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- Annex 1 Topic Guide for Interviews
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- Annex 3 Findings – Stage 1
- Annex 4 A Selection of Ongoing Initiatives in Scotland
EXECUTIVE SUMMARY

Introduction
The Health Improvement Strategy Division of the Scottish Government commissioned a proposal for ‘Health Literacy – A Scoping Study’ in December 2008. The main purpose of the study was to identify and examine current approaches to health literacy, and to identify options for potential policy responses on this topic. The objectives of the study were to:

a. Identify and review current definitions of health literacy;
b. Examine whether and how health literacy has been measured both in the UK and elsewhere;
c. Identify examples of policy and practice initiatives in health literacy which have been implemented elsewhere, together with information about the evaluation of their impact where these are available;
d. Map the nature and extent of relevant links between health literacy and extant and developing Scottish Government policy;
e. Identify possible options for developing programmes, policies, and / or approaches on health literacy which merit further investigation.

Study Methods and Approach
The study was conducted in two stages. Stage 1 was desk based, and consisted of a document analysis, together with online searches. Stage 2 was conducted using key informant interviews. Twenty-five interviews were conducted.

The work was designed to be conducted in a short timescale and to provide a platform from which a more detailed policy response could be developed. The document review was not intended to be a comprehensive literature review; and the key informant interviews were not intended to be a comprehensive account of all health literacy work ongoing in Scotland. Rather the work is illustrative, and provides examples of the kinds of initiatives and responses which are being tried, tested or implemented in relation to health literacy.

Findings of Stage 1
The key findings from Stage 1 are:

- There is no universally agreed conceptualisation or definition of health literacy. The term has been used in a variety of ways over the last 30 years or so. Earlier definitions concentrated on what is generally referred to as ‘functional’ health literacy; this is quite a narrow concept in which health literacy is seen as the ability to read and comprehend written medical information and instructions. Later definitions of health literacy have become broader, and have emphasised empowerment and citizenship aspects. A useful working definition of health literacy for the purposes of this report which resonates with a public health orientation to the topic is ‘the wide range of skills and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, and increase quality of life’.
• There are a variety of tools available to measure ‘functional’ health literacy, but work on measuring wider aspects of health literacy is in its infancy. Despite the lack of definitive estimates, which is in part due to the complexity of developing good measures, there is agreement that there is a substantial and widespread problem of low or inadequate health literacy.

• Low health literacy is particularly prevalent amongst lower socioeconomic groups, ethnic minorities, the elderly, and those with chronic conditions or disabilities. People with low health literacy have a range of associated problems including poorer health status, greater risk of hospitalisation, less knowledge of disease management and health promoting behaviours, and less ability to self manage and to share decision making with healthcare professionals.

• Over the past 5-10 years the USA, Canada, and some other countries have adopted targets and objectives for improving health literacy within their strategic policy processes. In addition, there has been a focus over a similar timescale on international reviews of research evidence to examine what initiatives in health literacy have been tried and what the impact of these have been.

• The most relevant, comprehensive and recent review of the research evidence has concluded that ‘initiatives designed to specifically target low literacy groups have had mixed results, with some studies showing beneficial effects on knowledge and behaviour, but there have been relatively few attempts to test the effects of these initiatives on reducing health inequalities’.

• Health literacy is strongly linked to current policy within NHS Health Scotland and more widely within the Scottish Government. The key policy links are to health inequalities; patients rights; patient safety; self care and the management of long term conditions; anticipatory care; shifting the balance of care; eHealth; mental health and wellbeing; adult literacy and numeracy; and workforce policy and planning. Health literacy is also closely linked to the six dimensions of quality / improved care: patient centred, safe, effective, efficient, equitable and timely.

• Policy responses to health literacy could include any or all of the following: improvements to written materials; service redesign to improve the healthcare experience from the perspective of the patient; building on the adult literacy and numeracy strategy; developments to and support for health professionals to develop their competencies.

