed or just uncomfortable, this could all affect a their capacity to understand, use, apply and act on information at a specific point in time. Consequently, a person's individual health literacy can vary from day to day.

The same research found that personal preferences will also influence the extent to which a person will want to engage with their healthcare provider and organisation, and the extent to which they want to understand, use, apply and act on health information. Some people may prefer to leave decisions and actions to their healthcare provider, whereas others may seek a more active role in their care (see Section 5.4.2). A person's personal preferences should always inform whether - and how - interventions aimed at improving health literacy are offered or applied to that individual;[92] this is the crux of 'person-centred care' (see Section 5.4.1).

5.4 Related healthcare concepts

Health literacy is linked with several other health and healthcare concepts which are discussed below. These concepts tend to overlap and are often interdependent. Recurring themes across all these concepts include:

- The involvement of patients and clients in decision-making;
- Healthcare providers being aware of the needs and preferences of individual patients and clients; and
- Healthcare providers being proactive and taking steps meet these needs.

5.4.1 Person-centred approaches to care

Person-centred care is an approach to the planning, delivery, and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare providers, patients and families. According to a 2017 policy document published by the Northern Ireland Department of Health[72]:

"Our Health and Social Care system belongs to all of us and we all bring valuable insights to how it can improve. We must work in partnership - patients, service users, families, staff and politicians - in doing so we can co-produce lasting change which benefits us all. Everyone who uses and delivers our Health and Social Care services must be treated with respect, listened to and supported to work as real partners within the HSC system."

Person-centred systems focus on collaboration and partnerships between providers, patients and clients to make sure that the needs and preferences of all are met. Interactive health literacy is important to support effective communication, and an effective health literacy environment is required to make it easier for patients and clients to form partnerships and communicate their needs and preferences.

5.4.2 Patient activation

Patient activation, or the motivation to act on information about health and healthcare, closely interacts with health literacy. A patient can be provided with information in a way that is understandable and that logically leads to a conclusion, but if patients and clients are not motivated, they may not act on the information or make the decision needed.

This lack of action may be a result of patients and clients ceding their right to choose to the healthcare provider – they may prefer not to make the choice. Or it may be that the consequences of *not* acting have not been communicated effectively. Either way, patient activation complements health literacy because both determine the individual's ability and motivation to transform the health information they receive into action. Higher levels of activation are associated with a greater likelihood of engaging in preventive health behaviours, actively seeking information on health and healthcare, and fewer hospital visits[73]

5.4.3 Shared decision-making

Shared decision-making is a collaborative process that allows patients and clients and their healthcare provider to make decisions together about care, considering the best scientific evidence available, as well as the person's values and preferences. Generally, the healthcare provider offers options and describes their risks and benefits. Patients and clients and those close to them discuss these options with the healthcare provider and, taking all information into account, negotiate a care pathway with which they are all comfortable. This process ensures that each person is equipped with a better understanding of the relevant factors and shares responsibility in the decision about how to proceed.

The Northern Ireland Department of Health's policy document, '*Delivering Together*'[72], stated that co-production will empower patients, service users and staff to be partners in the care they receive, with a focus on increased self-management and choice, especially for those with long-term conditions. As such, shared decision-making is reliant on individual health literacy: giving patients and clients understandable information and options about their health and healthcare equips them with the tools they need to share decisions and partner in their own care. Patients can then choose to use these tools to the extent they feel necessary.

6.0 Approaches to addressing health literacy

This section provides an overview of approaches that have been used in different contexts to promote health literacy or address low health literacy. Examples range from national strategies and policies to specific techniques and interventions that have been used in practice to support such efforts. The section is organised by the stakeholder groups or settings in which approaches have been or may be implemented; this reflects the many and varied sources of health information and the wide range of stakeholders with a potential part to play in addressing health literacy.

6.1 Government approaches

By guiding, developing and/or enacting policies, guidelines, regulations and laws that influence the availability of and accessibility of public health information and of education programmes and services, governments are major catalysts for spurring political and community 'traction' for health literacy. As one commentator states: *"Governments should provide supportive environments that foster the growth of health literacy"* by creating *"a voice for health literacy in the political process"*. For this to happen, however, the issue of health literacy must be raised within *"the political agenda and have designated advocates within the political process"*[74]. In addition, government agencies are generally responsible for gathering and storing information on population health literacy, which should form the basis for policy and guidance.

Barriers to health literacy can be reduced by learning from and adapting the approaches adopted by governments elsewhere. Some examples of national policies that touch upon health literacy have been set out in Section 3.2. Other nations, like Scotland and the United States, have developed national action plans with the *exclusive* aim of improving health literacy, with evidence that these policies have been key drivers for improvement.

6.1.1 Scotland

As a starting point, specific actions in Scotland were devised and prioritised by reviewing literature on the effectiveness of health literacy interventions. Ongoing work in other countries with mature health and care systems - such as the Republic of Ireland (Section 3.2.1), the US (Section 6.1.2) and Australia - was also reviewed.

Based on findings, and on a set of underlying concepts and assumptions (**Textbox 5**), four areas of focus were prioritised in Scotland's 2014 health literacy action plan, *'Making it easy'*, in the hope that these could initiate and sustain a movement of health literacy responsiveness within the health and care system:

- 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.

Figure 5: Key assumptions 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.*
- *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.*

In order to meet the main objectives, four strategic actions were developed:

- 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.

The process was also mindful of the need to build in evaluation. Evaluating the impact of health literacy interventions is still a challenging and developing area. Since the main goal was to initiate health literacy action, the evaluative priority in Scotland was to explore what possibilities would emerge and how, rather than focus on specific health, personal or economic outcomes.

In light of policy developments and emerging evidence, the Scottish Government developed a second action plan, '*Making it easier: A health literacy action plan 2017-2025*', published in November 2017. This involved a public consultation on health literacy through Scotland's 'Our Voice' programmes, including a citizens' jury focused on shared decision-making. The aspiration of the new action plan is to expand beyond the initial focus of '*Making it easy*' and to support activity across the whole health and social care landscape, and associated services. To achieve this, it focuses on three concurrent approaches to improve people's confidence, knowledge, understanding and skills around their health and healthcare:

- 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, to embed 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, to mitigate against any potential negative impact, and to avoid barriers to health literacy being created in the first place.

6.1.2 United States

The '*National Action Plan to Improve Health Literacy*' was published in May 2010 by the US Department of Health and Human Services. The Action Plan *"seeks to engage organisations, professionals, policymakers, communities, individuals, and families in a linked, multisector effort to improve health literacy"*[75]. It contained seven goals, each with identified strategies that will enable a variety of organisations and fields to improve health literacy from their particular angle (**Textbox 6**).

Figure 6: The US - A coordinated national approach to improving health literacy

The Department of Health and Human Services in the United States developed the 'National Action Plan to Improve Health Literacy' in 2010. The plan provides a framework for consistent action to address health literacy. It proposes coordinated societal action across seven different areas to improve systems, information communication and education:

***Goal 1**: Develop and disseminate health and safety information that is accurate, accessible and actionable.*

***Goal 2**: Promote changes in the health care delivery system that improve health information, communication, informed decision-making and access to health services.*

***Goal 3**: Incorporate accurate, standards-based and developmentally appropriate health and science information and curriculums in child care and education through to university level.*

***Goal 4**: Support and expand local efforts to provide adult education, English language instruction, and culturally and linguistically appropriate health information services in the community.*

***Goal 5**: Build partnerships, develop guidance and change policies.*

***Goal 6**: Increase basic research and the development, implementation and evaluation of practices and interventions to improve health literacy.*

***Goal 7**: Increase the dissemination and use of evidence-based health literacy practices and interventions.*

This inclusive approach encouraged other sectors outside healthcare to address health literacy. Notably, the Action Plan described how "*education across the lifespan can contribute to a more health-literate population*" by including objectives for early childhood through to university-level education, and even adult literacy education and English language instruction. It also focused on creating partnerships between sectors, which has been a successful overall strategy for addressing health literacy.

While the Action Plan did not dictate any specific policy or mandate any activities, it contained two important components. First, by addressing health literacy from many angles with multiple stakeholders, it positioned health literacy as an important national priority. Advocates from diverse organisations from healthcare to education to research could use the Action Plan to leverage support and buy-in from leadership and funders. Second, in addition to detailed guidance on implementing each of the seven goals, the Action Plan offered a template that organisations could use to create their own internal action plans. As such, it provided a practical framework for organisations to create health literacy policies and interventions.

Between 2010 and 2012, three nationwide discussions about the Action Plan were hosted as part of the '*Health Literacy Discussion List*'. Consultation with *"many different organisations about what exactly they were doing to implement the goals, including state-wide health literacy coalitions, adult education programmes, community health centres, advocacy agencies,*

primary care providers, researchers and others"[108,109,110] revealed extensive and varied activity spurred on by the Action Plan. Activities were geared toward educating audiences throughout the lifespan and improving health system capacity to serve diverse communities. Examples included:

- Maternal and child health organisations creating pregnancy and baby care books written in easy-to-read language;
- Programmes for children in day care centres addressing early health literacy skills through nutrition education units;
- Universities creating health literacy courses for health professionals;
- Adult education programmes creating health literacy curricula to integrate into adult education and English language instruction;
- Hospitals implementing techniques to help patients - especially older adults - to manage their medication regimes; and
- Government agencies putting out more funding calls for research related to health literacy.

