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Health Literacy in Wales

A scoping document for Wales

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Purpose and Summary of Document:

In April 2010, Public Health Wales was requested by the Welsh Assembly Government to scope health literacy for Wales. The aims were to identify a Welsh definition, explore implications for Wales, provide an overview of current activities, consider measurement opportunities, and offer evidence-based recommendations for the Welsh Assembly Government's consideration.

Work Plan reference: Healthcare Improvement Team (1000 Lives Plus)

Executive Summary

In April 2010, Public Health Wales was requested by the Welsh Assembly Government to scope health literacy for Wales. The aims were to identify a Welsh definition, explore implications for Wales, provide an overview of current activities, consider measurement opportunities, and offer evidence-based recommendations for the Welsh Assembly Government's consideration.

Health literacy is a public health topic which has grown to considerable status across the globe in recent years. We describe it as 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.

Research from around the world is quickly deepening our understanding of the vast potential that optimising health literacy can have in reducing inequalities and inequities. However, more research is needed in this field as there are currently no evidence based-interventions that can clearly achieve this goal yet available.

Consideration of the current financial climate and the developing evidence has been taken into account. Public Health Wales has devised the recommendations included in the final report, taking into account existing activities in Wales, international policies, and areas of work proven to positively affect health literacy. A multi-stage consultation process with local and international experts and members of the public has been undertaken to devise and quality assure the recommendations. The Welsh health literacy definition and associated recommendations have received a very positive response, and been praised as a “broad, knowledgeable, and forward looking plan¹”.

Health literacy provides great opportunities to empower individuals and communities to better manage their own health whilst providing great potential savings to the healthcare system. However, this can only be achieved through a long term vision and commitment to measure health literacy at population level. This will provide understanding and support to all frontline improvement work which will require multi-agency and cross-departmental collaborations.

¹ Professor Kristina Alexanderson; Karolinska Institutet; Sweden (email 6.11.10)

Introduction

Health literacy has been simply described "as the ability to read, understand and act on health information². However, this empirical definition falls far short of describing the essential elements of health literacy and the motivation, skills, abilities and behaviors that individuals need to acquire it. It is widely understood that inadequate health literacy affects people of all ages, races, educational levels and social groups across the globe. Nevertheless, its definition is still debated and approaches on how to tackle this issue are still being tested.

Research³ indicates that low health literacy results in poorer health status. Previous studies suggest that people with "inadequate or marginal health literacy skills have a 50% higher mortality rate over a five year period than those with adequate skills"⁴. Studies in the USA have also found that "medication errors, excess hospitalizations, longer hospital stays, more use of emergency departments, and a generally higher levels of illness (all attributable to limited health literacy) are estimated to result in excess cost for the US health care system of between \$50 billion and \$73 billion a year."⁵

These studies suggest that by measuring and tackling the health literacy level of our Welsh population we will be able to diminish the health inequities gap, whilst empowering staff and patients to engage in a more balanced and effective relationship. Hence, providing better managed, more cost effective and sustainable care.

This report proposes an all embracing and more workable definition of health literacy which can be used in the context of scoping health literacy in Wales. The report considers the links between health literacy and inequities in a wider context and specifically for Wales. It highlights the great impact that optimising the population's health literacy level would have in bridging the current inequity gap.

The report looks at ways in which the scope of the problem can be assessed at population level. This is key to understanding the size of the problem and the implications for the Welsh population. The development of a national assessment method will not only provide a greater understanding of this issue, but will help monitor the impact of any health literacy specific intervention that will also be recommended as part of this report.

However, assessing health literacy skills is not limited to population level and the report considers the widely-used assessment tools for individuals, outlining their benefits and possible applications.

² "Eradicating Low Health Literacy: the first public health movement of the 21st Century. Overview White Paper" Pfizer Inc. 2003

³ Nielsen-Bohlman L. Et al. "Health Literacy: a prescription to end confusion" Executive summary accessed from <http://www.nap.edu/catalog/10883.html>

⁴ Rootman I and Gordon-El-Bihebety D. "A vision for a health literate Canada. Report of the Expert Panel on Health Literacy. CPHA – ACSP. 2008 (p 20)

⁵ Barry DW, et al. " Health Literacy and patient safety: help patients understand. Manual for clinicians" AMA Foundation. 2009

An overview mapping of current activities in Wales is collated, showing the wide range of activity existing in Wales, and highlighting opportunities for improvement within the existing provision.

Finally, the report provides a set of recommendations initially selected by a national group of experts from various sectors and quality assured by members of the public and international experts.

What is Health Literacy?

Definitions of health literacy continue to be debated, and as Nutbeam⁴ has pointed out, the concept of health literacy has simultaneously evolved from two differing perspectives - educational research into literacy, concepts of adult learning and health promotion, and from findings of clinical research studies that have found those with poorer literacy skills have poorer health outcomes⁶.

Health literacy is a relatively new concept, first used in a 1974 paper entitled “Health Education and Social Policy”⁷ and it was simply described as the ability to read and comprehend written medical information and instruction⁸.

More recently, the World Health Organization defines health literacy as “the cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand and use information to promote and maintain good health.”⁹

The above definition implies a much broader set of skills than in the original description:

- Basic health knowledge;
- Reading, comprehending and evaluating health information;
- Application of health preventing, promoting and self-care behaviours;
- Verbal communication with health professionals;
- Health decision making; and,
- Health advocacy and activism.

In 2000, Nutbeam developed a model suggesting three levels of health literacy¹⁰:

⁶ Nutbeam, D “The evolving concept of Health Literacy” Elsevier Ltd 2008

⁷ Simonds, S. K. “Health education as social policy”. Health Education Monograph. 1974

⁸ Coulter A, Ellins J “Patient Focused Interventions: a review of the evidence” Picker Institute Europe. 2006

⁹ Kickbush, I. S. “Health Literacy - assessing the health and education divide”, 2001

¹⁰ Nutbeam, D. (2000) 'Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century'. *Health Promotion International*, 15 (3): 259-267.

Functional Health Literacy:

Defined as the sufficient basic skills to function in everyday life. In a healthcare setting this would at least translate as the ability to read and understand information such as appointment letters and understand the 24 hour clock.

Interactive Health Literacy:

Defined as the ability to interpret and balance information from different sources as part of the decision-making process. This element is important for social marketing as it translates into the ability to interpret and balance information from competing sources (media, peers, clinicians, etc).

Critical Health Literacy:

This is an extension of Interactive Health Literacy, plus the ability to articulate oneself in a discussion of complex medical issues or conditions, recognise one's own environment, and issues from a broader public health prospective.

It is arguable that this definition does not take into account the "hard to reach" population whose health literacy skills are below Nutbeam's Functional level. For example, some individuals may be unable to understand basic written information such as appointment letters, prescriptions or medicines labels.

Although it is undeniable that literacy and health literacy are linked, and some argue that health literacy is simply literacy in a health context, we believe that health literacy is in fact a different concept and is affected by different variables and contexts of which literacy is one of many possible variables.

For example, a diabetic patient who has managed their condition for many years could have a very high health literacy level in relation to their condition, even though they may be unable to read or write. However, the same patient would be likely to have low health literacy skills when faced with new health issues or if required to engage new healthcare settings. An individual may have high levels of health literacy but low literacy levels (or vice versa) due to familiarity with their condition, and their position will change according to the circumstances.

In the same way, individuals with high literacy levels may find themselves in emotionally vulnerable situations, as the recipient of complex information or as part of an imbalanced health profession/patient relationship, which could result in a lower health literacy level. Barry et al. describe how a long practiced obstetrician undergoing surgery reported to be unable to fully understand his orthopaedic pre-op instructions.¹¹

¹¹ Barry DW, et al. "Health Literacy and patient safety: help patients understand. Manual for clinicians" AMA Foundation. 2009

Individuals with low health literacy levels may develop coping strategies to master situations beyond their skills and to manage simple and routine interactions with the health service. This could be the reason for the under recognition of this issue by health professionals.

Population wide studies¹² have shown that low or inadequate health literacy is found in all sections of society. However, studies¹³ seem to suggest that health literacy tends to vary at different stages of an individual's life, with the elderly being mostly at risk. Individuals with limited education and lower social classes are also high risk groups, as are ethnic minorities and those who are not native speakers of the resident country's native language.

The bilingual context of Wales and the changing dynamics of bilingualism across the lifespan offers the opportunity for further studies to explore the relation between primary language skills and health literacy. Very limited studies are available for bilingual populations and there is a gap in the analysis of the impact of bilingualism on an individual's health literacy level.

However, studies suggest that an individual's health literacy skills are higher in their native language¹⁴ than in their second language. This may present an opportunity for further studies in Wales looking at the interaction of bilingual speakers with health information and how this impacts on an individual's health literacy level.

Defining Health Literacy for Wales:

The Canadian Expert Panel has recently defined health literacy as “the degree to which people are able to access, understand, evaluate and communicate information to promote, maintain and improve health in a variety of settings across the life-course¹⁵”.

Although this definition is very comprehensive, it does not define clearly enough that health literacy is used as a general term to encompass both narrative and numeric abilities and it does not take into account the motivational dimension included in the World Health Organization's definition.

The following amendments to the Canadian definition are proposed:

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.

¹² Barry D. Weiss. “Removing barriers to better, safer care. Help patients understand. Manual for Clinicians” AMA Foundation. 2007

¹³ Baker et al. “The association between age and health literacy among elderly persons” J Gerontol Series B-Psychol Sci Soc Sci. 2000

¹⁴ Smedley, B.D., Stith, A.Y., & Nelson “Unequal treatment: Confronting racial and ethnic disparities in health care” Washington, DC: National Academies Press. 2003

¹⁵ Rootman I and Gordon-El-Bihebety D. “A vision for a health literate Canada. Report of the Expert Panel on Health Literacy. CPHA – ACSP. 2008

This Welsh definition has received positive feedback from the international consultation.

The image below was created by Professor Richard Osborne from Deakin University, Australia, who praised the Welsh definition as one of the best currently available, while speaking on health literacy at the “Embracing the Challenge - Changing conditions” conference in Cardiff in November 2010.

His representation of the Welsh definition provides a clear visualisation of the capabilities and activities required to effectively promote, manage, and improve health, which will deliver optimised health and health literacy and optimise the use of health services. These outcomes will in turn help reduce the health inequities gap.

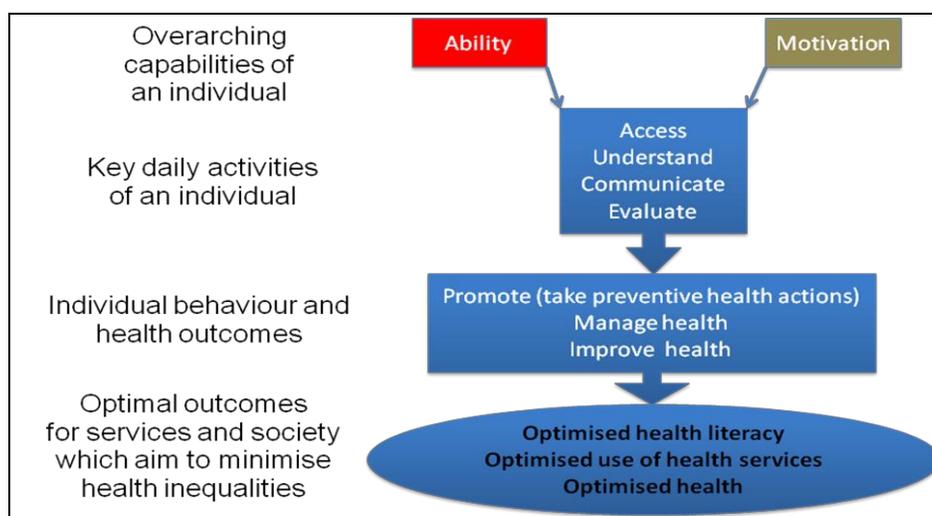


Figure 1 Professor Richard Osborne, Welsh health literacy definition

We anticipate that definitions of health literacy will evolve as more research is undertaken, but for the purpose of the report the above definition is used.