**Findings from Stage 2**

The key findings from Stage 2 are:

• Respondents relate strongly to the ideas underpinning the various conceptualisations of health literacy; however only a minority actually use the language and vocabulary of health literacy. There is no clear or shared view of the exact meaning of the term ‘health literacy’ amongst those who use it; usage varies across the spectrum from something fairly close to ‘functional’ health literacy to something much broader.
Respondents believe there is a widespread lack of awareness within the NHS about the extent of low or inadequate health literacy (and general literacy), and that there are insufficient resources devoted to addressing problems of low health literacy. The inadequate communication skills of NHS staff and health care professionals, together with the large amount of poor quality written information circulating in the NHS are thought to be some of the most important contributory factors.

Respondents think that health literacy is strongly linked to current policy within NHS Scotland and within the Scottish Government more generally. Respondents believe that if the vision of a truly ‘mutual NHS’ is to be realised, then substantial improvements in levels of health literacy are required. The policy links identified include health inequalities, patients rights, patient safety, self care and self management, anticipatory care, shifting the balance of care, eHealth, mental health and wellbeing, adult literacy and numeracy, and workforce policy.

There are many ongoing initiatives and projects relevant to improving health literacy in Scotland. These cover aspects such as training on literacy, numeracy and health literacy; improving communications; improving written materials; improving access to services; eHealth; knowledge management; and improving the management of multiple morbidities and long term conditions.

Respondents would like the capacity of the NHS to respond to people with literacy and health literacy deficits to be built. This could include raising awareness of the issues; better training of healthcare professionals; improvements to the quality of written materials; more support for identifying those with low health literacy; more capacity to build personal and tailored solutions for those with low health literacy; and better awareness by health care professionals of what support is available and how to access it.

Respondents regard the improvement of health literacy as vital for delivering current policy priorities. Respondents have many ideas for new initiatives which could be pursued; however there is also recognition that this is a large and daunting agenda, and that it will be important to focus on a limited set of priorities in the first instance.

Respondents favour taking an integrated approach, and adopting the ideas of health literacy into mainstream policy, practice and planning. It was suggested that this integration is already happening to some degree and should be further encouraged.

**Recommendations**

There are five recommendations arising from this work as follows:

**Recommendation 1:** There is no appetite for, or requirement for a ‘health literacy strategy’ for Scotland. This is mainly because the ideas underpinning health literacy are complex and diffuse. Pursuing a separate policy on health literacy would be counterproductive, and would not achieve the aim of improving health literacy across the population of Scotland. No ‘policy lead’ for health literacy is required.
**Recommendation 2:** There should instead be a focus on the practical integration of the ideas underpinning health literacy into existing programmes, projects and initiatives. This will involve the setting up of coordinating arrangements to ensure that learning is shared across the range of stakeholders, and that significant developments are tracked. The coordination will extend beyond the Health Directorates to include, for example, the work on adult literacy and numeracy.

**Recommendation 3:** There are a number of ongoing initiatives which will make important contributions to the development of the conceptual framework and the empirical landscape, and these should be tracked. An international study of health literacy, which will define and measure levels of health literacy across a number of European countries will take place between 2009-2011 and it will be important to follow the development and delivery of this study. Second, the National Social Marketing Centre has commissioned a study to assess the costs of poor health literacy both to individuals and society; the results of this study should be followed up. Third, a new government funded baseline study of adult numeracy and literacy in Scotland is currently being undertaken and this will provide up-to-date evidence of the scale of the more general problems of low literacy and numeracy in Scotland.

**Recommendation 4:** Given the wide range of ongoing relevant projects and programmes ongoing in this area, an exploratory external event on the topic of health literacy should be held. The purpose of such an event would be to increase awareness of the topic, to identify current activities, to assist with the integration of the ideas of health literacy into policy development, and to share knowledge and expertise. Such an exploratory event might usefully be preceded by an internal meeting to coordinate, share, and build understanding of the current range of activity in this area.