The Action Plan also became a common framework for the goals and activities of the health literacy coalitions and initiatives that were forming at the state and local levels around this time. Around half of the 50 US states now have formal health literacy coalitions, which typically aim to bring together a variety of stakeholders to increase health literacy awareness in order to improve health within the state.

So, while the Action Plan was neither a law nor a policy, it lent both government support and specific guidance that catalysed a huge number and range of health literacy interventions. Examples include:

The Plain Writing Act of 2010 requires all federal agencies to follow plain language guidelines in their communications. The goal is to *"improve the effectiveness and accountability of Federal agencies to the public by promoting clear Government communication that the public can understand and use"*. It includes provisions for training staff in plain language writing and overseeing the process of creating or revising all communication to meet the standards. While the Act sent a strong message about the importance of plain language and clear communication, and it was in fact a mandate, it does not seem to have had as significant an impact as other programmes on lowering health literacy-related barriers for most citizens[76].

Healthy People 2020 is a set of national goals and benchmarks around health promotion and disease prevention. It includes a specific objective for improving health literacy, to be measured by how many healthcare providers give instructions to patients in an easy-to-understand format. Other health literacy related objectives in *Healthy people 2020* included increasing or improving:

- The proportion of healthcare providers who have good communication skills;
- Shared decision-making;
- Personalised health information resources; and

- Easy-to-use health websites.

The *Healthy People 2020* objectives supported the Action Plan and the *Plain Writing Act 2010* by providing measures and targets that can be used to track progress on population-level health outcomes and specifically to hold healthcare providers accountable for improving health literacy.

Addressing health literacy in the US began as a grass-roots movement, growing from real needs identified by a wide variety of health and social care professionals struggling to serve vulnerable populations. These needs, and the solutions that were created organically, were the driving force behind the federal policies that were then introduced to provide top-down support. This support has grown significantly over the past decade.

While the laws, mandates and policies have pressed organisations to prioritise health literacy, it has largely been the practical guidance that has helped them to create the programmes and interventions that put health literacy principles into action. The support for health literacy from so many diverse agencies and sectors has helped the US to address this issue from the many different angles that are needed for widespread impact. The fact that several of these agencies stepped up with guidance around the same time - in 2010 - helped to create a 'splash' of awareness that put health literacy firmly in the US national consciousness.

6.2 Health and social care system approaches

6.2.1 Health and social care organisations

As healthcare costs continue to rise, health systems are increasingly pressed to balance quality of care on the one hand and optimal use of dwindling resources on the other. Improving health literacy can support this effort because, as well as equipping individuals to make sound decisions concerning their own health, improved health literacy is shown to reduce use of health services, thereby cutting costs[77] and benefiting the wider healthcare system. This section provides specific examples of how health and social care organisations can support, and have supported, health literacy.

Embedding service user education in care pathways is one method by which health and social care providers can improve health literacy to the benefit of patients/clients. Targeted educational interventions can help people with low health literacy to increase knowledge and understanding of their condition. For example, there is evidence that health education and stress management programmes can improve health outcomes for people with coronary heart disease[78], and that self-management education programmes may lead to small, short-term improvements in participants' self-efficacy, self-rated health and cognitive symptom management[79].

Textbox 7: Flash glucose monitoring - building capacity for diabetes management

Historically, people living with diabetes have monitored their condition and calculated insulin doses using 'snapshots' of blood glucose levels obtained using a conventional blood glucose monitor. In recent years, flash glucose monitoring systems (FGMS) have become increasingly common and are now available on NHS prescription. FGMS consists of a sensor worn just under the skin which records glucose levels continuously. Via a reader, the user can:

- *Scan the sensor to get instantaneous glucose readings, including indications on the direction in which levels are currently moving and a chart showing glucose levels over time;*
- *Explore statistics and trends around their glucose levels, including averages by time of day, percentage of time spent within a target range, etc.*

The device is designed to improve users' understanding of their diabetes and increase their visibility of how their condition 'behaves' at different times and under different conditions. Ultimately, users should be equipped to manage their diabetes more effectively and responsively which should lead to improved long-term health outcomes.

The decision to provide flash glucose monitoring systems on prescription to people with Type I diabetes in Northern Ireland is an example of how learning can be integrated into people's day-to-day management of a condition (**Textbox 7**). **Textbox 8** outlines how HSC organisations have facilitated informed self-management for people living with breast cancer in Northern Ireland.

Textbox 8: Patient education to support self-management in breast cancer care

Advances in treatment mean that more people are living with and beyond cancer, with many having to manage the consequences of cancer treatment. Current models of cancer follow up are not as effective as they could be which leads to increased pressure on the system. For example, a study by the Nuffield Trust showed that, fifteen months after diagnosis, people with cancer had 50% more GP visits, 60% more A&E attendances and 97% more emergency admissions than expected.

To address these issues, Macmillan Cancer Support worked with Health and Social Care bodies in Northern Ireland to develop a new model for cancer follow up, to improve patient's experience, health and wellbeing; improve resource utilisation; and enhance communication and coordination across boundaries. The Transforming Cancer Follow-Up (TCFU) programme was launched in 2012, having been co-produced with people affected by cancer. It introduced risk stratified pathways for breast and prostate cancer, delivered by a multi-disciplinary team.

At the heart of the approach was a new Self-Directed Aftercare (SDA) pathway for breast cancer, whereby patients deemed suitable were discharged from hospital care at the end of their treatment, having been provided with information and training on preventive behaviours and on the signs and symptoms of recurrence. This equipped these patients to self-manage and to re-enter the cancer care system if and when they needed to, rather than attending routine review appointments for five years or longer.

An external evaluation of TCFU was conducted and found that:

- *58% of all new patients with breast cancer were allocated onto the SDA pathway;*
- *79% of patients were made aware of importance of life style changes as opposed to 45% at the programme outset;*
- *67% felt supported to manage the emotional impact of cancer as opposed to 44% at the programme outset.*

Planning and delivering public-facing information campaigns to promote healthy behaviours or to raise awareness of available services largely falls within the remit of Health and Social Care organisations. When managed effectively, such campaigns - which, in Northern Ireland, are typically coordinated by regional HSC organisations like the Public Health Agency (PHA) or Health and Social Care Board (HSCB) - can support health literacy by building health knowledge within the population (or within sub-groups of it). **Textbox 9** provides an example of a regional campaign within Northern Ireland.

Textbox 9: Choose Well - Improving knowledge of available health service options

The Choose Well campaign was launched in November 2013 in response to a number of reports which suggested that the public were not as informed as they could be about the full range of services provided by Trusts in Northern Ireland. The campaign aimed to inform and educate the public about the range of options available from self-care right up to 999, to encourage appropriate use of these services and to re-align demand across the range of services provided. Information was disseminated using television, radio and online advertising, as well as booklets distributed in Trust premises.

An independent evaluation of Choose Well found that the campaign was successful in raising awareness and empowering people to choose more appropriately. However, the Department of Health acknowledged that, based on learning from other campaigns, it takes a number of campaign runs to reinforce messaging and translate increased awareness of appropriate choices into tangible behavioural and cultural change.

Figure 10: Regional Obesity Strategy

Systematic approaches to providing adequate nutritional education and dietary intervention, encouraging regular physical activity, and improving environments and food supply, are needed to prevent obesity and to reduce the increase of obesity-related disorders.

The PHA's work on obesity prevention is based on, 'A Fitter Future for All: The regional framework for preventing and addressing overweight and obesity in Northern Ireland 2012-2022'. The framework sets the strategic direction to tackle this important public health challenge with the aim of empowering the population of Northern Ireland to make healthy choices, reduce the risk of overweight and obesity related diseases and improve health and wellbeing, by creating an environment that supports and promotes a physically active lifestyle and a healthy diet.

To enable successful participation in such health management in the long term, it is recognised that improvement in health literacy will be crucially important. Improved health literacy can nurture the public's knowledge, personal skill and confidence to take action in order to enhance individual and community health by helping to change lifestyles and living conditions.

COVID-19 is unlike previous medical crises, in part because of the public's access to communication technologies. In this context, the information environment can become saturated and overwhelming, despite the best efforts of some media to provide information in a careful and responsible way. People may struggle to 'stem the tide' of information or to judge what they should or should not believe.