Health Literacy and Health Inequities: Why is it important?

Previous studies¹⁶ have shown that literacy and health literacy are linked to poorer health outcomes and are strong contributors to health inequalities. Inequalities are defined by the Oxford Dictionary as the lack of fairness or justice.¹⁷

In Wales, health inequities have been the key focus of recent governmental initiatives and policies.

The 2007 Chief Medical Officer's Annual Report¹⁸ called for a focus on inequities rather than inequalities in health, adopting the World Health Organization's Commission on Social Determinants of Health view that "Not all health inequalities are unjust or inequitable. If good health were simply unattainable, this would be unfortunate but not unjust. Where inequalities in health are avoidable, yet are not avoided, they are inequitable."¹⁹

James Wilson²⁰ explains the difference between health inequalities and inequities as: "Health inequalities [are] 'the generic term used to designate differences, variations, and disparities in the health achievements of individuals and groups,' (Kawachi et al. 2002, p.647), while [...] health inequities [are] those health inequalities which are, all things considered, unjust."

'Our Healthy Future' was launched in 2009 and it aims to "increase the pace of change in improving health in Wales, increase fairer health outcomes, increase years of healthy life, reduce (or eliminate) barriers to leading a healthy life and provide the strategic direction for national and local public health."²¹

Six strategic themes have been selected as key strategic priorities to achieve the aims set by 'Our Healthy Future'.

The six themes are:

1. Health and wellbeing through the life course

¹⁶ Kickbush et al. "Navigating health. The role of health literacy" International Longevity Centre-UK. Accessed from www.ilcuk.org (21.07.2010)

¹⁷ Accessed from www.oxforddictionaries.com on 16.8.2010

¹⁸ Dr Tony Jewell "Chief Medical Officer Annual Report – 2007" Welsh Assembly Government. Accessed from <http://www.wales.nhs.uk/documents/cmo-report-2007-e.pdf> in November 2010.

¹⁹ World Health Organisation Commission's on Social Determinants of Health. 2007 Interim statement accessed from http://www.who.int/social_determinants/resources/interim_statement/csdh_interim_statement_inequity_07.pdf in November 2010.

²⁰ Wilson J. "Health Inequities". Public Health Ethics: Key Concepts and Issues in Policy and Practice. Cambridge University Press. 2009

²¹ "Our Healthy Future working paper". Welsh Assembly Government. 2009

2. Reducing inequities in health
3. Healthy sustainable communities
4. Prevention and early intervention
5. Health and shared goal
6. Strengthening the evidence and monitoring progress



Our Healthy Future lists six areas for action from now through to 2020.

It is arguable that the complex nature of health literacy and its ever changing status for all members of society mean that by tackling this issue we will impact all six themes.

However, health literacy greatest potential is in reducing health inequities.

As we have seen, health literacy is more than just the ability to read and understand health related information; it also includes the motivation, ability and confidence to make informed decisions to help manage and improve health. As such it is relevant to the whole population, including those who may not be currently in receipt of care.

Although inadequate health literacy levels can affect all segments of society, it is more common amongst the most disadvantaged and hard to reach. Research²² has identified the following “high risk” groups: the elderly, those with limited education, ethnic minority groups, and those whose first language is not that of the resident country. People with a lower socio-economic status are also at risk of limited health literacy skills. People who are visually impaired and those who have learning disabilities are also identified as at risk populations, although they may not be as prominent as the previously mentioned groups.²³

However, health literacy is dependent on many variables and people with low skills will not easily fit any stereotype. Therefore, any policy or strategy targeting this issue should not limit attention to specific sections of society.

A number of surveys^{24 25} looking at information provision to members of the public suggest that no matter the age, many individuals will seek information from people they know such as members of their family and/or peers. This is an important factor when planning an improvement strategy around health literacy as it shows the importance of optimising the population health literacy level, and not simply focusing on the few with poor literacy and numeracy skills.

²² Barry D. Weiss. “Removing barriers to better, safer care. Help patients understand. Manual for Clinicians” AMA Foundation. 2007

²³ Ibid

²⁴ “Get connected generation report 2010” accessed from www.getconnected.org.uk in September 2010

²⁵ “In the dark – Information needs for older people” Eastleigh Southern Parishes Older People’s Forum. Accessed from <http://www.espopf.org/research> in September 2010.

By empowering all members of society to better manage their health throughout their life time, improve their ability to access healthcare, while also removing system's barriers and increase the system's ability to identify, engage and assist all members of society who may be experiencing inadequate health literacy level, we will create a fairer, more inclusive and sustainable society.

An all encompassing approach should be applied, similar to that suggested by the 'Fair Society, Healthy Lives. Strategic review of health inequalities in England post 2010'. "Greater intensity of action is likely to be needed for those with greater social and economic disadvantage, but focusing solely on the most disadvantaged will not reduce the health gradient, and will only tackle a small part of the problem"²⁶.

To successfully achieve an improvement in this population wide public health topic, Wales will require commitment from "a broad range of policy areas [...] and across the public, private and third sector organisation"²⁷.

This argument is supported by Kickbush, a leading health literacy expert, who suggests that "the influence of social capital and health literacy is part of the development of a more integrative public health agenda that moves beyond a disease-by-disease and risk-by-risk approach"²⁸. This approach is also supported by the Marmot report which sets out the English vision for tackling health inequalities through a multi-agency and departmental approach.

At risk populations and implications for Wales:

Limited literacy skills

Health literacy and literacy are very closely related. Literacy requires knowledge and abilities needed to perform in all different domains of society (home, work, communities, politics, etc) and the range of such skills varies from basic to high-level. Literacy is recognised as an "important predictor of community participation, employment, and health status."²⁹

According to Ronson and Rootman, "Literacy skills predict health status even more accurately than education level, income, ethnic background, or any other socio-demographic variable"³⁰. The National Survey of Adult Basic Skills in Wales³¹ (2004) suggests that as many as 25% of the survey's sample had literacy skills equivalent to a seven year old, numeracy skills reported an

²⁶ Michael Marmot et al. "Fair Society, Healthy Lives. Strategic review of health inequalities in England post 2010" The Marmot Review. 2010

²⁷ "Our Healthy Future working paper". Welsh Assembly Government. 2009

²⁸ Kickbush I. "Health literacy: addressing the health and education divide". Health Promotion International. 2001

²⁹ Kirckbush I and Maag D. "International Encyclopedia of Public Health" first edition (2008), vol 3, pp. 204-211

³⁰ Ronson, B. and Rootman, I., Literacy: one of the most important determinants of health. In: D. RAPHAEL, ed., Social determinants of health: Canadian perspectives. 1st ed. Toronto, ON: Canadian Scholars' Press, 2004

³¹ Williams J, Kinnaird R. "The national survey of adult basic skills in Wales" Basic Skills Agency. 2005

even poorer outcome with 53% of respondents below Level 1 (abilities similar to a seven year old).

Respondents who reported poor health, or a long term illness or disability of some kind tended to perform at a lower than averages level in the assessments. For example, more than four in 10 (43%) of those reporting 'fair', 'poor' or 'very poor' health were classified at Entry Level in the literacy assessments.

Whilst most public bodies are conscious of the need to use basic English, the majority of literature is targeted at literacy skills similar to that of an 11 year old³². The figures above show that our current efforts may not go far enough to include those with poorer literacy and numeracy skills.

Although health literacy is reliant on basic literacy skills, people with advance literacy skills in normal life circumstances (home/work environment for example) may still have insufficient health literacy to effectively navigate the healthcare system. They may be unable to evaluate competently the vast and sometimes conflicting information required to manage or improve one's health status.

Health practices are continually re-examined and revised in light of new information. Treatments and medications are improving and expanding at a faster rate than ever, new research is continually challenging society's concept of what is healthy, and the healthcare system itself is continually redefined. When we account for the constantly changing nature that defines health and healthcare, it becomes necessary to regard health literacy as an active process. Individuals are constantly required to learn and challenge their health knowledge to be able to maintain good health and act as informed patients.

With this in mind, it is clear that when looking at health literacy it is paramount to apply a universal approach, and not simply focus on the literacy and numeracy skills of the population.

Age

Wales, like other developed countries, is facing an increasing challenge in caring for an aging population. The elderly are one of the high risk groups identified by various studies and even after taking into consideration the higher prevalence of chronic conditions, the elderly are disproportionately represented as having low levels of health literacy^{33 34}.

³² Welsh Assembly Government "Writing Style Guide for all Welsh Assembly Government Communications"

³³ Parker R. "Health literacy: a challenge for American patients and their health care providers" Health Promotion International. 2000

³⁴ "Health Literacy: a prescription to end confusion". National Academy of Sciences. 2003

Wales has a higher concentration of older people than the rest of the UK, with just over 17% population aged over 75 (compared to 16% rest of UK)³⁵. It is estimated that “By 2020 [...] there will be almost the same number of people aged sixty and over as there will be in their twenties and thirties.”³⁶

Older people are more likely to have a disability. In 2003 nearly half of disabled people in the UK were 65 and over, with their most common problems relating to movement, vision and hearing.³⁷

In Wales, the policy agenda for Older People’s service development is driven by the Older Persons National Service Framework (NSF) launched in 2006³⁸. NSFs are part of the Government’s agenda to improve standards and equity of access to health and social services across the country. The NSF for Older People in Wales sets national standards designed to ensure that as individuals grow older they are enabled to maintain health, wellbeing and independence for as long as possible, and receive prompt, seamless, quality treatment and support when required.

The Welsh Health Survey 2003/4 found that the use of many health services increased with age, including the use of GPs and practice nurses, community based nurses, chiropractors, opticians and hospitals (except casualty departments). Older people often have multiple chronic pathologies, requiring multiple medications, which, if not well managed, can lead to avoidable hospital admission and readmission. As well as being the main users of acute hospital services, older people tend to experience a longer length of hospital stay.³⁹

Baker et al studied the relation between cognitive ability, health literacy and mortality in older people.⁴⁰ This study found that “Both health literacy and cognitive abilities independently predict mortality. Interventions to improve patient knowledge and self-management skills should consider both the reading level and cognitive demands of the materials.”

A survey of older people’s information needs from Eastleigh Southern Parishes Older People’s Forum⁴¹ shows that multi-format material that was accessible in the community was the favourable choice of the survey respondents.

³⁵ Welsh Assembly Government “Health Aging Action Plan for Wales”. Assessed from <http://wales.gov.uk/dphhp/publication/improvement/older/action/ageing.pdf?lang=en> in October 2010.

³⁶ Ibid

³⁷ Ibid

³⁸ Welsh Assembly Government “Older Persons National Service Framework” access from <http://www.wales.nhs.uk/sites3/documents/439/NSFforOlderPeopleInWalesEnglish.pdf> in November 2010.