**Recommendation 5:** Given the wide ranging nature of this topic, it will be important to prioritise areas for further development, and not to attempt to tackle all aspects simultaneously.
INTRODUCTION
1.1 The Health Improvement Strategy Division\(^1\) of the Scottish Government commissioned a proposal for ‘Health Literacy – A Scoping Study’ in December 2008. This report describes the study context, recaps the aims and objectives of the study, describes the methods and approach taken, presents the findings, and sets out the conclusions and recommendations.

2. STUDY CONTEXT
2.1 NHS Health Scotland suggested in late 2007 that the Scottish Government examine the concept of health literacy and its application to policy and practice in Scotland. In July 2008, a meeting was convened within the Health Improvement Strategy Division of the Scottish Government on the topic of ‘health literacy’.
2.2 Briefing available for the meeting identified current policy and practice approaches which interact with the topic of health literacy, enumerated a range of partner organisations with interests in this topic, and began to map out what further action might be required to advance thinking on the issue. The briefing provided the basis for the development of this scoping study.

3. AIM AND OBJECTIVES
3.1 The main purpose of the study is to identify and examine current approaches to health literacy, and to identify options for potential Scottish policy responses on this topic.
3.2 The objectives of the study are to:
   a. Identify and review current definitions of health literacy;
   b. Examine whether and how health literacy has been measured both in the UK and elsewhere;
   c. Identify examples of policy and practice initiatives in health literacy which have been implemented elsewhere, together with information about the evaluation of their impact where these are available. (Note that this is not a comprehensive exercise, but an attempt to identify any ‘promising interventions’);
   d. Map the nature and extent of relevant links between health literacy and extant and developing Scottish Government policy. (Again, this will not be comprehensive, but selective on the basis of the main findings emerging from the project);
   e. Identify possible options for developing programmes, policies, and / or approaches on health literacy which merit further investigation.

4. STUDY METHODS AND APPROACH
4.1 The study was conducted in two stages. Stage 1 was desk based, and consisted of a document analysis, together with online searches. Stage 1 addressed objectives a and b as well as parts of objectives c and d. Stage 2 was conducted using key informant interviews. Stage 2 addressed mainly objectives c, d and e. This report presents the findings of both stages.
4.2 The purpose of the interviews was to test out the key messages emerging from the document analysis, to fill gaps where no published material was available, to allow a range of views to be

\(^1\) In February 2009 the Health Improvement Strategy Division became part of a broader Chief Medical Officer and Public Health Directorate.
heard, to capture a selection of current ideas and actions which relate in some way to health literacy and its improvement, and to identify possible options and approaches which merit further investigation.

4.3 The report based on the documentary analysis conducted at Stage 1 was sent to all interviewees in advance of the interview itself, together with the Topic Guide (see Annex 1) which was developed from the Stage 1 work. However, it is important to emphasise that the coverage of individual interviews varied substantially, depending on the particular background, interests and knowledge of the respondent.

4.4 The list of interviewees (see Annex 2) was developed in collaboration with the commissioners of the work after Stage 1 had been completed. The focus was on selecting interviewees who are practitioners, policy makers and professionals in the field or who were known to work in areas with some relevance to health literacy; the voice of patients, carers and the general public was not specifically sought, although some interviews touched on accounts and experiences of these wider population perspectives.

4.5 In total, 252 interviews were conducted – 19 were conducted face-to-face with the remaining 6 conducted by telephone. Interviews lasted between 40 minutes and 1.5 hours.

4.6 The findings are presented separately for each stage in Section 5 and Annex 3 (Stage 1) and Section 6 (Stage 2) below. The conclusions and recommendations which follow in Sections 7 and 8 below are derived from an integrated and synthesised analysis of both elements of the work.

4.7 It is important to note that this work was designed to be conducted in a short timescale and to provide a platform from which a more detailed policy response could be developed. The document review (Stage 1) is NOT intended to be a comprehensive literature review; and the key informant interviews (Stage 2) are NOT intended to be a comprehensive account of all health literacy work ongoing in Scotland. Rather the work is illustrative, and provides examples of the kinds of initiatives and responses which are being tried or tested or implemented in relation to health literacy.