Ultimately, there are a few ways professionals conveying formal information on COVID-19 can develop and maintain trust:

- Understanding their audiences (class, age, risk, communication style) and tailoring the message to reach them. This may mean using platforms like social media to impart facts and resources.
- Communicating uncertainty clearly—saying that not all information is available is more effective than speculating or saying nothing.
- Not over- or under-reassuring, but simply laying out risk and potential consequences transparently with the appropriate tone.
- Providing numbers, context, history, and changes to procedure in a timely and straightforward fashion, which can help bolster trust.
- Telling people what they should do and how they should behave to keep themselves and others safe.
- Monitoring social media to understand what questions and knowledge gaps are emerging, and proactively deploying strategies to counter misinformation or address gaps in understanding.

Providing training for Health and Social Care professionals in communication skills / health literacy-friendly practice is another means by which Health and Social Care organisations can address health literacy. The type, intensity and content of education and training required will vary by role, ranging from simple health literacy awareness training to full Advanced Communication Skills training. **Textbox 10** provides examples of health literacy training for Health and Social Care staff in Northern Ireland.

Textbox 10: Health literacy training for healthcare staff in Northern Ireland

Health Literacy Communication Training for Healthcare Professionals

In 2019, Belfast Healthy Cities, in partnership with the Community Development and Health Network, completed the delivery of a Health Literacy Communication Training Programme to seventeen Integrated Care Partnerships across Northern Ireland through the Health and Social Care Board (HSCB) 'Making Every Contact Count' programme.

This programme was designed by University Medical Centre Groningen (UMCG) working with health care professionals across multiple disciplines from the Netherlands, Ireland and Italy as part of IROHLA (Intervention Research On Health Literacy among Ageing population) – a three year European health literacy project. Delivery in Northern Ireland is through a Memorandum of Understanding between Belfast Healthy Cities and UMCG.

The training is a way to help and support Health and Social Care professionals to consider a health literacy approach to ensure more effective communication of health messages. It was targeted at those working in primary care settings across a range of provider organisations and sectors including GPs, practice nurses, practice staff, community pharmacists, community pharmacy staff and those working in the community and voluntary sector.

Introduction to health literacy

This half-day workshop developed by Belfast Healthy Cities; explores the definition of health literacy, the link between health literacy and inequalities and highlights tools and techniques to include health literacy in policy and practice.

To *assure the quality of their own written or visual information*, health and social care organisations may:

- *Develop or adhere to quality standards:* For example, in the UK, The Information Standard (TIS) has been established by NHS England. This is an independent certification scheme for all organisations that provide evidence-based healthcare information to the public. The TIS principles against which information are assessed include the relevance and credibility of its sources and the quality of the end product[80].

  Within Northern Ireland, meanwhile, 'Effective Information and Communication' is one of the five themes in the Department of Health's *'Quality Standards for Health and Social Care'*, which set out the standards that people can expect in their care from HSC. Key standards under this theme relate to clear information and communication principles for staff and service users and the existence of an effective strategy for information and communication[81].

  The ten attributes of a health literate organisation identified in the US National Action Plan to Improve Health Literacy (Section 6.1.2) are a

further useful point of reference for Health and Social Care organisations (**Textbox 11**).

Textbox 11: Ten attributes of a health-literate organisation

1. *Has leadership that makes health literacy integral to the mission, structure and operations of the healthcare organisation*
2. *Integrates health literacy into planning, evaluation measures, patient safety and quality improvement*
3. *Prepares the workforce to be health literate, and monitors progress*
4. *Includes populations served by the organisation in the design, implementation and evaluation of health information and services*
5. *Meets the needs of populations with a range of health literacy skills while avoiding stigmatisation*
6. *Uses health literacy strategies in interpersonal communication, and confirms understanding at all points of contact*
7. *Provides easy access to health information and services, and navigation assistance*
8. *Designs and distributes print, audio-visual and social media content that is easy to understand and act on*
9. *Addresses health literacy in high-risk situations, including care transitions and information about medicines*
10. *Communicates clearly about what is covered by health plans and what individuals will have to pay for services*

Making services easier for users to navigate also helps to improve the health literacy environment. 'Way-finding' is the concept of helping people find their way from one place to another and affects how people reach and access health services. The ease – or difficulty – of that process can cause stress and frustration for consumers, their families and staff.

Investment in understanding consumers' experiences of way-finding HSC services throughout the healthcare journey can help to identify barriers to health literacy within services, and areas where improvements to service design and delivery, or to consumer information may be required.

Attribute 7 of the US Action Plan (**Textbox 12**) describes the elements of a health literate organisation – those that provide easy access to health information and services and navigation assistance. The self-assessment process for Attribute 7 asks an organisation to identify whether it:

- Has facilities with features to help consumers find their way
- Uses easily understood language and symbols on all signage
- Uses signage in commonly spoken languages for the region
- Responds to navigational queries in an effective manner without assuming things such as map-reading skills or car ownership
- Assists consumers to complete relevant forms and documents.

Guidance produced for the NHS in 2005 (*Wayfinding – Effective wayfinding and signing systems: guidance for healthcare facilities, TSO, 2005)* explains the main factors that affect how people successfully find their way around healthcare facilities. Rather than setting out a series of rules that must be followed by everyone, the guidance recognises that each NHS trust, and each site, has its own problems and priorities. It provides guidance to enable trusts to develop tailored solutions to suit their own situation. Where appropriate, it includes recommendations, and describes good and bad practice, highlighting approaches to avoid as well as ones to adopt. It also provides a checklist and survey questionnaire sheets which can be used to evaluate sites.

- *Gain accreditation:* Several organisations provide accreditations for high quality health information in the UK. The National Institute for Health and Clinical Excellence conducts accreditation of guidance and advice development processes[82]. The Crystal Mark is an internationally-recognised mark awarded to individual documents based on their clarity and use of 'plain English'. The Department of Health in Northern Ireland has been awarded the Crystal Mark.

Involving service users, carers and the public in the production and testing of health information is another important part of the Health and Social Care system's remit around health literacy. This is reflected by:

- The inclusion of service user/carer participation within the Quality Standards for Health and Social Care in Northern Ireland;
- The requirement in NHS England's TIS principles that *"end users are involved at the outset and throughout in the production"* of health information; and
- The recent publication of the *'Co-Production Guide for Northern Ireland'*[83] and its ambition that, by 2026, HSC organisations and staff will *"value and embed co-design and co-delivery as a core practice in improving health and wellbeing"*.

Personal and Public Involvement (PPI) is also a legal responsibility of HSC organisations (**Textbox 12**).

Textbox 12: Personal and Public Involvement in Northern Ireland

Personal and Public Involvement (PPI) is a process whereby service users, carers and the public are empowered and enabled to inform and influence the commissioning, planning, delivery and evaluation of services in ways that are relevant and meaningful to them. People have a right to be involved and they increasingly expect to be actively involved in decisions that affect them.

PPI is a statutory responsibility as detailed in the HSC (Reform) Act (NI) 2009 through the Statutory Duty to Involve and Consult. Each Health and Social Care organisation to which the legislation applies is required to involve individuals in the planning and delivery of Health and Social Care (HSC) Services. Specifically, sections 19 and 20 of the above legislation require that service users and carers are involved in and consulted on:

- *The planning of the provision of care;*
- *The development and consideration of proposals for change in the way that care is provided; and*
- *Decisions that affect the provision of care.*

Supporting the public and service users to assess the reliability of information that they have been given - or that they have sourced themselves - about health and healthcare is another area into which health and social care organisations have put effort. Information about health and healthcare has become increasingly abundant and accessible in the online era. It has, in turn, become much more difficult for the public to assess the quality and reliability of information, which, depending on the source, may be unreliable, incomplete or contradictory. Determining the reliability of information can be a particular problem for those with low health literacy. **Textbox 13** describes a decision support tool funded by NHS England to address this issue.

Textbox 13: DISCERN - Supporting the public to assess the quality of information

There is currently a lot of information available on healthcare treatment choices available from a variety of sources, including the internet. Not all of this information is high quality, and only a small proportion is based on good evidence. Many of the available sources provide inaccurate or confusing advice, and it may be hard to know which information to use and which to discard.

The DISCERN on the Internet Project is a UK project established in 1999 and funded by the NHS Executive Research and Development Programme, which seeks to help people work out how reliable a piece of health information might be. DISCERN is a brief questionnaire which provides consumers with a valid and reliable way of assessing the quality of written information on treatment choices for a health problem. DISCERN can also be used by authors and publishers of information on treatment choices as a guide to the standard that users are entitled to expect.

Web page: www.discern.org.uk/index.php

6.2.2 Health and social care professionals

Although health information is now widely available from a variety of sources, people still tend to rely on healthcare providers for information about their health and health care, mainly using other sources (e.g. social media) to supplement this information[84].

Even when people rely on official sources of information, they often have difficulty recalling, understanding or applying what their healthcare providers tell them, with some evidence suggesting that people are unable to recall between 40 and 80 percent of the medical information recently given to them by their healthcare provider[85]. This hampers patient satisfaction and adherence to medical recommendations, thus compromising patient safety and health outcomes[86]. The amount of health information forgotten by people has been shown to be directly related to the amount of information presented, the person's medical knowledge, anxiety level and potentially their age[87].