³⁹ Ibid

⁴⁰ Baker et al. “Health Literacy, Cognitive Abilities, and Mortality Among Elderly Persons” J Gen Intern Med 23(6):723–6 (2008)

⁴¹ “In the dark – Information needs for older people” Eastleigh Southern Parishes Older People’s Forum. Accessed from <http://www.espopf.org/research> in September 2010.

Language

Reports from the 2001 census suggest that 20.8% of the total population of Wales is Welsh speaker. Although the majority of Welsh speakers are bilingual, a survey by the Welsh Consumer Council in 2000 found that bilingual service users “often demonstrate a distinct language preference” in situations where they feel stressful or vulnerable.⁴² The same survey highlighted “fundamental deficiencies in the services provided for Welsh speakers, placing them at a real disadvantage in healthcare.”⁴³ These findings are in agreement with other International studies of bilingual minority groups’ interaction with healthcare settings.

Language barriers can have a negative effect on the quality of care received. Patients with limited language proficiency will show “decreased patients recall, question-asking behaviour; patient satisfaction; a lack of comprehension of medication side effects and/or doctor’s instructions; poor decision-making on the part of providers and patients; and decreased uptake of preventative services.”⁴⁴

Groups that are particularly vulnerable include young children, older people, those with mental health problems and learning disabilities, where denying access to services in their preferred language has been shown⁴⁵ to compromise care delivery. Given that these groups are already identified as having low levels of health literacy, Welsh speakers amongst them may be further jeopardised in accessing and understanding information to maintain good health.

UK Studies^{46 47} have shown practitioners are often unable to rectify difficult communication issues with bilingual patients which often leads to misinterpretation of the information and advice given, poor medication and treatment compliance and poor psychological support for the patients.

Increasing commitment in the devolved bilingual Wales towards language-appropriate services has prompted attempts to overcome many of these challenges through language planning interventions at strategic and organisational levels. Nevertheless, a programme of research is

⁴² Minsell, A “Welsh in the health service: the scope, nature and adequacy of Welsh Language provision in the National Health Service in Wales.” Welsh Consumer Council. 2000 accessed from www.llais.org

⁴³ Minsell, A “Welsh in the health service: the scope, nature and adequacy of Welsh Language provision in the National Health Service in Wales.” Welsh Consumer Council. 2000 accessed from www.llais.org

⁴⁴ Dr Fiona Irvine and Ms Gwerfyl Roberts. “Language appropriate practice in health and social care” 2006

⁴⁵ Barry D. Weiss. “Removing barriers to better, safer care. Help patients understand. Manual for Clinicians” AMA Foundation. 2007

⁴⁶ Vydellingum V. “South Asian patients’ lived experience of acute care in an English hospital: a phenomenological study” *Journal of advance nursing*. 2000

⁴⁶ Gerrish K. “The nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients and their carers”. *Journal of advanced nursing*. 2001

⁴⁷ Welsh Assembly Government “Improving health and wellbeing in Wales. A Framework for supported self care” WAG. 2009

required to guide best practice approaches and enhance the evidence base. This includes exploring the constructs of bilingual healthcare communication and its impact on health literacy amongst vulnerable groups; the linguistic and psychometric validation of Welsh language versions of patient reported outcome measures; and impact evaluations of language appropriate interventions, such as language awareness / skills training and service delivery models. Given the dearth of studies on bilingualism and health literacy, health researchers in Wales are in a prime position to inform the wider evidence base.

Ethnicity

Members of ethnic minority groups are identified as at risk of low levels of literacy. The 2001 census shows that 98,791 black and minority ethnic individuals live in Wales⁴⁸. These groups tend to be concentrated in the biggest urban areas, but due to employment opportunities arising in the agricultural industries in rural areas, we now see an expansion of ethnic minority numbers in rural areas.

Current legislation requires all public bodies to offer equal services and opportunities to all members of society and to promote race equality and monitor employees' employment status and access and uptake of opportunities. To meet these requirements all public bodies need to promote equal access to health care services and provide accessible health information in various formats and languages.

However, Walters has shown that ethnic minority groups, asylum seekers and refugees are less likely to visit their GP and seek treatment. This is often due to a lack of understanding of the health system and/or lack of information about available services.⁴⁹ Studies have also highlighted practitioners' poor understanding of cultural issues due to a gap in the current medical training. This knowledge gap impacts on the assessment and treatment of patients from minority groups.⁵⁰

A study by MEWN Cymru of Black and Minority Ethnic (BME) women in Wales⁵¹ recorded that although most respondents (60%) were happy with the help and support provided by their Local Health Board, 35% of BME women reported that their GP surgery did not use Language Line (a free translating service for patients). Acting upon the data collected, the organisation ran a number of members' training sessions on basic health information topics and an introduction to the healthcare system in Wales and how to access it. The Charity also delivered healthcare providers with ethnic awareness training. The charity found that these sessions helped increase members' awareness of the healthcare system and their role in maintaining their own health. As a consequence of the training, over 70% of women from one specific ethnic group underwent breast screening after attending the sessions.

⁴⁸ Lidubwi N. "Mind the gap: addressing inequality in access to mainstream health care by BME women" MEWN Cymru. 2008

⁴⁹ Walters V. "Health, well-being and access to health and social care of selected minority groups" 2004

⁵⁰ Lidubwi N. "Mind the gap: addressing inequality in access to mainstream health care by BME women" MEWN Cymru. 2008

⁵¹ Ibid

MEWN Cymru also reported that the lack of understanding of how to access healthcare services was experienced equally by long term British residents and new comers, highlighting the overarching impact of ethnicity on health literacy. The study does, however, show the importance of empowering patients and raising awareness, and increasing and improving the communication skills of healthcare professionals.

Learning Disabilities

As mentioned previously, people with learning disabilities have been highlighted by a number of studies as an 'at risk' group for low health literacy skills. This is particularly worrying when we consider that depending on the nature of the disability they may require an increased use of health services.

Moreover they are also more likely to "have general health problems, sensory impairments, mental health problems, epilepsy, cerebral palsy and other physical disabilities".⁵² However, people with learning disabilities tend to access primary care services less than they need to and we know that the uptake rate of screening services is very poor for this section of society, often resulting in undetected conditions.⁵³ This is exacerbated by difficulties in identifying and describing symptoms and struggling to navigate the health system to access treatments⁵⁴ which are also associated with individuals with learning disabilities.

Statistically, a GP with a patient list of 2,000 will include about six individuals with severe learning disabilities and approximately 44 with mild-moderate learning disabilities.⁵⁵ Furthermore, the "prevalence of learning disabilities in the general population are expected to rise by about 1 % per annum for the next ten years and to grow overall by over 10% by 2020."⁵⁶

The Welsh Assembly Government Learning Disability Strategy⁵⁷ aims to help and support patients with a learning disability to live an enhanced and independent life. The strategy addresses the evidence highlighted by the Primary care, Evaluation Audit and Research in Learning disabilities study which, in 2002 found that "of 181 people with learning disabilities who underwent a health review, over half had a new health need identified."⁵⁸ The strategy specifically acknowledged the need to increase primary care access and screening uptake for learning disability patients. For this purpose it is now required that all GMS doctors undertake a free yearly health check for all patients with a learning disability. Practice teams are also allowed to adopt a more pro-active approach and spend more time with patients with

⁵² "Directed enhance service for the care of adults with learning disabilities" accessed from <http://www.lidiag.org.uk/> (26.7.2010)

⁵³ Ibid

⁵⁴ Michael J. "Healthcare for all" 2008

⁵⁵ Ibid

⁵⁶ Ibid

⁵⁷ "Section 7 Guidance on Service Principles and Service Responses" Welsh Assembly Government. 2004

⁵⁸ Michael J. "Healthcare for all" 2008

learning disabilities and their carers. Although this is a welcome change, it does not address the issue around information provision and communication skills identified by researchers.

A NICE audit in 2002⁵⁹ indicated that almost 60% of unexpected epilepsy learning disabilities child deaths and 40% of unexpected learning disabilities adult deaths were potentially avoidable. Poor documentation, communication and information sharing were all challenging areas identified for all these cases⁶⁰. Poor communication and information sharing could be positively supported by health literacy interventions. As described in more detail in future chapters, targeting the way staff communicate, empowering patients (and their carers) to take a more active role in their health care and by making the environment more health literacy aware could help address these poor performing areas.

Carers are essential partners in maintaining and managing the health of patients with learning disabilities. A study from Swansea University⁶¹ found that carers of adults who have Down's Syndrome and dementia felt their information needs were not met. Carers also reported to have detected changes in the patients much earlier than dementia was diagnosed, but were unaware of patients with learning disabilities increased likelihood of developing dementia⁶² and had therefore not sought medical help sooner. Studies^{63,64} have shown that early detection of dementia is an important factor in the on-going care of dementia sufferers, to allow access to services and medications to slow down the condition. This study highlights the importance of adequate health literacy levels of carers' to enable them to be equal partners in the detection, management and maintenance of patients with learning disabilities health.

Increasing the health literacy levels of people with learning disabilities and their carers has the potential to impact on life expectancy and quality of life for this section of society. However, the language used by the healthcare system and improving the way people navigate and access healthcare environments should also be considered. A broad approach it's required to achieve the desired outcome.

⁵⁹ "The epilepsies: diagnosis and management of the epilepsies in adults and children in primary and secondary care, National Institute of Clinical Excellence. London 2004

⁶⁰ Michael J. "Healthcare for all" 2008

⁶¹ McLaughlin K., Jones A. "'It's all changed': carers' experiences of caring for adults who have Down's syndrome and dementia" British Journal of Learning Disabilities. 2010

⁶² Ibid

⁶³ Watchman K. "It's your move" Learning Disability Practice. 2003

⁶⁴ Watchman K. "Keep talking about dementia. Information for siblings and professionals about Down's syndrome and dementia" Edinburgh, Down's syndrome Scotland. 2003

Self care/ condition management

In 2009, the Welsh Assembly Government's "Improving health and wellbeing in Wales - A framework for supporting self care"⁶⁵ reported that one third of the Welsh population is already suffering from at least one chronic condition.

The framework identifies better provision of information as one of the key actions to ensure Wales can meet the challenges ahead. Effective communication is key to the delivery of good care and leads to increased compliance, greater patient satisfaction and improved outcomes⁶⁶.

The 2009 national survey of chronic condition patients' experiences of care found that patients' capacities to self manage was strongly related to their self reported health status. Patients who described their health as good or excellent were much more likely to have higher PAM (Patient Activation Measure) scores. "PAM scores measure the patients' knowledge of their condition and their confidence and skills for self-management." ⁶⁷

Patients who understand and are able to self manage their chronic condition effectively are more likely to perceive their health as good or excellent. The survey reported that 11% of respondents were at the lowest PAM scores, hence unable to understand their role in their own health care and significantly more likely to have attended hospital.⁶⁸

The same survey reported that 53% of respondents with the lowest confidence and skills to self manage their condition (PAM Patient Activation Measure) felt that they had not been provided with enough information to help them understand and/or manage their condition.⁶⁹ An information gap was also reported for information and advice on exercise and for information at time of diagnosis. Younger people and those with lowest PAM scores were the main groups reporting such gaps.

Various initiatives have been implemented in Wales such as the Expert Patient programme which is aimed at providing chronic condition patients with life and health skills to manage their conditions. Evaluation of these programmes has been very successful and shown a decrease in GP consultations, outpatient visits, A&E attendances and an increase in pharmacy visits. The strategic 'Delivering a Five-Year Service, Workforce and Finance Framework for NHS Wales' recently published recognises the importance of such initiatives by stating "engagement, train and utilise patients in managing their diseases⁷⁰" as gold standards to improve long-term care pathways.