5. FINDINGS – STAGE 1

5.1 The findings of Stage 1 of the scoping exercise are organised in 6 sections as follows:
   - Definitions of Health Literacy
   - The Measurement of Health Literacy
   - The Impact of Inadequate or Low Health Literacy
   - Policy and Practice Initiatives to Improve Health Literacy and their Impact
   - The Nature and Extent of Links between Health Literacy and Scottish Government Policy
   - Possible Options for Development.

5.2 Note that early on in the development of the material for Stage 1, a highly relevant – and recent – publication was unearthed (1). The Picker Institute was commissioned by the Health Foundation, under their Quest for Quality and Improved Performance (QQUIP) initiative to produce an

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2Twenty four of the interviews were conducted with a single individual; in one case, the interview at NHS Health Scotland, two individuals were interviewed together.
overview of the research evidence on the ‘effectiveness of patient-focused\(^3\) interventions’. Seven areas – one of which was improving health literacy – were identified for review. Chapter 1 of the review report, which was published in August 2006, is entitled ‘Improving health literacy’, and this material has been drawn on in what follows, especially in the section which sets out the findings in relation to ‘Policy and Practice Initiatives to Improve Health Literacy and their Impact’.

5.3 In order to improve the narrative flow of the report, and to focus the reader’s attention on current and future action, the detailed findings from Stage 1 have been reported in an annex (Annex 3).

6. FINDINGS – STAGE 2

6.1 The findings of Stage 2 are organised in sections as follows:
- Usage and Understanding Of and Attitudes Towards the Terminology of ‘Health Literacy’
- Perceived Scale of Low Health Literacy
- Links (Overlaps) Between Health Literacy and Other Policy Topics / Areas
- Perceived Main Issues in Health Literacy
- Ongoing Relevant Initiatives
- What do Respondents See as the Next Steps for Health Literacy?
- Tensions and Challenges.

**Usage and Understanding Of and Attitudes Towards the Terminology of ‘Health Literacy’**

6.2 All those interviewed related strongly to the ideas underpinning ‘Health Literacy’ which are mapped out in Annex 3, and they were pleased to see that these issues had found their way onto the ‘radar’ of Scottish Government. However, only a minority (about one third) of respondents actually used the language and vocabulary of ‘Health Literacy’. A few more recognised the term, and had heard it being used by others, but did not use it themselves.

6.3 This is in itself a key finding, as it demonstrates that the terminology is not widely used; if the term ‘health literacy’ is not widely used by those interviewed for Stage 2 of this scoping exercise, then it is highly unlikely to be used by others whose remits link less clearly to the topics discussed here.

6.4 For those who did use the terminology, it was used in a variety of ways. A few individuals used it to mean something close to the ‘functional health literacy’ idea set out in Paragraph 6 of Annex 3. The others used it to mean something broader – closer to the empowerment / citizenship / whole systems definitions as described in Paragraphs 10-17 of Annex 3. However, as anticipated, there was no clear or shared view of the exact meaning of the term ‘health literacy’ amongst those who used it.

6.5 For those who were not familiar with the terminology, or who were familiar with it but deliberately did not use it, there was a spectrum of reactions to the term ‘health literacy’ ranging from the fairly neutral to the distinctly against.

6.6 As far as the more negative views were concerned, one respondent said he was aware of the terminology but doesn’t use it, mainly because ‘people use it to mean all sorts of different things so it’s not that useful’; another found it ‘not that relevant to patients’; whilst one respondent who is

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\(^3\) ‘patient focused’ interventions implies or suggests a clinical consultation focus; in fact the interventions covered in the overview are much broader and include public health type interventions.
himself very involved with work in the health literacy field said he found it ‘a loaded term that dates back 30-40 years and comes from a very “old school” view of health’.