In this context, healthcare and social care professionals can, for their part, have a significant and direct influence on the health literacy demand that is placed on service users, through the way they communicate and present information to patients and clients so that it is as meaningful, relevant and useable as possible.

According to the Australian Commission on Safety and Quality in Health Care's *'National Statement on Health Literacy'*[88], healthcare providers can:

- Recognise the needs and preferences of individual patients and tailor their communication style to the person's situation;
- Assume that most people will have difficulty understanding and applying complex health information and concepts;
- Use a range of interpersonal communication strategies to confirm information has been delivered and received effectively (see **Textboxes 14 and 15**);
- Encourage people to speak up if they have difficulty understanding the information provided;
- Communicate risk information about treatment options to people using methods that are known to be effective;
- Participate in improvement projects aimed at reducing barriers to health literacy within the healthcare organisation's physical environment; and
- Participate in health literacy education and training, if available.

The second of these points underpins much of what is considered good practice in health literacy-friendly patient/client care. A number of studies highlight a mismatch between the information that the healthcare provider thinks they are communicating, what they assume the patient/client is capable of understanding, and what the patient/client is actually understanding and recalling[89,90,91]. The priorities for healthcare providers should therefore be to avoid making assumptions about the recipient's health literacy level and to tailor information and communication to the individual,

based on circumstances, prior experience and feedback from the patient/client.

Health Literacy Universal Precautions are another approach which was first put into operation in 2010 to address the complex demands faced by patients in the US. The approach asks that all health care organisations and professionals assume that all patients may have difficulty comprehending health information and accessing services. The Universal Precautions Toolkit[120] provides guidance for healthcare organisations and professionals to conduct a baseline organisational assessment, develop a plan for addressing health literacy, take steps to improve spoken communication (e.g., regular use of Teach Back), improve written patient education materials and signage, and enhance patient empowerment and self-management.

As discussed in Section 6.1.1, Scotland has been at the forefront in developing innovative approaches to improving health literacy; this includes techniques for optimising communication between service staff and service users/carers. Under its national plan for health literacy[92], changes to practice have been kept simple, focussing on the five tools and practices presented in **Textbox 14**.

Textbox 14: Five simple techniques from Scotland's health literacy action plan

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 that their intelligence 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 can 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 support people to 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 number of other techniques have been shown to increase uptake and recall of health information at the level of individual interactions between service users and healthcare professionals (**Textbox 15**).

Textbox 15: Other techniques to increase uptake and recall of health information

- *Giving people **multiple opportunities to access health information**, to ask questions and to confirm their understanding of information. This can be done by providing information in different formats, scheduling follow-up appointments, providing web links or putting consumers in touch with peer support groups;*

- *Using **plain language** - and avoiding jargon - when communicating health information, instructions and choices;*

- ***Decision aids**, which have been shown to lead to improvements in knowledge and understanding of screening, prevention and treatment options[93], and are often used to clarify the likelihood of risks and benefits of different care options;*

- ***Shared decision-making processes** (Section 5.4.3), which have been seen as the foundation of patient- centred care, are associated with favourable health outcomes[94].*

Textbox 16: 'It's Okay to ask': getting the most out of your health care appointments

'It's okay to ask' is a public information campaign delivered by Health and Social Care in Northern Ireland, which aims to equip and encourage service users to get the most out of their healthcare or social care appointments. Central to the campaign is the below 'checklist' resource:

Before you leave your appointment make sure that:

- *You understand everything that has been said*
- *You've covered everything on your list*
- *You know what should happen next – and when. Write it down.*

Ask:

- *Who to contact if you have further problems or questions*
- *For copies of letters written about you if you want to see them. You are entitled to see them. There may be a charge for providing them.*

After your appointment don't forget to:

- *Write down what you discussed and what should happen next, and keep your notes*
- *Ask what's happening if you don't receive your appointment details*
- *Ask for the results of any test. If you don't get the results when you expect – ask for them. And it's okay to ask what the results mean.*

NHS inform Helpline on 0800 22 44 88. This information is also available from the following websites:
www.nhsinform.co.uk www.hris.org.uk

Figure 17: HSC Hospital Passport

The *HSC Hospital Passport* was developed in 2019 by the PHA and Northern Ireland's Regional General Hospital Forum for Learning Disability. It is a form for people with a learning disability to complete (with or without help) and present to staff every time they have contact with a general hospital. It gives staff important information on the person and how they prefer to communicate, their medical history and any support they might need while in hospital. Staff can then make any reasonable adjustments in order to provide the best possible care for people with a learning disability.

The version of the Hospital Passport to fill in electronically allows patients or carers to type their details directly into the document before saving, printing off and bringing to hospital. There are also Guidance notes to help those completing the *HSC Hospital Passport*. These publications were distributed through HSCTs and the community and voluntary sector.

6.2.3 Professional bodies

The associations that represent and support health and social care professions (e.g. Royal College of Nursing, British Dental Association) have the potential to influence their membership and, specifically, to shape the priorities for the development of their professional group. In this role, these types of organisations can support health literacy by:

- Leading and coordinating action on health literacy within their profession;
- Developing policies and position statements on health literacy;
- Encouraging and supporting professional development opportunities and influencing education programmes for healthcare providers in communication, health literacy and person-centred practice in general (**Textbox 16**); and
- Collaborating across the healthcare sector on health literacy activity, including sharing strategies and approaches across professions and sectors.

Textbox 16: Royal College of General Practitioners Curriculum; Core Competence - 'Establish an effective partnership with patients'

Use the general practice consultation to bring about an effective doctor-patient relationship, with respect for your patient's autonomy, for example, by:

- *Adopting a **patient-centred consultation model*** that explores your patient's ideas, concerns and expectations, integrates your agenda as a doctor, finds common ground and negotiates a mutual plan for the future*
- ***Communicating findings in a comprehensible way**, helping patients to reflect on their own concepts and finding common ground for further decision-making*
- ***Providing explanations that are relevant and understandable** to patients and carers, **using language appropriate to the patient's understanding***
- ***Exploring the patient's and carer's understanding** of what has taken place in the consultation*
- ***Providing easy access to professional interpreters when required**, being aware of their role in the consultation and **using a variety of communication techniques and materials to adapt explanations to the needs of the patient and carer***
- ***Enhancing health literacy in patients** from a range of backgrounds, by **providing tailored information, facilitating communication and checking understanding as appropriate***

**Emphases added by the author*

6.3 Education sector approaches

As discussed in Section 5.2, schools can play a crucial role in developing health literacy skills[95,96]. In particular, general literacy and numeracy, which are core to school curricula in Northern Ireland[97] and elsewhere, influence people's skills and capacity to make informed decisions about health and healthcare.

However, health-specific education from early childhood is also important in laying the foundations for basic hygiene, good eating habits, sun protection and other preventive behaviours. From pre-school through primary and secondary school, children are taught about health and healthcare as part of a wider curriculum around developing life and social skills. As such, partnership with the education sector is vital to achieving health literacy in the population.

As early as 2013, the WHO published their report "Health literacy: the solid facts", which recommended strengthening the health literacy of school-aged

children by including health literacy as a core component in the whole school approach[98]. In addition, the OECD report "The Future of Education and Skills 2030" named health literacy as a core competence for the 21st century and a critical target for education in order to empower citizens, increasing their control over their own health[99].

The report on European Standards and Indicators for Health Promoting Schools by the Schools for Health in Europe Network Foundation (SHE) emphasises that health literacy is a valuable teaching and learning objective for European schools[100]. The report also outlines challenges and opportunities for addressing health literacy of pupils within the whole educational sector. In particular, the report prioritises:

- Positioning health literacy in schools within the wider WHO health literacy strategy;
- Highlighting the critical role of the education sector and necessary resources;
- Providing key health literacy learning objectives and indicators; and
- Drafting an action agenda in order to implement monitoring of health literacy in schools.

The 5th European Conference on Health Promoting Schools has also emphasised that health literacy should not be dealt with in isolation, but should be integrated into the holistic framework of the Health Promoting Schools approach[101]. In recent years, there have been numerous attempts to define the core dimensions and fields of action of Health Promoting Schools. A common theme across models has been the holistic approach of moving beyond individual behavioural change towards organisational change, including strengthening of interpersonal relationships, school management, policy structures, and teaching and learning conditions. By addressing the whole school environment, the individual health literacy competencies of pupils and staff, as well as the organisational health literacy capacities within the school – including the wider school community – can be addressed[102].

In terms of specific educational interventions for health literacy, in the late 1990s, the WHO developed the Global Schools Initiative, which was based on the Ottawa Charter and focused on supporting the development of health-promoting schools[102]. **Textbox 17** describes how the Initiative was implemented in Germany.

Textbox 17: 'Health-promoting schools' in Germany

Since the early 2000s, Bertelsmann Stiftung's programmes - Anschub.de (Alliance for Healthy Schools and Education in Germany) and Kitas bewegen ("good and healthy kindergartens") - have been implemented in several regional education ministries in Germany through mixed public-private partnerships.