⁶⁵ Audit Commission. "What seems to be the matter? Communication between hospitals and patients" HMSO, London. 1993

⁶⁶ AWARD "How do patients with chronic conditions experience care in Wales? A baseline study" 2009

⁶⁷ AWARD "How do patients with chronic conditions experience care in Wales? A baseline study" 2009

⁶⁸ Ibid

⁶⁹ Ibid

⁷⁰ "Delivering a five-year service, workforce and financial strategic framework for NHS Wales". Welsh Assembly Government. 2010

What is the Health Literacy level for Wales?

There are currently no easily available “off the shelf” measures specifically related to health literacy currently accessible in Wales.

The 2005 National Survey of Adult Basic Skills⁷¹ in Wales showed that literacy levels for parts of Wales are very limited and the findings of this survey may suggest that as many as 25% of the survey’s sample had literacy skills equivalent to a seven year old. In a healthcare setting, this would translate as the ability to tell a health professional that the individual is not feeling well but not to describe the level or type of pain. When looking at numeracy, the proportion of the population grows to an estimated 53%. Unfortunately, this survey does not currently include questions relating to health literacy for the population⁷².

A different insight into the scope of the issue for Wales was highlighted by the national survey of chronic condition patients’ experience of care. The survey reported that 11% of respondents were unable to understand their role in their own healthcare and to be significantly more likely to have attended hospital.⁷³ The survey also highlighted a definite information gap between what is provided to the patient and what the patient requires to help understand and manage their condition.

How can Health Literacy be assessed?

The ability to measure health literacy levels is essential to the successful implementation of a strategy intended to tackle this issue, as “successful measurement is a cornerstone of successful improvement”⁷⁴.

Data can be collected and used in various ways. The 1000 Lives Plus programme in Wales has worked closely with all NHS Wales organisations to ensure the collection and use of measurement as an improvement tool. Measures are now collected and used at a local level to monitor progress over time and analyse the effect of small tests of change. Measures are also collected at a national level.

We currently do not have reliable overarching inequity measures in Wales. For this reason it becomes paramount to be able to measure, especially at population level, areas known to have strong impact on health inequities, such as health literacy.

In the case of health literacy, baseline data is not available to help assess the impact of future interventions. For this reason, it is extremely important for Wales to commit to regularly and reliably assess health literacy at population level.

⁷¹ Williams J, Kinnaird R. “The national survey of adult basic skills in Wales” Basic Skills Agency. 2005

⁷² The National Survey of Adult Basic Skills in Wales. Basic Skills Agency 2004

⁷³ AWARD “How do patients with chronic conditions experience care in Wales? A baseline study” 2009

⁷⁴ Doig-Evans et al. “How to improve. The guide for reliable and sustained improvement” 1000 Lives Plus and Health Foundation. 2010

Population Level

Early research has focussed on the development of tools in three main areas: “direct testing of an individual’s abilities, self-report of abilities, and population-based proxy measures.”⁷⁵ The content of such tools and methodologies concentrated mainly on reading, comprehension and numeracy skills.⁷⁶

Over the past few years many countries have attempted to use such tools, however most are now directly involved or scoping the development or application of more comprehensive and modern methods for measuring more functions associated with health literacy levels according to current definitions (the ability and motivation to seek, access understand and act upon health information).

In 2003 the National Assessment of Adult Literacy ⁷⁷ (NAAL) provided a snapshot of the adult literacy levels in America. A component designed to measure English-language health literacy was built into the main assessment, and this component could also provide a separate health literacy score as well as being part of the main NAAL.

Australia has used information from the 2006 Adult Literacy and Life Skills Survey (ALLS) to extract health literacy levels information as a bi-product (or proxy measure) of the survey domains (prose literacy, document literacy, numeracy and problem solving). Australian researchers have developed, tested and validated the HeLMS methodology and are also collaborating in the development of the European Health Literacy Survey.

In Canada, a health literacy scale similar to the ones above was developed to extract health literacy levels from the International Adult Literacy and Skills Survey. This methodology suggested that that 55% of working age adults have less than adequate health literacy skills, 88% of over the age of 65 appear to be in this situation⁷⁸.

In England, The National Institute of Adult Continuing Education (NIECE) is working closely with the English Health Literacy Network to include some tested questions to the National Survey of Adult Skills 2010 survey. These questions will allow researchers to extract health literacy scales using the HALS methodology (a similar methodology to the ones used in Australia, Canada and USA).

⁷⁵ Jordan J.E. et al. “Critical appraisal of health literacy indices revealed variable underlying constructs, narrow content and psychometric weaknesses” *Journal of clinical epidemiology*. 2010

⁷⁶ Ibid

⁷⁷ Rudd R, Kirsch I, Yamamoto K. “Literacy and Health in America” Centre for Global Assessment Policy Information Center Research and development Educational Testing Service. 2004

⁷⁸ Rootman I and Gordon-El-Bihebety D. “A vision for a health literate Canada. Report of the Expert Panel on Health Literacy. CPHA – ACSP. 2008

Although some research has found that within population based surveys non-respondents are generally less educated⁷⁹ ⁸⁰, have a lower income⁸¹ and a lower literacy skill / level⁸², the above international research indicates that population based surveys can be appropriate for assessing health literacy. However all the methodologies discussed above provide a proxy measure and not a comprehensive and direct measure of health literacy.

Measuring health literacy for the population provides similar challenges to any national measure; there are a variety of methodologies, disputed approaches and new tools being developed and piloted. As the definition of health literacy continues to develop, national measures are being piloted across the world, moving away from measuring literacy in a health context to a focus on the decision making process.

Until 2010 there was no methodology able to provide a comprehensive and direct measure of health literacy. Fortunately over the past year, two new approaches have been developed and validated. Both are able to assess different competencies which make up an individual's health literacy level, hence providing a direct and more complete measure.

The following applications and methodologies for assessing population wide health literacy levels have been considered for application in the Welsh language:

I. Health Literacy Management Scale (HeLMS)

This new methodology has very recently been developed and validated in Australia and consists of 29 questionnaire items across 8 domains. Five of the domains focus on individual abilities and three on broader factors that influence these abilities. HeLMS has been designed to allow applications at either an individual level (clinical) or population level and it can be modified to allow for application in diverse settings and cultures as required. Questionnaires are run over telephone interviews with large randomised population samples.

These questionnaires have been developed using psychometric techniques, in-depth interviews and concept mapping workshops, with patient groups across disease and healthcare continuums in Australia.

Six key individual abilities (knowledge of where to seek health information, literacy skills, verbal communication skills, being proactive, capacity to retain and process information and application skills) and 11 broader factors (cultural, social and economic and environment) that influence individuals' abilities were identified and the questionnaires and domains

⁷⁹ Woolf, S.H., et al "Selection bias from requiring patients to give consent to examine data for health services research" Archives of Family Medicine 2000

⁸⁰ Young A. F. Et al. "Health services research using linked records: who consents and what is the gain?" Australian New Zealand Journal of Public Health. 2001

⁸¹ Huang N. Et al., "Record linkage research and informed consent: who consents?" BMC Health Services Research. 2007.

⁸² Ibid

developed use patient sentences and are therefore accessible to patients with suboptimal literacy skills.

This methodology is currently the most comprehensive measure available for all aspects of health literacy and countries across the globe are considering their use at population level.

The flexibility to modify the questionnaires according to local needs makes this methodology extremely versatile. In Wales this methodology should be owned by each health board and trust, to allow each organisation to monitor their population's abilities and needs. However, a set of standard questions included in all questionnaires would allow for national amalgamation of data to provide a comprehensive measure of the skills and abilities of the Welsh population. This would provide the most comprehensive measure for health literacy both at regional and national level, hence supporting frontline improvement, providing clearer understanding of regional needs to support targeted resource allocation and supporting policy makers.

The questionnaires would need to be validated for the Welsh population and it is estimated that this process should take no more than 3-4 months and require limited funding.

We recommend that a cost analysis is undertaken to identify the most cost effective way (licensing of the tool, consultancy agreement with methodology designers).

The regular running of the survey would also require extra allocation of funding for each health board and trust and we advise that a detailed cost analysis of undertaking yearly telephone interviews should be undertaken. However, we believe that this methodology could be successfully amended for Wales to complement the patient surveys currently undertaken by organisations.

We recognise that the initial local adaptation and subsequent running of the survey may be costly in the current financial climate. However, this methodology is the most comprehensive available. It will develop understanding of health literacy at a local, regional and national level, tracking improvement over time and enabling a reduction in the health literacy inequity.

II. The European Health Literacy Survey:

This survey is currently being tested in three European countries and it applies a methodology developed by researchers in Maastricht University. The development of the methodology has been funded by the European Union and surveys will run in 2011 in a number of countries (8 have been confirmed so far and 7 are currently negotiating terms). Non-European countries are also considering taking part in this survey.

This survey will provide an in-depth understanding of an individual's perception of health and the health service, their decision making abilities and reading and writing abilities. The survey is currently being run as a combination of face to face interviews and a self completing survey and it takes an average of 20 minutes to complete. The survey is based on a small sample of 1,000 randomly selected individuals.

Testing so far suggests that this is currently the most comprehensive methodology available for measuring an individual's health literacy level; however, the methodology is still being finalised.

The need for a bilingual survey has been discussed and researchers agree on such needs for Wales. The possibility to include specific sections/questions for Wales is also available.

Funding may be available via a pharmaceutical company to undertake this survey and England is open to the submission of a joint bid with Wales.

If Wales was part of this survey it would not only provide a comprehensive and in-depth baseline for Wales but the data would also be comparable across Europe and our neighbouring nation.

Currently there are no plans to repeat this survey although negotiations with the European Union are underway. Nevertheless, Wales should not miss the opportunity to be part of such a high profile and ground breaking survey.

Public Health Wales has been advised that a co-funding opportunity for Wales and England's inclusion in this survey may be available from MSD UK pharmaceutical company.

III. The National Survey for Wales

This Welsh Assembly Government's survey is based on face-to-face interviews with a representative sample of people aged 16 and over across Wales. The survey aims at reaching a study population of approximately 13,200 adults each year.

The inclusion of the Newest Vital Sign UK assessment tool in the 2012 survey should be considered, and if proven effective it, could its inclusion in subsequent survey could be reviewed.

The Newest Vital Sign (NVS) assessment tool was developed by The University of Arizona, College of Medicine, and modified and quality assured for UK use by the London South Bank University. However, no Welsh version is currently available and modification and quality assurance for the Welsh population would require some funding.

This is a quick screening tool (three minutes to administer) that rapidly assesses an individual's ability to read and apply information from a generic nutrition label for ice cream. The tool requires the individual to answer six questions, which require a combination of literacy and numeracy skills and the raw score (0-6) indicates the likelihood that the patient has limited health literacy. This tool does not have a ceiling effect and it therefore discriminates "amongst individuals across the upper part of the distribution of literacy skills"⁸³.

⁸³ Von Wagner C. et al. "Functional health literacy and health promoting behaviour in a national sample of British adults". J Epidemiol Community Health. 2007

Access has been gained to the UK version of this tool from both the original owner (Professor Barry Weiss) and London South Bank University that has developed the UK version. Inclusion of the tool in the National Survey for Wales is free for all ministerial requests but there is a cost for all requests from outside the Welsh Assembly Government.