6.7 Many who were neutral about the term ‘health literacy’, talked about the ideas of health literacy by referring to other frameworks / paradigms which were of more direct relevance to their work. So for example, one respondent talked about the framework of ‘information literacy’, which she felt ‘sits in the middle of health literacy, general literacy, and numeracy. Information literacy is broader than health literacy and gives an ‘in’ to other relevant organisations and institutions – e.g. schools’. Another respondent said the ‘prism’ through which he understood the issues was that of ‘risk management, risk perception and risk communication’; others came at the ideas of health literacy through the frameworks of adult literacy and adult literacy in health (rather than health literacy), through equality and diversity and equality impact assessment, through patient centred care and patient centredness, through improving access to services, or through health care improvement more generally.

6.8 Thus, defining and disseminating a shared language of health literacy – if this is to be a goal – would require a substantial amount of effort. It is not – at this point in time - clear what the benefits of this would be.

6.9 Whether or not respondents used the terminology of health literacy themselves, the interviews used this terminology. Respondents were asked to think of this as a shorthand for the underlying ideas, and to answer by reference to their own conceptualisation.

Perceived Levels of Low Health Literacy

6.10 Respondents were generally of the view that low health literacy (or their equivalent concept) was widespread. Respondents also thought that awareness of health literacy problems was limited. Problems of low health literacy were discussed in relation to patients and carers, but also in relation to health care professionals, policy makers, and politicians. Few interviews touched directly on health literacy in its wider general population context; however on a number of occasions respondents made comments such as ‘the medical model is limited’ or ‘focussing only on clinical consultations is too restrictive’.

6.11 Some respondents thought the problem of low health literacy was restricted to patients and carers, with the problems for professionals being their lack of awareness of health literacy as an issue; others thought that all population groups suffered to a greater or lesser degree from low health literacy.

6.12 There was agreement that measuring health literacy given the diffuse nature of the underlying concepts, was difficult. One respondent pointed specifically to the difficulties in distinguishing between poor health literacy and (non evidence based) health beliefs; for example in a clinical or public health setting it could be particularly difficult to identify through screening educated and articulate individuals who requested treatment without a good evidence base (or indeed treatment which might actually be harmful) as having low health literacy.

6.13 Few respondents would direct limited resources into an exercise to measure the extent of the problem. The questions from the Better Together patient surveys were not thought to provide robust measures of these complex concepts.

6.14 Two ongoing exercises were identified which will provide relevant quantitative evidence. First, a new government funded baseline study of adult numeracy and literacy in Scotland is currently
being undertaken by Glasgow University. This will provide updated information on the levels of ‘functional health literacy’ as discussed in Paragraph 6 of Annex 3.

6.15 Second, a team at Maastricht University is currently developing a questionnaire for use in an international study of Health Literacy which will run from 2009-2011. The approach to measuring health literacy will be developed during April-August 2009, ahead of the data collection in Autumn 2009. It is anticipated that the results of this study will be available in Autumn 2012. The countries participating in this exercise are the Netherlands, Austria, Bulgaria, Poland, Spain, Germany, Greece and Ireland. More countries may join over the summer. It will be important to follow this work as it develops.

Links (Overlaps) Between Health Literacy and Other Policy Topics / Areas

6.16 Respondents think that health literacy is strongly linked to current policy within NHS Scotland and within the Scottish Government more generally. Respondents believe that if the vision of a truly ‘mutual NHS’ is to be realised, then substantial improvements in levels of health literacy are required.

6.17 Respondents identified policy in the following areas – which all have recent Scottish Government policies associated with them - as being particularly strongly linked to / dependent on improvements in health literacy:
- Health Inequalities;
- Patients Rights;
- Patient Safety;
- Self Directed Support / Self Management Strategies / Self Care (including shared decision making, care plans, and the self management of long term conditions);
- Anticipatory Care (including Keep Well – formerly Prevention 2010);
- Shifting the Balance of Care (including accessing health services in primary care);
- eHealth;
- Mental Health and Wellbeing;
- Adult Literacy and Numeracy, and English as a Second Language;
- Workforce Policy.