The programmes link health and education, carrying out interventions to achieve long-lasting improvement in the quality of education and learning within an overall context of children's development. Indicators of success include various aspects of the

learning and teaching process; leadership and management; and the school climate and culture.

The health-promoting schools model has also informed the development of a local framework in Northern Ireland, which takes into account the physical, social and emotional needs of all members of the school community. Other stand-alone health-based initiatives that teach health literacy skills within the formal education context in Northern Ireland include programmes such as MindMatters and KidsMatter.

More recently, the Public Health Agency, has introduced ‘e-Bug’, a free, online educational science resource covering the topics of microbiology, hygiene and health. It teaches children and young adults in Key Stage 1 to Key Stage 5 about microorganisms and the spread, prevention and treatment of infection. Belfast Healthy Cities is currently piloting a Self-Care Pharmacy schools resource which aims to improve pupils’ knowledge and understanding of self-care for minor ailments through a health literacy approach’.

Further examples of health literacy approaches in the education sector may be found among the outcomes of the US National Action Plan for Health Literacy (Section 6.1.2). These include the introduction of initiatives for children in day-care centres that addressed early health literacy skills through nutrition education units, health literacy courses for health professionals delivered within universities, as well as the addition of health literacy materials into the curricula for adult education and English language instruction.

Education providers may also partner with non-statutory organisations to provide programmes to improve health literacy, by raising awareness and promoting healthy behaviours. For example, Cancer Focus NI has been working with schools in Northern Ireland for almost 50 years, using age-appropriate methods and relatable characters (**Textbox 18**).

Textbox 18: Cancer Focus NI - Phased health education in primary schools

Cancer Focus NI's Schools Health Education Package (SHEP) is a primary school package (for all year groups from nursery to P7) which delivers key health messages relating to health promotion and cancer prevention. SHEP aims to educate children about the importance of a healthy lifestyle including healthy eating, physical activity, sun safety and the dangers of smoking.

Nursery: Bernard the Bear - *Demonstrates to pupils how to stay safe in the sun, choose healthy foods when helping with the grocery shopping and exercise when outdoors.*

P1: Genevieve and the Farmyard Olympics - *Uses a traffic light games to encourage pupils to eat healthy foods and have daily exercise.*

P2: Starring Genevieve - *Reinforces the healthy eating message and uses storytelling and interactive learning to emphasise messages about sleep and healthy bodies.*

P3: Fit Factor - *Pupils become 'Fit Factor Superheroes' learning to differentiate between light, moderate and intense activity and reach their target of 60 mins physical activity per day.*

P4: Food Detectives - *Pupils become 'Food Detectives' when investigating the content of processed foods and can detect their fat, sugar and salt content.*

P5: Sun Scientist - *Uses ultra-violet beads to investigate the effect of the sun on our skin; introduces the 'Slip, Slap, Slop, Slide, Shade' approach to sun safety.*

P6: Smokebusters Programme (A) - *Pupils learn about second-hand smoke and how to avoid it. They become aware of addiction to substances and develop skills to exercise self-control.*

P7: Smokebusters Programme (B) - *The harmful effects of cigarette chemicals are highlighted, role play is used to empower pupils to resist experimentation and pupils help achieve smoke-free environments*

6.4 Business / employer approaches

Improving health literacy in the workplace - and particularly on sites or within professions with elevated risk of physical injury - can bring about two benefits:

- Enhanced employee safety on the job; and
- Improved employee skills for accessing and understanding the information required to manage personal and family health on a day-to-day basis.

Johnson & Johnson provides a case study in how a business can, through sustained effort, address health literacy, and how this can contribute to

improving the health of a workforce as part of a wider suite of health promotion initiatives (**Textbox 19**).

Textbox 19: Johnson & Johnson Workplace Wellness programme

Since 1979, Johnson & Johnson have developed and implemented a comprehensive, holistic, onsite wellness programme for their employees. This programme is accessible by more than 135,000 employees worldwide and includes the following features:

- *Financial incentives for employees to complete a health risk assessment and counselling process;*
- *Onsite health education and health coaching, with employees able to access health services including stress management and wellness coaching and instant biometric health screenings such as height, weight, body mass index, blood glucose testing and cholesterol testing;*
- *Access to fitness facilities and exercise rooms;*
- *Vending machines that offer healthy snack and beverage choices;*
- *Smoke-free campuses; and*
- *Personalised health referrals for employees who need ongoing assistance for illness and managing risks.*

Evaluations of the programme conducted from 1995–1999 and again from 2007–2009 have shown high staff participation in the programme, lower corporate healthcare spending and lower employee absenteeism. Risk factors for employee health have also reduced significantly, including sedentary behaviour (from 39% to 20%), smoking (from 12% to 4%), high blood pressure (from 14% to 6%) and high cholesterol (from 19% to 5%).

In 2016, Health Matters (Health & Safety) Ltd announced a new contract with the PHA to provide and co-ordinate an effective Workplace Health and Wellbeing support service, to any business located within the Southern Trust, South Eastern Trust and Belfast Trust regions. The contract involves Health Matters engaging with local businesses, providing them with free support, educational workshops and training programmes. The ultimate aim of the initiative is to seek ongoing commitment to improve the health, safety and well-being of employees within the workplace setting.

6.5 Community-based approaches

For many people in Northern Ireland and elsewhere, their local community is a cornerstone of their lives. Communities can serve valuable functions in supporting people and promoting social interaction for those who otherwise may not have such opportunities; they may also serve as a source of information or a gateway to local services for their members. As such, the community can offer many opportunities for improving the health literacy of

the local population, e.g. community groups or community-based initiatives to provide information and advice to people on accessing services, lifestyle behaviours and health management (**Textbox 20**). In this way, community organisations have an important role to play in addressing individual health literacy.

Figure 20: Community health promotion initiatives aimed at hair salon workers

Bad Hand Day

In 2006, the UK Health and Safety Executive targeted workers in hairdressing salons with efforts to promote general hand hygiene, prevent influenza and reduce the occupational hazard of skin problems as a result of chemicals or inadequate drying. Keeping written information to a minimum, 'Bad Hand Day' packs contained a simple leaflet, poster, stickers and fridge magnets (all delivered by post following a media campaign), with a wider campaign including posters in trade outlets and trade journals and education sessions in training colleges.

Heads Up!

In eastern England, the 'Heads Up!' campaign made use of the salon setting and salon workers' relationships and interactions with clients to raise the issue of mental health. 'Heads Up!' was part of 'Time to Change', a UK-wide 'social movement' to tackle mental health stigma. The workers were able to direct clients to materials and service information made available in the salon relevant to topics that arose in conversation.

In November 2020, Northern Ireland's Community Development Health Network (CDHN) ran a three-hour facilitated online training programme which aimed to improve health literacy understanding and skills for those supporting people in the community.

Participants could learn more about what health literacy is, how to navigate the healthcare system, the community pharmacy offering and how to self-care. The learning outcomes expected from the course were:

1. Increased understanding of health literacy and why it is important
2. Increased understanding of Health and Social Care services (including community pharmacy) and knowledge of choosing the right service at the right time
3. Increased awareness of where to access reliable sources of health information and how to identify misinformation and fake news.

Social prescribing is another important advance in supporting health literacy within communities. Through social prescribing, GPs, nurses and other primary care professionals can refer people to a range of local, non-clinical services in addition to appropriate medical care. It aims to address people's needs in a holistic way and also to help support individuals to take greater control of their own health.

Social prescribing schemes can involve a variety of activities provided by voluntary and community sector organisations. Examples include volunteering, arts activities, group learning, gardening, befriending, cookery, healthy eating advice and a range of physical activities.

There are many different models for social prescribing, but most involve a link worker or navigator who works with people to access local sources of support.

Social prescribing initiatives delivered by Integrated Care Partnerships include:

- Belfast's Connected Community care service which offers a single point of access through which GPs and Trust social work community teams can refer people to community and voluntary groups close to their home so they can remain independent and have a good quality of life.
- The IMPACTAgewell® (Involving Many to Prescribe Alternative Care Together to Age Well) initiative is a community development approach to support and improve the health and wellbeing of older people aged 65 and over, by integrating health services and linking them with sources of support available within the local community.
- The social prescribing scheme in the Western area, offering older people who suffer from loneliness, bereavement and anxiety a chance to link up with a range of activities within their local community

Libraries hold a wealth of information and provide a range of free services to consumers of all ages and backgrounds. Personnel routinely help patrons search for and obtain useful information on many topics, so libraries have significant potential as a catalyst for health promotion and improved health literacy. Unfortunately, this potential remains largely untapped. Specialised training and ongoing support in health literacy could give staff the added tools required to tailor health information to the specific needs of patrons and identify the barriers to meeting these needs[103].

Much research has shown that ***mass media*** can have both health-compromising and health promoting effects on population health behaviour[104]. The positive potential of the media lie in their capacity for providing health information, leadership in health-promoting norms and lifestyles, and campaigns to help reduce risk behaviours[105]. Thus, while the negative influences of the media on public health must be recognised, its great potential for positive influence should not be overlooked.