However, this tool does not measure motivation, individual health knowledge or decision making processes, which are intrinsic aspects of health literacy. It does simply measure the literacy and numeracy ability in a healthcare setting, and hence it provides a very limited measure of health literacy. By simply focussing on literacy and numeracy level in the English language, the tool will be unsuitable for Welsh translation. Food labels are not translated in the common culture and therefore Welsh speakers would be unfamiliar with the model, rendering this option unsuitable for Wales.

IV. Adult Basic Skills Survey:

This survey is repeated every four to five years and is run independently in England and Wales. There is currently no agreed date for the next Adult Basic Skills Survey. The survey population is all adults aged between 16 and 65, and normally resident in Wales.

The survey is divided into two parts, with a sample of respondents from the first interview taking part in the second. The first interview comprises a 'background' questionnaire, collecting behavioural and demographic data, and two assessments, one for literacy and one for numeracy with a mean total length of 65 minutes. The second interviews are significantly different, involving a test of practical skills and a spelling assessment.

This survey does not include any health literacy specific questions but Wales could follow England and include extra health related questions to the existing survey. This will enable the data to be analysed using the HALS methodology, based on a specially devised algorithm, to provide a health literacy score.

A similar methodology has been successfully applied in other countries (Canada, Australia, USA) in similar surveys. However the resulting score is not a direct measure of health literacy but a proxy measure, and the methodology will require amendments to be used in the Welsh context.

The time lag between surveys (four to five years) makes this application unsuitable to support improvement work, unless combined with strong process measures at local level and regular alternative regional population measurement for areas identified as having the greatest need for improvement.

Recommended Population Measure for Wales:

Public Health Wales strongly recommends the amendment of the HeLMS methodology for application in Wales and to begin implementation by every Health Board and Trust by 2012. Amendment of the methodology should be undertaken collaboratively by the Welsh Assembly

Government, Public Health Wales and representatives of all Health Boards and Trusts in Wales. This is estimated to take about one year.

We recognise that this application is not without cost, but the benefit of being able to understand community needs and abilities to access and interact with the health service will allow Wales to target specific improvement work, undertake groundbreaking research and reduce the health inequity gap. We envisage that this survey will complement, or in some cases replace, the current Patient Surveys undertaken by health boards and trusts.

Public Health Wales also recommends that if an agreement for co-funding of the European Health Literacy Survey in 2011 can be reached with MSD UK, Wales should not miss the opportunity to take part in such a high profile and in depth survey. This will provide data comparable across countries.

Individual Level

Over the years researchers have equally researched ways to assess the health literacy levels of individuals. It is recognised that literacy assessment tools generally used in educational settings are not effective in the health care environment. Literacy tools tend to assess the individual ability to read and write, whereas a health literacy assessment tool needs to appraise the ability to access, understand and act upon health information. Time constraints are also identified as a limitation to using existing educational literacy assessment tools in the health care settings.

Qualitative research⁸⁴ from America shows that many patients with low health literacy skills feel a degree of shame and avoid revealing their helplessness to those around them (family and friends, colleagues, health professionals, etc). Literature⁸⁵ is available showing patterns of coping strategies used by people with low health literacy skills to navigate everyday life requirements above their skills levels to avoid the need to request assistance or having to divulge low health literacy levels.

Due to the embarrassment described above, many patient groups advocates have claimed that using a formal assessment tool would alienate patients and some may avoid contacting the healthcare setting as a result. However, studies have shown that this is not the case. A study⁸⁶ where the assessment tool has been used in healthcare settings by healthcare staff has found that the patients' uptake rate for the assessment was very high (99%) and patients reported an increased satisfaction due to the increased interaction with the service.

⁸⁴ Bennett D., et al "Low literacy, high risk: the hidden challenge facing health care in California" .California literacy. 2003. Accessed from <http://literacyworks.org/healthliteracy/index.html> (12.08.2010)

⁸⁵ Weiss B.D "Health literacy and patient safety: help patients understand. Manual for clinicians" AMA Foundation. 2009

⁸⁶ Weiss B.D "Health literacy and patient safety: help patients understand. Manual for clinicians" AMA Foundation. 2009

Nevertheless, assessment tools at individual levels have so far been used prominently for research and although they could be very helpful at highlighting the issue with healthcare professionals there are other ways to identify patients who may have limited health literacy skills.

Some tested techniques can help health care personnel identify people who may have low health literacy levels without the need to use a formal assessment tool. Asking patients questions such as “Are you happy with the way you read?”, “What is the best way for you to learn?”, “How confident are you with filling out medical forms by yourself?” or “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” have proven to have sensitivities for detecting limited skills ranging from 54% to 83%.⁸⁷

Another tested technique is to ask patients to bring all their medications and to perform a medication review by asking the patient to name each medication and asking them to explain what they are for and how to take them. If patients identify the medications by looking at the pills rather than reading the labels, this could be a symptom of limited health literacy.⁸⁸

In the majority of cases it is not necessary to use formal assessments tools to identify the health literacy level of patients. Simple techniques as described above can provide the healthcare professional with an indication of possible limited competencies. Meanwhile, effective communication training for all healthcare staff and raising the awareness and understanding of health literacy will be a much more beneficial approach, at least until a suitable and tested assessment tool is available in Wales. Wales’ bilingual nature will also require that a sensitive version for the Welsh speaking population is available.

Individual assessment tools could be a valuable resource in some settings and may also be included in national surveys to assess the population level, as seen in the previous section with the inclusion of the NVS tool to the National Survey for Wales.

However, there is an obvious downside to all available assessment tools, as they are only able to measure literacy and numeracy abilities in a healthcare setting, hence making these tools very limited measures of health literacy.

Examples of individual assessment tools:

Below are details of the three most widely used and evaluated assessment tools for health literacy skills. We must highlight that none of these assessments have been tested in Wales to our knowledge; however REALM and TOHFLA have been validated for use in the UK, whereas NVS is currently being validated for UK use by the London South Bank University.

Newest Vital Sign (NVS): Developed by The University of Arizona, College of Medicine, as a quick screening tool (three minutes to administer), for the clinical setting to rapidly assess an

⁸⁷ Ibid

⁸⁸ Ibid

individual's ability to read and apply information from a generic nutrition label for ice cream. The tool requires the individual to answer six questions, which require a combination of literacy and numeracy skills and the raw score (0-6) indicates the likelihood that the patient has limited health literacy⁸⁹. Unlike the next two assessment tools, NVS does not have a ceiling effect and it therefore discriminates "amongst individuals across the upper part of the distribution of literacy skills"⁹⁰.

Rapid Estimate of Adult Literacy in Medicine shortened version (REALM-S): This tool is a quick reading recognition test (one to two minutes to complete), which measures a person's ability to pronounce 66 common medical words and lay terms that adult primary care patients are expected to recognise⁹¹. The raw score is the number of correctly pronounced words with the dictionary pronunciation taken as the scoring standard. This score is used to derive US High School grade range estimates as an approximation of literacy⁹².

Test of Functional Health Literacy in Adults short version (S-TOFHLA): This test is derived from hospital materials to assess reading comprehension and numeracy skills. The test has 40 questions and takes less than 10 minutes to administer. The numeracy section consists of four items. The reading comprehension section has 36 items based on reading comprehension. Every fifth to seventh word in each passage is deleted and individuals must choose between four multiple choice options⁹³.

An Australian team tested the sensitivity of the three tools on the same population sample and found that although the three were moderately correlated, substantial mismatch between tests was still observed⁹⁴. The TOFHLA identified 6.8% of participants as having inadequate or marginal health literacy, while the REALM identified 10.6% with reading levels below the ninth grade. The NVS identified 26.0% of the study population as having either a high likelihood or a possibility of limited health literacy. This indicates what previous studies had already suggested, that NVS may overestimate limited health literacy levels⁹⁵.

What current activity in Wales is seeking to increase Health Literacy Levels?

⁸⁹ Barber M. N. et al. "Up to a quarter of the Australian population may have suboptimal health literacy depending upon the measurement tool: results from a population-based survey". Oxford University Press. 2009.

⁹⁰ Von Wagner C. et al. "Functional health literacy and health promoting behaviour in a national sample of British adults". J Epidemiol Community Health. 2007

⁹¹ Davis T et al., "Rapid assessment of literacy levels of adult primary care patients." Family Medicine. 1991

⁹² Barber M. N. et al. "Up to a quarter of the Australian population may have suboptimal health literacy depending upon the measurement tool: results from a population-based survey". Oxford University Press. 2009.

⁹³ Ibid.

⁹⁴ Ibid

⁹⁵ Weiss B, et al., "Quick assessment of literacy in primary care: the newest vital sign." Annual Family Medicine. 2005.

There are a considerable number of initiatives that tackle health literacy in Wales, and a number of examples of activities which have an effect on health literacy have been identified for each of the groupings below:

- Development of alternative resources
- Medication and condition specific education for patients
- Advocate the use of health literacy communication tools for patients
- Plain language and pictorial written health information
- Targeted mass media Campaigns
- Communication skills training for clinicians
- Self-help groups and peer support
- Advocacy
- Embed health literacy into a person's education throughout their life span
- Improving the healthcare system navigability
- Research and understanding of health literacy

Examples of the initiatives identified are included in Appendix 3 of this report.

However, a lack of knowledge of health literacy as a topic means that most of the interventions listed in the Appendix 3 are not classified under such subject matter and therefore are very difficult to uncover. Moreover, as a result, the initiatives that are available are not aligned with and benefitting from the research and knowledge available in the fast developing research field of health literacy. There is a need to develop a way to connect frontline improvement work with the academic research in this field.

The evaluation process:

Pharmacists across Wales provided the strongest examples of evaluated interventions and their input and commitment in this field must be commended.

Unfortunately, the same methodological evaluation process was not repeated for many of the interventions uncovered. Lack of appropriate evaluation methods for many interventions has been identified as a barrier to understanding their impact and ability to reach their aim (Appendix 3 shows evidence, where this has been identified). However, we acknowledge that other activities and evidence are available in Wales and the list included in Appendix 3 is only intended as a high level overview. Nevertheless we believe that any evidence should be made clearly accessible to increase the potential of learning and greater consideration should be given on effective evaluation of any initiative, especially in light of the current financial demands.

Locally developed process measures should be applied to support any initiative applied in Wales, this will allow service providers to ensure reliable implementation and help inform the overarching national level measure.

Combining these two measurement approaches has been successfully tested in the healthcare improvement field in Wales as part of the 1000 Lives Plus national programme.