6.18 So, for example, the Patients Right Bill will come into force in 2010. Underpinning this Bill is the idea that if people understand their rights and responsibilities better, then they will be better able to be involved in determining their own care. It is clear that improvements in health literacy will lead to greater understanding by patients of their rights and responsibilities and thus improved health literacy is important to this agenda.

6.19 To take a second example, self care is ‘what people do to care for themselves, their children, other family members and their communities. In relation to health and health care, it is all that people do to maintain health, prevent illness, seek treatment, manage symptoms, treatments and side effects, accomplish recovery and rehabilitation and manage the impact of chronic illness and disability’. Supporting self care is a major part of Scottish Government programmes to improve health and to make best use of health care resources. Self care requires a high degree of health literacy in order that patients can participate in shared decision making with health care

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4 The project coordinator is Kristine Sorenson, based at the University of Maastricht. Email: K.Sorenson@INTHEALTH.unimaas.nl
5 Alliance for Self Care Research. http://www.ascr.ac.uk/selfcare.htm
professionals, evaluate alternative treatment options, and follow through on a self management plans. Linked to this is the idea of ‘self management’, which is described as ‘a person-centred approach in which the individual is empowered and has ownership of their life and conditions’\(^6\); people with long term conditions self care but also have to manage their condition(s).

6.20 The third example is taken from eHealth. The eHealth Strategy (2009-2011) specifically mentions health literacy\(^7\). The eHealth Strategy states that ‘eHealth will contribute to ‘health literacy’ to ensure that all citizens have the necessary skills, knowledge and confidence to manage their own health.’ Thus the eHealth Strategy adopts a fairly broad definition of health literacy and links it to ideas of empowerment.

6.21 The fourth and final example relates to the educational work going on across Scotland in general Adult Literacy and Numeracy. The Scottish Government funds a national team of staff in Learning Connections, who support local partnerships to engage adults in literacies learning. This work enables individuals to become more confident and critical partners in their own healthcare and there is evidence that this often leads to a change in health behaviour (50, 51, 52).

6.22 In addition to these substantive policy areas, respondents talked about the links between health literacy and the six dimensions of quality / improved care identified in Better Health Better Care\(^8\) : patient centred, safe, effective, efficient, equitable and timely. Respondents thought that improving health literacy would help to improve each of these dimensions of health care.

**Perceived Main Issues in Health Literacy**

6.23 When asked what the main issues / problems relating to health literacy were, respondents talked about:

- the lack of awareness within the NHS about the extent of low or inadequate health literacy (and general literacy) and the specific lack of awareness of NHS staff about where to go to get support when faced with an individual with low or inadequate health literacy;
- the lack of continuity and stability of funding of those initiatives which aim to address problems of low literacy / low health literacy;
- the time taken to establish projects to address issues relating to low literacy / low health literacy, the resource intensive nature of the interventions, and the lack of sensitive indicators of success;
- the poor or inadequate communication skills of many health care professionals;
- the poor quality of many written materials used within the NHS.

6.24 A point made over and over again in interviews was that ‘the NHS is not sufficiently sensitive to the low levels of health literacy (and literacy more generally)’ which those using NHS services have. Respondents thought that health care professionals were simply not aware of the difficulties

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\(^7\) Note that ‘Towards a Mentally Flourishing Scotland’ – the policy for Mental Health improvement – also uses the term ‘health literacy’. These are the only two policy documents – as far as the author is aware – to specifically make mention of ‘health literacy’.

\(^8\) These dimensions were set out in the Institute of Medicine’s 2001 report ‘Crossing the Quality Chasm’
faced by many service users. This lack of sensitivity and awareness meant that ‘patients are not properly helped to identify, access, use, and benefit from services’.  

6.25 Those who worked on projects which had a specific focus on improving literacy and health literacy faced ‘difficulties associated with the stability and continuity of funding’. Even where services had been evaluated positively, there was no long term commitment to continuing services. Respondents were frustrated that good projects could not be sustained and the work which had gone into setting up projects was lost. 