7.0 Towards an action plan for health literacy in Northern Ireland

As discussed, the purpose of this paper is to stimulate discussion about actions that can be taken to increase individual health literacy and improve the health literacy environment in Northern Ireland. Based on the findings of this review, three fundamental areas for action have been identified for improving Northern Ireland's responsiveness to the issue of health literacy:

- Action Area 1: **Develop knowledge** - Develop and maintain an extensive repository of knowledge, providing access to research and practice-based evidence on effective and proven ways to improve health literacy;
- Action Area 2: **Promote effective communication** - Develop and implement communication strategies to influence key stakeholders by conveying the importance of health literacy. Develop and provide learning opportunities that enhance the knowledge, understanding and abilities of the public and private sector workforce, professionals and community members in their efforts to support and promote integrated health literacy;
- Action Area 3: **Build infrastructure and partnerships** - Allocate sufficient fiscal, human, organisational and physical resources to support and sustain a coordinated effort to build the partnerships and implement the activities outlined in the Action Plan.

The remainder of the current section briefly sets out a menu of proposals for a systematic approach to addressing health literacy in Northern Ireland, based on the research discussed in this report so far, and again organised by the Action Areas and by the different stakeholder groups or sectors within which action is required. Alongside each action, we provide:

- A priority level, estimating how urgently action is needed; and
- References to the evidence/precedent upon which it is based within this report.

7.1 Actions for regional and local government

Regional and local government, including Department of Health			
Action Area	**Action**	**Priority**	**Evidence / Precedent**
1. Develop knowledge	*Conduct a wide-scale review to identify existing, emerging and promising health literacy practices, with a particular focus on interventions to benefit those groups most at risk of low health literacy (children/young people, older adults, lower socio-economic backgrounds, migrants)* *Act as regional 'curator' for the resulting portfolio of interventions and key contacts*	High	Section 6.1.1
	Conduct a public consultation on how best to increase awareness of health literacy and to actually improve health literacy (individual and environmental)	Medium	Section 6.1.1 Section
	Develop, implement or refine methods for monitoring and improving health literacy levels across Northern Ireland: • Develop questions to gauge health literacy, for inclusion in recurring regional and local surveys, e.g. annual Health Survey of Northern Ireland • Partner with regional and local organisations - e.g. universities and charities - to support the development and evaluation of 'new' research and interventions around health literacy	Medium	Section 4.1 Section 4.3 Section 3.2.1 Section 6.1.2
	Use the evidence generated through the above actions to identify areas/populations most 'at risk' of limited health literacy and target interventions and resources accordingly	High	
2. Promote effective communication	*Reinforcing the importance of health literacy - and its potential for improving health outcomes and reducing costs - among policy makers, decision makers and other government staff:* • Ensure the application of government guidelines on clear communication and use of language, for example, Plain English and Crystal Mark • Develop, deliver and evaluate health literacy training for staff across regional and local government - as part of induction or retrospectively for existing staff • Explore using technology for internal dissemination of health literacy-related content (via webinars, blogs, social media)	Medium	Section 6.1.2 Section 3.2.3
	Develop and deliver health literacy awareness-raising campaigns for different sectors – business, education, civil service	Low	Section 6.2.1

Regional and local government, including Department of Health			
	Identify effective tools to support the public in assessing publicly available health information and promote accordingly (e.g. the 'fact-checking' tool developed by the CDHN; survey on sourcing health information carried out as part of Pharmact Self-Care initiative)	Medium	Section 6.2.1
3. Build infrastructure and partnerships	*Develop infrastructure in regional and local government to adequately support health literacy initiatives* • Consider establishing a dedicated regional 'centre of excellence' to coordinate and lead health literacy activities around awareness raising, training and development, knowledge transfer, etc. • Allocate the required human resources to promote and improve health literacy in Northern Ireland	High	
	Continue to support and collaborate with the Regional Health Literacy Forum to transfer knowledge on health literacy across HSC	Medium	
	Organise an annual regional health literacy conference, involving researchers, service users/carers, practitioners and policy makers, potentially to tie in with Health Literacy Month each October	Medium	
	Incorporate health literacy into regional strategic plans (e.g. the review of Making Life Better/Age Friendly strategies) and grant funding calls/awards	High	Section 6.1.2
	Review the 2006 Quality Standards for Health and Social Care and, in particular, the content of Theme 8, 'Effective Communication and Information'; revise accordingly to ensure relevance to the current Health and Social Care context	Medium	Section 6.2.1

7.2 Actions for the Health and Social Care system

Health and Social Care system			
Action Area	**Action**	**Priority**	**Evidence / Precedent**
1. Develop knowledge	*Develop and implement tools for assessing health literacy levels of service users/carers at the point of care delivery (e.g. Universal Precautions)* • Analyse health literacy data by condition, Trust, demographics - and at the level of the Northern Ireland population - to inform the design of health literacy initiatives and interventions *Develop and implement tools for gauging HSC staff's baseline health literacy knowledge and skills*	High	Section 4.1 Section 4.3 Section 6.2.2
2. Promote effective communication	*Optimise written and visual HSC information for service users/carers to ensure it is as meaningful and useful as possible, based on relevance, clarity of language, layout, accessibility, quality of translation, etc.* • Review and revise - in partnership with service users/carers - existing HSC information resources according to health literacy principles • Establish processes for co-producing all new HSC information resources with relevant service users, carers or people with lived experience, according to health literacy principles	High	Section 6.2.1
	Provide HSC staff with training opportunities to improve their knowledge around health literacy, communication skills and cultural competency *Promote existing guidance documents for HSC staff outlining standards and good practice in communication*	High	Section 6.1.2 Section 6.2.1 Section 6.2.2
	Based on individual service users' recorded health literacy levels: • Encourage HSC staff to consider the best communication style, language and techniques and to tailor patient/client interactions accordingly • Continue to explore techniques for person-centred appointment processes, e.g. providing tailored pre-appointment information, discharge follow-up calls, flexible communication media	High	Section 5.4.1 Section 6.2.2
	In designing or developing care pathways, consider opportunities to embed patient education or to build capacity for self-management	Medium	Section 6.2.1

Health and Social Care system			
Action Area	**Action**	**Priority**	**Evidence / Precedent**
3. Build infrastructure and partnerships	*Enhance cross-disciplinary partnerships within and outside of HSC organisations* *Build networks with business, community and faith-based organisations and with community-based statutory services (e.g. libraries, social services) to increase opportunities for*: • HSC 'outreach' activity to deliver high quality health information / education at the right time, in the right place, by the right person to maximise impact • 'Inreach' bringing community adult education experts into HSC settings to deliver training to staff	Medium	Section 6.2.1
	Create patient-friendly environments that support clear communication, ease of comprehension and seamless navigation through and between Health and Social Care services • Create welcoming and shame-free environments with effective signage and help always on hand • Tailor architecture, imagery and language within health environments to the community being served	High	Section 6.2.1
	Consider establishing a benchmarking / accreditation scheme to recognise organisations as 'health literacy friendly', based on assessment of written information provided, environment(s) and communication practices	Medium	Section 6.2.1

7.3 Actions for the education sector

Education sector			
Action Area	**Action**	**Priority**	**Evidence / Precedent**
1. Develop knowledge	*Further and Higher Education Institutions* • Identify and address gaps in health literacy evidence by prioritising and conducting research in key areas, e.g. determinants / geographical distribution / cost of low health literacy in Northern Ireland • Develop rigorous and practicable instruments for assessing (a) health literacy levels in service users/carers and (b) HSC staff's health literacy knowledge and skills • Draw on extant literature, theory and models from relevant disciplines to develop, pilot and evaluate innovative health literacy interventions in partnership with HSC and the community • Integrate health education / promotion content in curricula for all primary and secondary teaching courses (pre- and post-qualification)	Medium	Section 6.1.1 Section 6.2.1
	Primary and Secondary Education System • Include health education and promotion in curricula for all primary and secondary education • Provide opportunities for primary and secondary teachers to undertake training on the link between early childhood literacy and health literacy	Low	Section 6.1.2 Section 6.2.1 Section 6.3
2. Promote effective communication	*Higher Education Institutions* • Integrate health literacy content in undergraduate curricula for all trainee Health and Social Care professionals • Prioritise disseminating outputs from health literacy research and evaluation to relevant HSC staff and focus on 'operationalising' research	Medium	Section 6.1.2
3. Build infrastructure and partnerships	*Primary and Secondary Education System* • Create a standalone, certified competence framework in health education for primary / secondary school teachers	Medium	
	Participate in forums for research and practice communities to collaborate and transfer knowledge on health literacy	Medium	
	Develop partnerships with service user groups and HSC stakeholders to ensure that health literacy training, interventions, measures and research projects are co-produced and carried out in partnership	Medium	