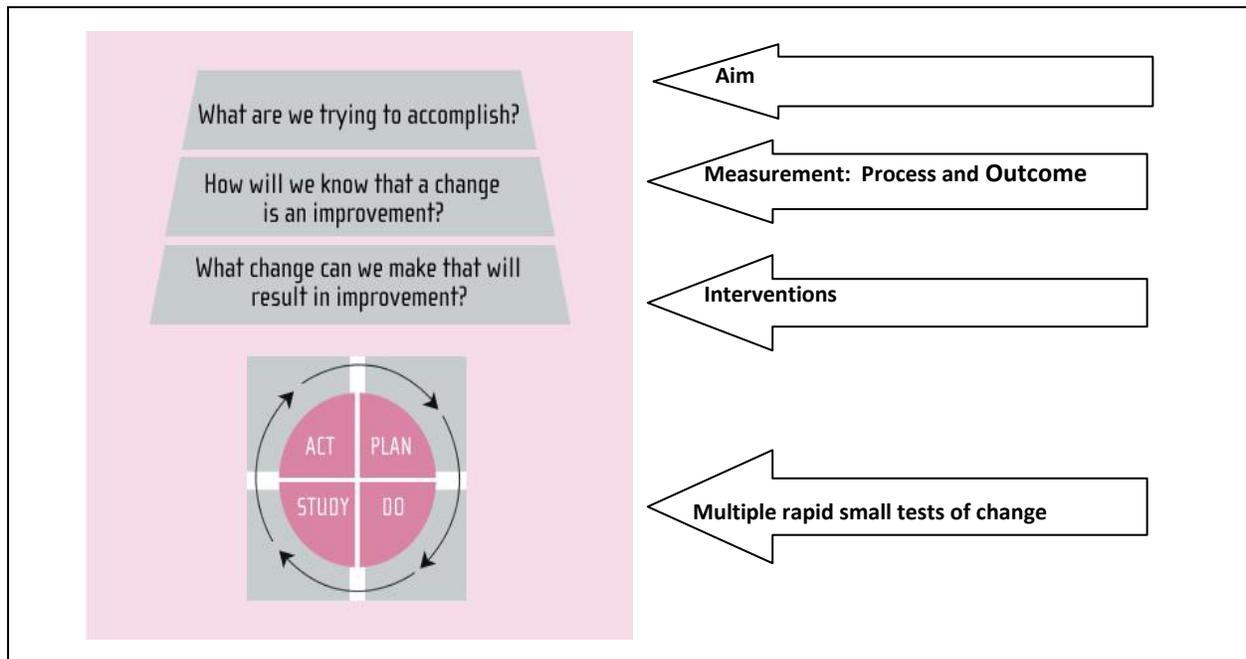


Figure 3: Model for Improvement (How to Improve - The guide for reliable and sustained improvement www.1000livesplus.wales.nhs.uk)

The National Programme aims to embed the use of the Model for Improvement methodology developed by Associates for Process Improvement. This methodology was developed “to provide a framework around which to structure improvement activity to ensure the best chance of achieving [...] goals and wider adoption of ideas”⁹⁶

Local teams with clear aims collect process measures to monitor and improve delivery of service and reliability of implementation of any interventions. Outcome measures linked to each interventions are also set at local level to help track (where possible) the impact of the intervention in its resident system. At the same time, regular (every six months in this case) measurement of overarching outcome data (mortality and harm in this case) is extracted at national level to identify the overall national improvement trend.

⁹⁶ Doig- Evans D. Et al “How to Improve – The guide to reliable and sustained improvement” accessed from www.1000livesplus.wales.nhs.uk

A similar approach should be applied to any improvement project, including health literacy. In the previous chapter we have highlighted the preferred overarching outcome measure (HeLMS methodology amended for Wales) which will also provide information on local communities and systems' needs. Local interventions should be devised at local level to respond to population and systems' needs highlighted by the HeLMS. Application of the Model for Improvement will ensure small tests of change help shape locally designed interventions and the collection of data will ensure that the impact of such changes is monitored at different levels.

What interventions can increase Health Literacy?

The USA Institute of Medicine's Committee on Health Literacy's framework identified three main areas of interventions for health literacy: educational systems, health systems, and culture and society. The Committee's framework shows that interventions and societal investments made in all three areas will contribute to improved health outcomes and costs⁹⁷.

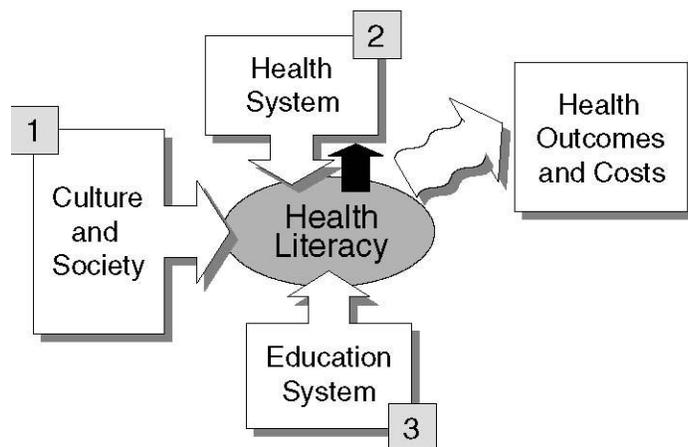


FIGURE 4: Potential points for intervention in the health literacy framework.

Education system:

Training for patients with chronic conditions or requiring high risk medications is already well developed, but is also often not flexible enough to cater to alternative religious and cultural beliefs and customs or language barriers, etc. Similar issues can be observed in many educational projects based in community settings around health topics; they are equally well developed, but are in many cases, also not cultural or language sensitive. Strengthening the links with charities, community groups and carers, and by providing support for local development of training courses would provide greater inclusion of 'hard to reach' groups and empower local communities and families to better manage their care and optimised use of health care services.

⁹⁷ "Health Literacy. A prescription to end confusion" National Academy of Sciences. 2003

As previously mentioned on page nine, individuals seek information or advice from people they know or family members, for this reason we must increase the general population health literacy levels, one initial step will be to create a Health Literacy Framework for Wales which will help monitor, standardise and quality assure training programmes and their delivery across sectors, while recognising learners' knowledge and/or competence across the four pillars of learning.

Equally important will be to ensure our workforce is able to effectively communicate health related messages to people with various levels of health literacy. It is important that all allied health professionals in employment, undergraduate or postgraduate education should be made aware of health literacy and should be skilled in effective communication techniques such as 'Teach Back' or shared decision making.

Health system:

The current health system can in itself be a barrier to achieving an optimised health literacy level. Navigating the system, accessing and understanding medical information can be difficult especially for those with limited or poor literacy and numeracy skills. Health Boards and Trust already have strong links with patient groups or representatives that provide support to ensure accessibility of material. However, experience tells us that patients groups and representatives have a better than average understanding of the healthcare system. For this reason we believe that NHS Wales should strengthen links with ESOL (English for Speakers of other Languages) and Basic Skills training providers to ensure that the material developed is accessible to those with the lowest literacy and linguistic skills. Students could also be involved in accessing navigability of the system and appropriateness of signage in the healthcare systems' physical environment.

The information provided by the healthcare setting is often confusing, not easily accessible, in the wrong format, or not culturally or language sensitive. Health boards and trusts should ensure closer links with local community and charities to ensure information material is language and culture sensitive. NHS Wales should also ensure material is developed in multi formats to increase accessibility of the material; all these extra information should complement the information already available on the NHS Direct Wales website.

To ensure information is widely available the Book Prescription scheme should be extended to allow health material available on the NHS Direct Wales website is available in the communities. Hospitals could also provide in-house learning opportunity for resident patients and their family and carers by setting up educational rooms that will contain the same information and it should be able to signpost any interested party to basic skills training in their local area.

The healthcare system should also locally own the HeLMS methodology to help organisations to better understand the needs and abilities of their service users and help them design, plan

and test locally developed interventions using the Improvement Methodology described in the previous chapter.

Culture and society:

Increasing engagement and strengthening links between agencies and departments will help share learning and increase collaboration, hence ensuring inclusion of the most disadvantaged groups and optimization of the health literacy of the wider population.

To help achieve this multi-professional awareness, sessions on health literacy and its implications for Wales should be delivered for all professionals who have regular opportunities to impact on individual's health behaviors (social workers, policy makers, teachers, police officers, prison services, etc).

It will be essential to be able to modify the 'motivational' element of health literacy, to have an impact in the public's perception of their role in managing and maintaining good health. To do so, a public awareness campaign to ensure everyone is aware of their own role in managing health should be launched to coincide with the international Health Literacy Month (October). This campaign should be combined with the awareness raising sessions for professionals we discussed in the previous paragraph.

Welsh university will be encouraged to further develop research in this field which in turn with increase our understanding of health literacy and advance the evidence based pool of interventions available to optimise health literacy.

Recommendations

The following recommendations have been compiled and quality assured through a multi stage consultation process with experts from Wales, members of the public and international academics. For further info on the methodology used, please read Appendix 1.

1 - Research and Development:

Led by the Welsh Assembly Government and supported by the 1000 Lives Plus national programme (subject to Board approval). Funding required to develop and maintain a health literacy measure.

1.1 The Welsh Assembly Government must commit to the regular measurement of the health literacy level of the population to provide policy direction and strategic action planning capacity. It is recommended that Wales adapts the HeLMS methodology for yearly use and explores co-funding opportunity for the HLS-EU survey.

1.2 To ensure the bilingual nature of Wales is effectively recognised and supported, all health literacy interventions and assessment tools should take account of

the principle of linguistic equality. This will ensure the development of health literacy interventions that are fit for purpose for the bilingual context; and tailored to empower the diversity of language speakers within the population, according to their needs.

1.3 Encourage research into the development of health literacy throughout an individual's life, its impact on bilingual populations and the dynamics of healthcare communication in the bilingual setting.

1.4 Apply the Model for Improvement methodology as supported by the 1000 Lives Plus national programme to evaluate all interventions/initiatives with health literacy implications. Measurement of process, outcome and balancing measures should become embedded practice across services. This will help better evaluate the short-term impact of any intervention, whilst also still measuring the high level impact on health inequities (which have a more long-term impact).

2 - Communicating good practice:

Led by Public Health Wales with technical support from the 1000 Lives Plus national programme (subject to Board approval), Health Solutions Wales and NHS Direct Wales (managed by WAST). Cost analysis and feasibility studies required.

2.1 Establish a health literacy network for Wales to ensure the spread of good practice, encourage cross sectional collaborations and learning, and develop bilingual patient information materials in various formats. This network will link closely with the UK Health Literacy Network and the European Health Literacy Network.

2.2 Expand the NHS Direct Wales website to support the health literacy network.

3 - Awareness Raising:

Led by Public Health Wales and supported by 1000 Lives Plus national programme (subject to Board approval). Limited budget required to implement this work.

3.1 Develop an evaluated bilingual mass media campaign to raise awareness of patients' role in managing own health status and to ask questions during consultations (similar to the 'Ask me 3' material). This could coincide with the International Health Literacy Month (October).

3.2 Awareness raising sessions for all allied health professionals and other professionals with access to disadvantaged and hard to reach communities such as homeless charities, prison services, social workers, ethnic and sexual minority groups, etc.

3.3 Awareness raising sessions for policy makers and senior public sector leaders to increase health literacy understanding.

3.4 Use Awareness raising sessions to encourage multi-professional learning and help establish collaboration across sectors and agencies.

4 - Increase health literacy levels in the general population/patient education:

Public Health Wales will lead in collaboration with key partners and stakeholders. It is anticipated that no extra funding will be required.

4.1 Promote the development of a Health Literacy Framework for Wales using the Credit and Qualifications Framework for Wales (CQFW). This will ensure the monitoring, standardisation and quality assurance of training programmes and their delivery across all sectors, while giving learners recognition of their knowledge and/or competence from Entry level (basic skills level) to level 7 (postgraduate level).

4.2 Extend and better promote the current provision of patient and health education to increase public uptake.

4.3 Aim to provide reoccurring support such as self-help groups, advocacy and repeated training opportunities throughout an individual's life.

4.4 Encourage better inclusion of minority and disadvantaged groups through greater engagement with the voluntary sector.

4.5 Basic skills and ESOL (English for speakers of other languages) training providers should collaborate with Health Boards and Trusts to ensure health topics are included as part of the basic skills curriculum. Training participants could also become involved in testing multi-lingual material readability and assessing system navigability.