6.26 Respondents were enthusiastic about projects which had been developed to improve literacy and health literacy skills, and felt privileged to be involved in work which ‘made such a difference to individual lives’. However, respondents stressed that this work had ‘long lead in times’, and could not be established quickly. It depended on partnership working which took time to ‘bed down’ and required trust and relationships to be built between a variety of agencies and organisations. The work was also ‘very labour intensive’. The focus on quantitative targets (for example for the uptake of courses, or for the number of new learners) was described as rather a ‘blunt instrument’ for measuring the impact of these services. 

6.27 The core issue for many respondents was the ‘poor communication skills of many NHS staff and health care professionals’. There was general agreement that the situation was improving, but there was still a large gap between the aspiration for a patient centred service and the day-to-day reality of NHS services.  

6.28 Respondents thought that there was a ‘large amount of poor quality written information circulating in the NHS’. There were some success stories; the user testing of some written materials – especially those relating to national programmes (e.g. for screening programmes) - had resulted in substantial improvements. And some organisations with national remits had invested substantially in the quality of their written materials by developing and using protocols, templates, style guides and peer review. However, respondents all had ‘horror stories’, many based on their own personal experience, of poor written communications. 

Ongoing Relevant Initiatives 

6.29 Respondents reported a large number of ongoing projects and initiatives in Scotland which are relevant to improving health literacy. These are listed at Annex 4. This list is not supposed to be comprehensive, but illustrative of the key areas of ongoing work. 

6.30 The categorisation of these initiatives into the various areas is not straightforward. There is no ‘neat’ categorisation that can be used, and each example could arguably feature under a number of different headings. Nevertheless, it is helpful to attempt a summary of the wide range of ongoing projects and initiatives. 

6.31 The main categories which have been identified are: 

- Training on Literacy / Numeracy / Health Literacy (including Keep Well – see Paragraph 40 in Annex 3); 
- Improving Communications; 

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9 Note that one of the interviewees from the Scottish Government pointed out that there are various programmes of work underway to support this including work to improve equalities monitoring of patients across the NHS. 
10 The Scottish Government explained that any response to this issue should be joined up with other ongoing work on monitoring and profiling across the NHS.
- Improving Written Materials (including understanding instructions for medication, consent form, appointment forms and so on);
- Improving Access to Services;
- eHealth;
- Knowledge Management;
- Management of Multiple Morbidities / Management of Long Term Conditions.

(Note that these categories span both the narrower definitions of ‘functional’ literacy / health literacy and the broader – more public health type definitions as described in Annex 3.)

6.32 Many of these projects and initiatives have a direct and obvious relationship to the topic of health literacy, and they were spontaneously mentioned by interviewees. However, what is potentially more notable in the context of this piece of work is some of the initiatives which are not – in the investigators eyes – directly linked to health literacy, but which are on closer inspection highly relevant.

6.33 In these latter cases, the link to health literacy was illuminated through the interview process itself. This illustrates the diverse and complex nature of the topic under investigation, and the context described in Paragraphs 6.2-6.8 above whereby respondents relate to the underpinning ideas whilst not necessarily using the language or terminology of ‘health literacy’. This suggests that there are likely to be many more ongoing relevant initiatives than the ones that are easily identified. Three examples listed in Paragraphs 6.33-6.36 below illustrate this; other examples could have been chosen.

6.34 The first example is a programme of research, funded by the Chief Scientist Office entitled ‘Living Well with Multiple Morbidities’. Over the next 4 years, the research team will undertake a trial – with an assessment of cost effectiveness – of a complex intervention within a highly deprived area of Glasgow. The intervention will be used with individuals with multiple morbidities (3 or more existing long term conditions) who are frequent users of services but who do not get much out of their consultations (a fact identified in previous research).

6.35 The intervention is being developed to work at three levels: at the organisational level, at the level of the health care professional / patient interaction, and at the level of individual behaviour change. At the organisational level, patients will be offered longer consultations with GPs, Practice Nurses, or both; consultations will be structured over time, with continuity of care being a key element of delivery. At the health care professional / patient level, the intervention will focus around problem definition and goal setting. At the individual level, patients will be given materials and resources to assist with behaviour change. Patients will be randomised to intervention or treatment as usual (if that proves acceptable at the pilot stage), and a full evaluation of the intervention will be conducted.