7.4 Actions for business and employers

Business and employers			
Action Area	**Action**	**Priority**	**Evidence / Precedent**
2. Promote effective communication	*Resource - and release time for - training to improve employees' skills in seeking information and making decisions about their health* *Provide general health information resources in the workplace that are easily understood, relevant and appropriate to staff*	Low	Section 6.4
3. Build infrastructure and partnerships	*Partner and consult with health information producers / providers (e.g. PHA, charities, community organisations) in developing or adapting health information resources*	Low	Section 6.4

7.5 Actions for the community and voluntary sector

Community and voluntary sector			
Action Area	**Action**	**Priority**	**Evidence / Precedent**
1. Develop knowledge	*Develop and deliver information / training sessions to the groups or communities they represent to promote health literacy, preventive behaviours and awareness of available services*	Medium	
2. Promote effective communication	*Improve how health information is communicated to the groups or communities they represent, through ongoing training of HSC staff to be as 'culturally competent' as possible*	Medium	
3. Build infrastructure and partnerships	*Partner with HSC organisations to ensure that initiatives / campaigns around health promotion and disease prevention are appropriate and accessible to the groups or communities they represent*	Medium	Section 6.3

8.0 Conclusion and next steps

The primary aims of this report have been to establish the case for a 'health literate' Northern Ireland and to suggest some steps towards achieving this. It proposes a range of individual and collective actions that can be taken within and across each of the identified stakeholder groups / sectors/individuals to positively influence health literacy and the determinants of health. Some of these actions are about sustaining or spreading existing work, but many are aspirational. Nonetheless, it is hoped that they can, at the very least, stimulate discussion and inspire key stakeholders in Northern Ireland to commit to tangible action on health literacy.

It would be easy to begin this process by focusing on the task of distributing more information to more people. However, health literacy interventions must move beyond this to focus, also, on: the ways in which information is shaped and conveyed; how and by whom it is accessed; how it is critically analysed; and how it can be more effectively used to bring about genuine change at the individual and community levels.

Transforming the actions outlined in this document into meaningful change will primarily require the sustained involvement and commitment of all those who work within the Health and Social Care system, as well as others in the education (youth and adult learning), community and business sectors. With this understanding, the following tenets should be incorporated into all efforts to support the vision which has been outlined:

- A participatory approach should be strived for, so as to meaningfully engage all relevant disciplines, professions and population groups as equal partners in creating, planning, implementing and evaluating initiatives;
- The most innovative and evidence-based health literacy programmes, policies and services available must be sought out and adopted or adapted to the Northern Irish context;
- Ongoing evaluation must be incorporated into all new activities and initiatives, in order to evidence outcomes, identify areas for improvement and determine what practices should or should not be replicated or rolled out;
- It is widely accepted that health literacy is determined by the individual *and* by the environment where they exist and with which they interact. Every approach selected or change enacted in order to improve health literacy - including policies, physical settings and processes - must be cognisant and reflective of this.

Health literacy is a relatively new concept and further research can help to explore its key determinants and identify ways of measuring health literacy levels across Northern Ireland's population, among at-risk groups and across different health issues. By helping to improve understanding of health

literacy, such research should complement and inform efforts to directly influence health literacy levels.

We propose that efforts by the five identified stakeholder groups / settings to address the three Action Areas can form a basis on which to build a regional plan for dealing with limited health literacy in Northern Ireland. A first step on this journey may be to produce a comprehensive Theory of Change for health literacy in Northern Ireland setting out:

- Details of the activities proposed in Section 7;
- Who should 'own' each of these activities;
- Expected short-to-medium term outcomes, with clearly defined causal links between activities and outcomes;
- Specific outcome measures; and
- An articulation of the expected long-term impact.

It is essential that this Theory of Change exercise be undertaken in partnership between all stakeholders groups, with commitments from each group to implement their respective actions to agreed timeframes.

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APPENDIX 1

SOURCE	DEFINITION
1. Joint Committee on National Health Education Standards (1995)	'Health literacy is the capacity of individuals to obtain, interpret, and understand basic health information and services and the competence to use such information and services in ways which enhance health.'
2. Nutbeam (1998)	'The cognitive and social skills which determine the motivation and ability of individuals to gain access to understand and use information in ways which promote and maintain good health.'
3. American Medical Association (1999)	'The constellation of skills, including the ability to perform basic reading and numeral tasks required to function in the healthcare environment.'
4. Nutbeam (2000)	'The personal, cognitive and social skills which determine the ability of individuals to gain access to, understand, and use information to promote and maintain good health.'
5. USDHHS (2010)	'The degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.'
6. Fok and Wong (2002)	'To understand and act upon physical and psycho-social activities with appropriate standards, being able to interact with people and cope with necessary changes and; demands reasonable autonomy so as to achieve complete physical, mental and social well-being.'
7. Nielsen-Bohlman et al (2004)	'The individuals' capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.'
8. Kickbusch et al (2005)	'The ability to make sound health decision(s) in the context of everyday life – at home, in the community, at the workplace, the healthcare system, the market place and the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility.'
9. Zarcadoolas et al (2005)	'The wide range of skills, and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks and increase quality of life.'
10. Paasche-Orlow and Wolf (2007)	'An individual's possession of requisite skills for making health-related decisions, which means that health literacy must always be examined in the context of the specific tasks that need to be accomplished. The importance of a contextual appreciation of health literacy must be underscored.'

11. Kwan et al (2006)	'... [P]eople's ability to find, understand, appraise and communicate information to engage with the demands of different health contexts to promote health across the lifecourse.'
12. European Commission (2007)	'The ability to read, filter and understand health information to form sound judgments.'
13. Pavlekovic (2008)	'The capacity to obtain, interpret and understand basic health information and services and the competence to use such information to enhance health.'
14. Rootman and Gordon- El-Bihbety (2008)	'The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life course.'
15. Ishikawa and Yano (2008)	'The knowledge, skills and abilities that pertain to interactions with the healthcare system.'
16. Mancuso (2008)	'A process that evolves over one's lifetime and encompasses the attributes of capacity, comprehension, and communication. The attributes of health literacy are integrated within and preceded by the skills, strategies, and abilities embedded within the competencies needed to attain health literacy.'
17. ABS (2008)	'The knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy.'
18. Yost et al (2009)	'The degree to which individuals have the capacity to read and comprehend health-related print material, identify and interpret information presented in graphical format (charts, graphs and tables), and perform arithmetic operations in order to make appropriate health and care decisions.'
19. Adams et al (2009)	'The ability to understand and interpret the meaning of health information in written, spoken or digital form and how this motivates people to embrace or disregard actions relating to health.'
20. Adkins and Corus (2009)	'The ability to derive meaning from different forms of communication by using a variety of skills to accomplish health-related objectives.'
21. Freedman et al (2009)	'The degree to which individuals and groups can obtain process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community.'
22. Massey et al (2012)	'A set of skills used to organise and apply health knowledge, attitudes and practices relevant when managing one's health environment.'

23. Paakkari and Paakkari (2012)	‘Health literacy comprises a broad range of knowledge and competencies that people seek to encompass, evaluate, construct and use. Through health literacy competencies people become able to understand themselves, others and the world in a way that will enable them to make sound health decisions, and to work on and change the factors that constitute their own and others’ health chances.’
24. Wu et al (2010)	‘Health literate individuals are able to understand and apply health information in ways that allow them to take more control over their health through, for example, appraising the credibility, accuracy, and relevance of information and action on that information to change their health behaviours or living conditions.’
25. Sørensen et al (2012)	‘Health literacy is linked to literacy and entails people’s knowledge, motivation and competencies to access, understand, appraise and apply information to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain and improve quality of life during the life course.’
26. Dodson et al (2015)	‘The personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health. Health literacy includes the capacity to communicate, assert and enact these decisions.’

APPENDIX 2

EXTRACT FROM "MAKING LIFE BETTER" - 2014

THEME 3 - EMPOWERING HEALTHY LIVING

Key long-term outcome 9:

People are better informed about health matters

*"**Health Literacy** – the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways that promote and maintain good health." – Nairobi, WHO, 2009*

7.12 ***Health literacy*** means more than being able to read pamphlets; it empowers people to make healthier choices, decide to change their life style and take action. Some published definitions present ***health literacy*** as a set of individual capacities that allow the individual to acquire and use new information. ***Health literacy*** is dynamic, being influenced by both the individual and the health care system.

7.13 Everyone has a personal responsibility for making decisions that can impact on their own health and wellbeing, but some may need more support than others, for example, when there are conflicting messages. Health and social care professionals including the independent Family Practitioner Services can help and guide people to make appropriate choices - the role of all professionals is not just about treatment when people are ill. It also encompasses supporting people to stay well and live more healthily, including those already living with a condition. This may be through giving them information and support about healthy living and guiding them to any further help they may need. The potential of the front-line workforce needs to be maximised. To this end, DoH is considering the workforce implications and recommendations following England's strategy *"Healthy Lives, Healthy People"* and the associated Public Health Workforce Strategy.