4.6 Engage basic skills pupils in the development of peer to peer accredited learning materials that could be tested with the aim of developing training that will be context, language and culture sensitive for Wales.

5- Better access to health information:

All health boards and trusts supported by Public Health Wales (dependent on the Network establishment. 2.1).

5.1 Ensure health information materials are accessible in the community by working with libraries to build on the 'Book prescription' system already in place.

5.2 Hospitals should be encouraged to set up patient education rooms which will provide better access to relevant, bilingual health information; staff working in these

rooms should be able to signpost patients to basic skills classes in their local communities.

5.3 Use the extended NHS Direct website to host multi-format information material and web-based bilingual educational material for patients, service users and professionals.

6- Patient Communication:

Dependent on Network establishment (2.1) to lead in partnership with Welsh Assembly Government, 1000 Lives Plus national programme (subject to Board approval) and Public and Patient Involvement Network Leads.

6.1 Create templates for all standard patient communication that can be locally adapted. Patient and Public Involvement Network Leads will be supported by advocacy groups, patients and charity groups to ensure culture and context sensitivity.

6.2 All material produced should be available in plain Welsh language (Cymraeg Clir).

6.3 As part of the 1000 Lives Plus national programme, ensure every prescription issued in Wales has clear advice on how the medication should be taken.

7- Professional Development:

Public Health Wales will lead in collaboration with key partners and stakeholders.

7.1 Health literacy concepts, communication skills (such as 'Teach Back') and shared decision making techniques should be formally taught at undergraduate, postgraduate and CPD level to encourage further patient engagement during medical consultations.

7.2 Develop an e-learning health literacy awareness module (based on existing courses already available in USA) and ensure all NHS frontline staff undertakes the course regularly (every two to three years). The training should include health literacy definitions and implication, language awareness, communication skills that are proven to be health literacy sensitive, how to access and signpost patients to multi-formats patient information material and signpost staff to the health literacy network/website for further info.

Appendix 1

Methodology for the selection of the report's recommendations:

Between May 2010 and August 2010, requests for information on activities related to health literacy were sent to:

- All academic bodies in Wales
- Trade unions (UNISON & RCN)
- NHS Public and Patient Involvement Networks
- Charities (MIND, GAVO, Voices from Care, NIACE Dysgu Cymru, Agored Cymru, Llamau, Community Learning Wales, ContinYou, Voices for Care, Minority Ethnic Women's Network Cymru)
- Local Authorities
- Communities First
- Welsh Local Government Agency
- National Leadership and Innovation Agency for Healthcare
- Public Health Wales
- Health Challenge Wales

The scoping exercise provided information on 54 health literacy related initiatives and supplied the talent pool from which 21 experts were selected to become members of the Technical Team.

Professor Sir Mansel Aylward agreed to Chair the group and provided invaluable guidance at every stage of the consultation.

Table 1: Breakdown of Technical Team representation

Organisations	Number of representatives	Consultation response
NHS organisations	8	7
Academic bodies	6	3
Charities	4	2
Welsh Assembly Government	2	0
Local Authorities	1	0
Total	21	12

A separate scoping exercise was also run in parallel to identify international policies, recommending a total of 82 interventions/statements of intent and areas of policy development.

The following policies were identified:

- USA Department of Health and Human Services Guide to health literacy
- Canada Experts Panel on Health Literacy Ideas for action
- Scotland Health Literacy Report
- The California Health Literacy Initiative
- USA National Action Plan to Improve Health Literacy
- World Health Communications Associates
- England Health Inequalities Policy (2008)
- Ireland Health Literacy Policy and Strategy

The 'Scottish Scoping Study' was not included as it was deemed to aim at high level policy makers, the 'Scotland Health Literacy Report' was instead identified as the most suitable representative of a Scottish strategic framework for the purposes of our consultation.

A total of 136 interventions were identified and grouped into 12 different categories according to an overarching aim.

Each category was mapped against academic research evidencing their effectiveness in reducing health literacy inequity (either by improving patients health literacy level or increasing the system accessibility) to ensure their validity. All material not easily classified under these aims were entered under a general 'Orphan' Intervention grouping.

The categories identified were:

- Development of alternative resources
- Medication and condition specific education for patients
- Advocate the use of health literacy communication tools for patients
- Plain language and pictorial written health information
- Targeted mass media Campaigns
- Communication skills training for clinicians
- Self-help groups and peer support
- Advocacy
- Embed health literacy into a person's education throughout their life span
- Improving the healthcare system navigability
- Encourage research and understanding of health literacy for Wales
- 'Orphan' interventions

All selected aims and their respective material were circulated to the Technical Team members who were asked to grade them according to their effectiveness in tackling health literacy and their applicability for Wales.

Members were asked to use a matrix (Grading scale: 1: very poor effect; 2: poor effect; 3: little effect; 4: some effect; 5: strong effect; x unable to comment), and to identify their preferred example from each grouping (adding + next to the grade). Comments on any missing interventions and the groupings selected were also encouraged.

The document was sent out to the Technical Team for consultation for seven working days. A limited response rate and members signposting to further members to be included resulted in the consultation process to be extended for a further week to allow members more time to complete the working table and new members to be engaged in the process.

12 members completed the consultation, but two members did not provide grading, resulting in only 10 tables accepted for quantitative analysis.

The information collected via the working table and the face to face consultations with the Technical Team members helped shape 13 draft recommendations. These recommendations were sent out to the Welsh Technical Team, experts from UK and further afield and a patient group (Involving People Network) for further consultation.

As a result of this final stage recommendations were split into separate headings for ease of read and two extra recommendations were included (1.2 & 4.1) and other changes were made to the original interventions which resulted in the set of final recommendations included in this document.

Feedback from this final consultation stage have been very positive, examples of comments are:

- “The recommendations seem sensible to me.”
Member of the public, Involving People Network, Wales
- “I believe you have done a very thorough job and made good recommendations” (Kristine Sorensen, Maastricht University health literacy researcher, The Netherlands);
- “..Lots of good stuff here..”, (Franklin Apfel, World Health Communication Associates Managing Director),
- “Following your suggestions will definitely have an impact in your population, and this approach might be of major importance for reducing health inequalities and inequities - something that has proven so difficult to achieve. [...] You are much ahead of us! We hope to learn from you later!” (Kristina Alexanderson, Professor at Karolinska Institutet, Sweden)
- “Wales can lead this area and stimulate other countries to utilize Health literacy and a way to reduce inequity, improve health, and prevent health from creating the downward spiral to social and material deprivation.” Richard Osborne, Deakin University, Australia)

Appendix 2

Breakdown for possible implementation

Recommendation	Lead	Partners	Existing resources available	Extra resources required	Notes
<p>1.1 The Welsh Assembly Government must commit to the regular measurement of the health literacy level of the population to provide policy direction and strategic action planning capacity. It is recommended that Wales adapts the HeLMS methodology for yearly use and explores co-funding opportunity for the HLS-EU survey.</p>	<p>WAG</p>	<p>Public Health Wales, all health boards and trusts</p>		<p>HSJ-EU: Possible co-funding available for a UK survey (awaiting more info) HeLMS: Licensing of the methodology and amendment of tool.</p>	<p>Cost analysis for telephone implementation to be undertaken</p>
<p>1.2 To ensure the bilingual nature of Wales is effectively recognised and supported, all health literacy interventions and assessment tools should take account of the principle of linguistic equality. This will ensure the development</p>	<p>WAG</p>				

Recommendation	Lead	Partners	Existing resources available	Extra resources required	Notes
of health literacy interventions that are fit for purpose for the bilingual context; and tailored to empower the diversity of language speakers within the population, according to their needs.					
1.3 Encourage research into the development of health literacy throughout an individual's life, its impact on bilingual populations and the dynamics of healthcare communication in the bilingual setting.	Academic organisations	Public Health Wales			
1.4 Apply the Model for Improvement methodology to evaluate all interventions/initiatives with health literacy implications. Measurement of process, outcome and balancing measures should become embedded practice across services. This will help	Public Health Wales	All NHS health boards and trusts; 1000 Lives Plus (subject to Board approval).	1000 Lives Plus national programme	Provide training to non NHS organizations (Local Authorities, NGOs, etc)	

Recommendation	Lead	Partners	Existing resources available	Extra resources required	Notes
<p>better evaluate the short-term impact of any intervention, whilst also still measuring the high level impact on health inequities (which have a more long-term impact).</p>					
<p>2.1 Establish a health literacy network for Wales to ensure the spread of good practice, encourage cross sectional collaborations and learning, and develop bilingual patient information materials in various formats. This network will link closely with the UK Health Literacy Network and the European Health Literacy Network.</p>	Public Health Wales	1000 Lives Plus (subject to Board approval).	Network establishment and management experience but no current resources to launch and maintain such a network	Inclusion of this work in existing delivery programmes or staff job roles.	
<p>2.2 Expand the NHS Direct Wales website to support the health literacy network.</p>	NHS Direct Wales (Managed by WAST)	Public Health Wales and Health Solution Wales	Website is already in place.	<p>Increase capacity and a separate area for network members.</p> <p>Ability to upload and download multi</p>	A cost analysis and feasibility study should be undertaken.

Recommendation	Lead	Partners	Existing resources available	Extra resources required	Notes
				format material.	
<p>3.1 Develop an evaluated bilingual mass media campaign to raise awareness of patients' role in managing own health status and to ask questions during consultations (similar to the 'Ask me 3' material). This could coincide with the International Health Literacy Month (October).</p>	Public Health Wales			<p>Additional communication team support.</p> <p>Merchandise, poster campaign and evaluation process will require specific budget allocation</p>	Cost analysis to be undertaken
<p>3.2 Awareness raising sessions for all allied health professionals and other professionals with access to disadvantaged and hard to reach communities such as homeless charities, prison services, social workers, ethnic and sexual minority groups, etc.</p>	Public Health Wales	1000 Lives Plus (subject to Board approval).	Limited supportive capacity for webex sessions available.	Increased funding for regional events or alternatively funding for one event per NHS Wales organisation.	

Recommendation	Lead	Partners	Existing available resources	Extra resources required	Notes
3.3 Awareness raising sessions for policy makers and senior public sector leaders to increase health literacy understanding.	Public Health Wales	PSMW/NLIAH			
3.4 Use Awareness raising sessions to encourage multi-professional learning and help establish collaboration across sectors and agencies.	Public Health Wales				
4.1 Promote the development of a Health Literacy Framework for Wales using the Credit and Qualifications Framework for Wales (CQFW). This will ensure the monitoring, standardisation and quality assurance of training programmes and their delivery across all sectors, while giving learners recognition of their knowledge and/or competence from Entry level	Public Health Wales	Relevant partner organisations and stakeholders to be indentified			Framework development is free but some subsequent funding may be required for curriculum development.

Recommendation	Lead	Partners	Existing available resources	Extra resources required	Notes
(basic skills level) to level 7 (postgraduate level).					
4.2 Extend and better promote the current provision of patient and health education to increase public uptake.	NLIAH / WAG	All NHS organisations, Local authorities	Trainings are already available	Increase advertisement of available courses and increased capacity	
4.3 Aim to provide reoccurring support such as self-help groups, advocacy and repeated training opportunities throughout an individual's life.	NHS Wales	Charities, Public Health Wales			
4.4 Encourage better inclusion of minority and disadvantaged groups through greater engagement with the voluntary sector	Public Health Wales	Charities and Third sector			
4.5 Basic skills and ESOL (English for speakers of other languages) training providers should collaborate with	Basic Skills and ESOL providers	NHS Wales			Cost analysis to be undertaken

Recommendation	Lead	Partners	Existing available resources	Extra resources required	Notes
Health boards and trusts to ensure health topics are included as part of the basic skills curriculum. These groups could also become involved in testing multi-lingual material readability and assessing system navigability.					
4.6 Engage basic skills pupils in the development of peer to peer accredited learning materials that could be tested with the aim of developing training that will be context, language and culture sensitive for Wales.	Public Health Wales	Basic skills providers; NHS Wales			
5.1 Ensure health information materials are accessible in the community by working with libraries to build on the 'Book prescription' system already in place.	Library services	NHS Wales and Public Health Wales		Increased quantity of material developed	

Recommendation	Lead	Partners	Existing resources available	Extra resources required	Notes
<p>5.2 Hospitals should be encouraged to set up patient education rooms which will provide better access to relevant, bilingual health information; staff working in these rooms should be able to signpost patients to basic skills classes in their local communities.</p>	<p>NHS Wales</p>	<p>Libraries services and Public Health Wales</p>			
<p>5.3 Use the extended NHS Direct website to host multi-format information material and web based bilingual educational material for patients, service users and professionals.</p>	<p>NHS Direct Wales (WAST)</p>	<p>Public Health Wales and all NHS organisations</p>	<p>Health Literacy Network to collaborate with NHS Direct (dependant on health literacy network development 2.1)</p>		
<p>6.1 Create templates for all standard patient communication that can be locally adapted. Patient and Public Involvement Network Leads will be supported by advocacy groups, patients</p>	<p>Public and Patient Involvement (PPI) Network Leads</p>	<p>Public Health Wales</p>	<p>PPI network already in place</p>		

Recommendation	Lead	Partners	Existing available resources	Extra resources required	Notes
and charity groups to ensure culture and context sensitivity.					
6.2 All material produced should be available in plain Welsh language (Cymraeg Clir).	Public and Patient Involvement (PPI) Network Leads	Public Health Wales	PPI network already in place		
6.3 Engage basic skills pupils in the development of peer to peer accredited learning materials that could be tested with the aim of developing training that will be context, language and culture sensitive for Wales.	NHS Wales/ Public Health Wales	Basic Skills providers and NLIAH		Accreditation and quality assurance would require some funding	
6.4 As part of the 1000 Lives Plus national programme, ensure every prescription issued in Wales has clear advice on how the medication should be taken.	1000 Lives Plus national programme	All NHS Wales organisations	Programme area already in implementation phase so no extra cost to the project		

Recommendation	Lead	Partners	Existing resources available	Extra resources required	Notes
<p>7.1 Health literacy concepts, communication skills (such as 'Teach Back') and shared decision making techniques should be formally taught at undergraduate, postgraduate and CPD level to encourage further patient engagement during medical consultations.</p>	<p>Public Health Wales</p>	<p>Academic Bodies</p>			
<p>7.2 Develop an e-learning health literacy awareness module (based on existing courses already available in USA) and ensure all NHS frontline staff undertakes the course regularly (every 2-3 years). The training should include health literacy definitions and implication, language awareness, communication skills that are proven to be health literacy sensitive,</p>	<p>Public Health Wales</p>		<p>A number of e-learning modules are already available in USA. These would simply require modification for Wales.</p>	<p>Development of moodle modules accessible to all NHS Wales. (PPI Moodle curriculum is being considered in Wales. Linking the two curriculums may provide cost savings.)</p>	

Recommendation	Lead	Partners	Existing available resources	Extra resources required	Notes
<p>how to access and signpost patients to multi formats patient information material and signpost staff to the health literacy network/website for further info.</p>					

Appendix 3:

Examples of Welsh health literacy initiatives

Development of alternative resources:

- Digital patient stories are used for peer – to peer training for cardiac patients in Aneurin Bevan Health Board.
- Mental health remote support (extensive support systems available from 3rd sector in various formats – phone line, chat, etc).
- Diabetes Cymru CD Rom.
- Video resources developed for new parents regarding birth options in Abertawe Bro Morgannwg University Health Board. The DVD shows facilities available for each birth options and contain interviews with other patients and members of staff.
- Video resources developed for patients who are dependent of secondary care to explain how the new hospital in Ystrad Mynach will be functioning as a single room hospital.
- Healthpoint Technology Kiosks based in 30 community pharmacies in Gwynedd in 2004. Evidence: 800,000 hits in the first 12 months of installation into 30 community pharmacies. Better management of asthmatic symptoms and improved inhaler technique have been feedback by users.
- NHS Direct Wales website provides vast easy read resource for patients spanning from condition specific to health issues and local services.
- Drink Wise Wales website provide guidance on responsible drinking and helps calculate unit intake and monitor personal use via a web based drink diary. The site also makes the link between unit drank and calories intake.

Medication and condition specific education for patients:

- Expert Patients Programme. Evidence: a 2007 evaluation of two pilot sites in Wales recorded that participants may report being more affected by their conditions but may still be better able to manage the problem following the EPP course. A three month follow up found an average of 50% less missed days compared to prior to taking part in EPP. High level of satisfaction with the course, increased self esteem, relaxation, and action planning were also reported.
- Credit for Patient curriculum, accreditation of condition management patient training (some examples are included below: h - k).
- Mental Health first aid, mental health literacy course. It helps participants to recognise the signs and symptoms of someone with mental health problems; to respond to various mental health crises, engage with, support and signpost people to appropriate help. Evidence: 48% of respondents reported an increase preparedness following the

training, 94% said the training had positively changed their attitudes towards mental health.

- Health trainers (to be tested shortly in the Heads of the Valley region).
- Self medication course run by Ceredigion community pharmacist. Evidence: Comparison of before and after questionnaires showed a significant shift away from doctor consultations towards self-treatment.
- Cynon's 'Simple cough and cold' training by 15 GP pharmacist and GP practices. Patients with cough or cold symptoms were referred to the local pharmacist for advice and free symptomatic medication (the project ran between October 2001 and March 2002). Evidence: Between January and March 2002 three thousand less prescriptions for antibiotics were dispensed in Cynon compared with the same period the previous year (21% decreases).
- Pharmacists led training for patients on more complex medications at Cardiff and Vale University Health Board.
- Health and Happiness course (weight management, nutrition and dieting course available in the Cwm, Waunlwyd and Victoria area).
- Routes to Recovery training delivered by Interlink in the Rhondda Cynon Taff area aimed at people with mental health difficulties.
- Diabetes education programme delivered by Aneurin Bevan Health Board.
- Managing Angina and Recovering from Cardiac Surgery training for patients with cardiac conditions in the Torfaen locality.

Advocate the use of health literacy communication tools for patients:

- 'Voices for Care' website holds information for teenagers on how to make the most of their Health Assessments.
- Encouraging patients to ask questions about their medications as part of the "Ask about medicines week".

Plain language and pictorial written health information:

- Screening services award winning patient information leaflet "Information for women"
- Children Eating Well, dietary and nutritional photographic resource for children and families.
- Reader's panel and patient information group supports and quality assures every patient Ensuring every prescription has clear advice on how to take the medication (tested in 9 LHBs between November 2004 and October 2005). Evidence: the proportion of prescriptions with one or more items with no specific dosage instructions fell from 29% to 3%.
- information developed for Betsi Cadwaladr University Health Board (Central area).
- Material aimed specifically at Learning Disabilities patients includes pictorial and universal symbols.

- Service users groups consulted in secondary care to proof read patient information.

Targeted mass media Campaigns:

- Public Health Wales' Bowel Cancer screening tool Campaign. Evidence: significant increase of bowel screening test awareness amongst target group, 8 out of 10 of the evaluation sample population was prepared to use test following advertisement campaign).
- Welsh Backs Campaign (developed in collaboration with Health Challenge Wales). Care advice for patients suffering from back pain, employers and health professionals on how to help patients.
- Health Challenge Wales. Government-run initiative and website to support the public to live an active and healthy life by signposting to activities and resources. The initiative also supports organisations in actively supporting a healthy work environment. Evidence: in 2009 43,290 people visited the site.
- Ask the expert column in the Western Mail.
- Royal Pharmaceutical Society in Great Britain media Campaigns (i.e. medication advice for Muslim during Ramadam; a Campaign advising patients to consult their pharmacist for a medication review, etc).
- Avoid medication waste campaign. Evidence: One participating health board evaluated its effects and found that 47% of sample population had seen the advert and of these 60% said they would change the way they ordered prescriptions as a result.
- Healthy Heart Roadshow, a cardiac nurse and clinician will be visiting various towns across Wales providing free lifestyle checks and provide training on how to lead a healthier lifestyle lowering the risk of heart disease.

Communication skills training for clinicians:

- Current Clinical communication skills training for undergraduate and post graduate medical students include effective communication techniques.

Self-help groups and peer support:

- Extensive third sector mental health self help groups.
- Cardiac patients coffee mornings (Betsi Cadwaladr University Health Board).

Advocacy:

- Black and ethnic minority women charity advocacy.

- Children and children and young peoples advocacy services as proposed by the 'The National Action Plan to Reduce Self-Harm in Wales'.

Embed health literacy in the school and academic curricula, adult learning and training in the work place:

- Healthy Schools Scheme.
- 'Kids for Fun Club' - Testing of a community learning programme based on 'Skilled for Health' in Rhyl aimed at improving health literacy levels. Evidence: participants reported an increase understanding of the benefit of healthy behaviours specifically around exercise and nutrition at completion of the course and at four weeks follow up. The course was well received by participants and tutors.
- Welsh Union Learning Fund project aims to maximise the contribution of Trade Unions to the achievement of the Welsh Assembly Government's workforce development objectives. Evidence: Abertawe Bro Morgannwg University Health Board reported 154 more qualifications due to WULF project. Nationally WULF has funded 115 projects nationwide since April 1999.
- UNISON Learning Education and Partnership programme promotes and encourages the ethos of lifelong learning in the workplace by providing new and different learning opportunities for staff working in the area of health and social care, enabling staff to develop skills and confidence at work through learning.
- Basic Skills Employer pledge.
- Math for healthcare course developed by Abertawe Bro Morgannwg University Health Board to help health professional calculating infusion drug rates.
- Math for nurses national training programme.
- Healthy eating and budgeting training for youth groups in the Cwm, Waunlwyd and Victoria area.

Improving the healthcare system navigability:

- My Health Online project, currently being piloted, aims at providing patients internet access to their own record and enabling them greater involvement in their own care. This tool will allow patients to book GP appointments, order repeat prescriptions, etc; enabling patients to organise their healthcare from the convenience of their home and gain access to specific condition and health information relevant to them.
- Health board requirements to provide pharmacists with details of health and social care providers in the areas which pharmacists can use to signpost patients as required.

Encourage research and understanding of health literacy for Wales:

- Welsh School of Pharmacy research into patients' knowledge and understanding of over-the counter medicines side effects.
- Language Awareness Infrastructure Support Service (LLAIS) based at Bangor University ensure that health and social care research in Wales takes full account of the bilingual nature of Wales and its speakers; and to enhance the delivery of health and social care services to Welsh speakers in Wales.
- Cardiff University PHD student researching the development and practice of health literacy in patients with a long-term.
- Health condition through self-directed learning, patient education and social interaction.
- Swansea University research on communication/interaction between health professionals and patients.
- Lampeter University research on the public ability to evaluate health information portrayed in the media.