7.14 In many cases it may be that individuals could be supported by a different service either within or outside of the Health and Social Care system, or perhaps by a wider public or community-based service. It will be important that HSC professionals look to build linkages to support services beyond their own specialty, and beyond the HSC to be able to signpost access to appropriate help.

7.15 Improving ***health literacy*** aims to influence not only individual lifestyle decisions, and decisions about treatment and self-care, but also raise awareness of the determinants of health, and encourage individual and collective actions – at all levels of society - which may lead to a modification of these determinants. Improving ***health literacy*** needs to go beyond a narrow concept of health education and individual behaviour, and address the environmental, political and social factors that determine health.

Actions and Commitments 2013 - 2015

A) Empower people to make healthier choices and informed decisions about their health by improving ***health literacy***. This will include –

• providing appropriate and accessible health information (making greater use of modern communication technology) and advice to all, which is evidence informed and tailored to meet specific needs, and that

- encourages more people to present with early symptoms of health problems to HSC services
- promotes self-care, and sign-posts to appropriate support through, for example patient education/self-management programmes

This should have a specific focus on groups at risk of developing conditions, and those with conditions who are at risk of exacerbating or developing complications. It will be important that appropriate links are made with the work being taken forward through Integrated Care Partnerships as part of TYC.

Key Partners
DHSSPS / PHA / HSC / Local government / Community and Voluntary sectors, others including eg NUS – USI

B) Promote healthy active ageing, including further opportunities for more active promotion of health and wellbeing in nursing and care settings

Key Partners
DHSSPS / HSC / others

C) Develop and deliver a Community Resuscitation Strategy to focus a drive to increase the number of people, of all ages, trained in Emergency Life Support skills and to coordinate the use of available resources

Key Partners
DHSSPS / PHA / DE / DCAL community and voluntary sector

One-Stop-Shops
In 2009, the PHA to developed a pilot programme of 4 'One Stop Shop' drop in services for children and young people that provide information, education, sign-posting and, where appropriate, referral to specialist services. The programme sought to address a range of issues including but not exclusively: substance misuse; suicide and self harm; mental health and wellbeing; sexual health; relationship issues; resilience; and coping with school/employment. Following positive evaluation, the PHA has been rolling out a range of 'One-Stop-Shops' across Northern Ireland. There are now eight services as follows:

- *Carrickfergus YMCA – Carrickfergus*
- *FUEL – Enniskillen*
- *Magnet Centre – Newry*
- *FASA – Belfast*
- *FASA – Bangor*
- *Dove House – Londonderry*
- *Opportunity Youth – Ballymena*
- *REACT – Banbridge*

42. A Community Resuscitation strategy has been launched to focus a drive to increase the number of people of all ages trained in Emergency Life Support skills and to co-ordinate the use of available resources. A regional implementation group is establishing structures and processes to engage with stakeholders including organisations in the private, public and voluntary and community sectors to enable delivery of the strategy.

49. Supporting people to self-manage their condition can help maintain or improve health outcomes and well-being. The Long-Term Condition Implementation Plan includes actions to increase patient education programmes. Such programmes can help people manage their condition by raising understanding and awareness of, potential risks or indicators of exacerbations, thereby supporting earlier recognition and prompt action.

50. A summary report for patient education programmes delivered in 2013/14 published in March 2015 showed a year on year increase in both the number of programmes delivered, and the number of programme participants during 2013/14 compared with 2012/13. During 2013/14, there were 12,741 participants on structured patient education/self-management programmes - a 10% increase on the number in 2012/13 (11,531). A total of 841 patient education/self-management programmes were provided in 2013/14, an increase of 7% on the number in 2012/13 (784).

APPENDIX 3

Output from Belfast Healthy Cities Health Literacy Workshop - Health Literacy in a Healthy City: Making the Case and Taking Action Wednesday 10 December 2014

How do we develop a common understanding of health literacy for people living in Belfast? (Discussion on this area of action identified a number of key elements/drivers viewed as important to develop a key understanding of health literacy.)

- **Clear communication:**
  - Produce and communicate easily understood health messages.
  - Support action on health messages, taking into consideration individuals personal circumstances.
  - Increase access, understanding and application of information.
  - Provide a variety of formats to users to access/promote and reinforce messages.
  - Develop communication skills and empower people to be confident to make informed decisions.
  - Develop communication skills of health professionals to be opportunistic in targeting all individuals and communities to develop health literacy skills.

- **Motivation of all stakeholders:**
  - Provide increased education to motivate staff to be aware of health literacy issues. Health professionals to be aware of individuals 'Not in frame of mind to take part', work with patient/client until they are ready to engage in health promotion.
  - Build screening for health literacy into pre-assessment consultations between user and health care professionals.
  - Consider variety of methods, including motivational interviewing with users and health care professionals, to support delivery of clear information.

- **Capacity building:**
  - Provide capacity building and improve health literacy levels of professionals, providers of education/information, individuals, and communities.
  - Learning strategy and models for building capacity on health literacy must be integrated into existing work, rather than additional and stand alone.
  - Identify sources of information/support to share across communities and between the individual user and health professional. Health practioners to provide clear messages and ensure communication is understood, for example, teach back method. Repeat appointments can be avoided if clear information is provided initially.
  - Health literacy implies understanding of health care professionals to respond appropriately when challenged by individual and also implies empowering local people to be confident to challenge professionals.

- **Linking health literacy to other thematic areas of work:**
  - Consider similar approaches taken elsewhere.
  - Health inequalities are strongly linked to health literacy.
  - Health literacy programmes require a partnership approach. In developing health literacy programmes, consider the impact of the educational and industrial background of Belfast.
  - Identify a baseline of health literacy to provide a basis for setting priorities in health literacy programme.

- **Challenges:**
  - English not first language.
  - Focus on one clear message or issue in developing a health literacy programme – evaluate information and make the right decision.

What do we need to do to improve health literacy in Belfast? (As part of the response to this question, consider priority areas for action and/or particular population groups who may require greater support. Participants identified a number of short, medium and long term priorities for action to develop health literacy in Belfast.)

- **Short-term goals for health literacy:**
  - Develop a baseline on health literacy to inform action plan, consider a life course approach and targeting groups within this.
  - Scope and map current programmes that contribute to health literacy.
  - Consider health literacy within professional development programmes with relevant professions. Include health literacy in every module for health professionals.

- **Medium term goals for health literacy:**
  - Using baseline to identify gaps and provide support for all ages, resulting in a health literate population.
  - Develop health literacy as an aspect of ongoing professional education/development.
  - Build partnerships in different settings eg. pharmacies and libraries, to promote health literacy.
  - Use online resources, media campaign, and variety of formats for message campaigns.
  - Use a tool like ALISS (A Local Information Service for Scotland) to map existing services, co-ordinating different activities in Northern Ireland.
  - Promote standardising methods of common/best practice in promoting health messages.
  - Encourage plain English language (simplyput.ie website).

- **Long-term goals for health literacy:**
  - Target education and professional sector to promote importance of health literacy and its impact on people and the use of health services.
  - Educate professionals to communicate using open questions, and use of technology to provide key messages where appropriate.

- Educate public to encourage asking questions to professionals. Priority groups identified during discussion: older people, pregnant women, lower socio economic groups, professionals, migrant population, young people, more multi- cultural Belfast, low literacy groups, low income families, long-term conditions, Black Minority Ethnic (BME) groups. Proportional universalism: participants stressed the importance of targeting groups, whilst ensuring that the population in general have the opportunity to develop full health literacy skills.

What resources are available to support the development of health literacy in Belfast? (As part of the response to this question, consider the organisations and agencies that could be involved, the local groups, people and their skills, the material resources, sources of information, and sources of financial support.)

Financial resources:
Identify existing funding sources, health improvement consortium, Big Lottery, Health and Social Care research funding, Horizon 2020.

Organisations and sources of information:

- Making use of community leaders as drivers for successful health outcomes.

- Use and be aware of existing data including Northern Ireland Neighbourhood Information Service, pharmacy, Community Development Health Network Building the Community-Pharmacy Project, Men's shed, women's groups, partnerships within Belfast, volunteers, Good Morning Service, Belfast City Council, Belfast Health and Social Care Trust, Education, Housing, Tenants Associations.

- Networking, partnerships, simplyput.ie, A Local Information Service for Scotland (ALISS) style database, build on what exists; community development, Community Development Health Network.

- Representation from education and Department for Employment and Learning on the working group.

- Ensure representation from education, industry, local government and community; government departments, disability groups.

- Promote a co-ordinated, integrated approach to the development of health literacy programmes.

- Belfast Healthy Cities co-ordinated think tank to bring forward programme as a result of priorities identified in workshop.

Next Steps:

- Be alert to health literacy already happening within classroom based ESOL (English for speakers of other languages) programmes. It is important that this learning is shared but also that the impact is being measured.

- It is important that case studies of good practice are showcased in order to raise awareness of health literacy amongst staff.

- Interested parties to be invited to attend next working group meeting to progress the health literacy agenda and ideas generated at the workshop.