6.36 The second example is the Ayrshire and Arran ehealth demonstrator site which will test out development of a website where people can see and update their personal health information in a secure and confidential way. It will provide support for people living with long term conditions to manage their personal health needs. An important aspect is that people with long term conditions and carers are participating in the design and development.

6.37 The third example is taken from the Gorbals Healthy Living Network, where the idea of a ‘knowledge worker’ has been piloted. In this instance, a community development worker who was
already in post was trained in ‘Information Literacy’\textsuperscript{11} techniques. She was then able to identify other groups who could benefit from this training and this type of approach, and it was rolled out locally. By this means, 120 individuals were trained in this approach.

**What do Respondents See As The Next Steps for Health Literacy?**

6.38 There was support for continuing, building on, strengthening and developing the whole range of projects and initiatives currently underway or under development which interviewees identified as effective. The main areas which were identified were those which have already been discussed in this report: raising the awareness of all health care professionals of the widespread problem of low or inadequate health literacy; better training for all health care professionals in communication skills, in listening skills, and in responding to difference; improvements to the quality of written materials circulating in the NHS; more support for identifying those with low health literacy; more capacity to build personal and tailored solutions for those with low health literacy; better awareness by health care professionals of what support is available and how to access it. As one respondent put it ‘We need to build the capacity for the NHS to respond to people with literacy and health literacy difficulties’.

6.39 A few respondents made the point that health literacy was just one of ‘a number of literacies’ which were important to enable patients and the public to interact effectively with the NHS. Other literacies thought to be important which were mentioned were general literacy (and numeracy), phone literacy, computer literacy, digital literacy, and financial literacy.

6.40 A wide range of respondents also talked about the importance of wider adoption of the ideas of ‘Ask Me Three Things’\textsuperscript{12} and the ‘Teach Me Back’\textsuperscript{13} methods of communication. They would like to see widespread teaching and adoption of these techniques within the NHS.

6.41 There was some impatience and frustration that initiatives which had been developed, were taking a long time to implement. An example of this was the ‘Happy to Translate’ logo, linked to the review of provision of interpretation and translation which had not yet reached full scale implementation; it was also thought that there was insufficient general awareness of the ‘Minimising Barriers’ checklists.

6.42 Respondents were asked what new ideas or initiatives in health literacy they would like to see developed and / or implemented. The following suggestions were made\textsuperscript{14}:

- having a health care professional available in a local practices who could review with patients what they had been told during their consultations and who could spend more time with patients ensuring that they understood what they should do next;
- information therapy, and information prescribing;

\textsuperscript{11} These are described in full in the NHS Education for Scotland document ‘Enabling Partnerships: Sharing Knowledge for a Mutual NHS’

\textsuperscript{12} What is my main problem? Why is it important? What do I need to do? This is taken from Dean Schillinger’s work.

\textsuperscript{13} This method is described

\textsuperscript{14} Note that it is not within the remit of this scoping exercise to check whether these suggestions are already being implemented in specific contexts. Moreover, featuring on this list does not imply endorsement by the Scottish Government that these ideas should be developed and / or implemented.
- bibliotherapy – which is seen as wider than information therapy, and which involves drawing on wider sources (poems, stories etc) to help individuals to understand and develop their capacity to manage their own health effectively;
- further development of the ‘knowledge worker’ role by defining and developing the competences;
- the development of team teaching rather than interventions with individuals only;
- partnership working with literacies staff both locally and nationally;
- developing ‘engaged libraries’ as defined in the “Engaged Libraries” Chicago initiative;
- local libraries to support national ELibrary by providing local updated information;
- extending the ELibrary so that basic leaflets and posters can be developed;
- developing the role of community pharmacies;
- the development of more sites like Polishinfoplus;
- improving ‘signposting’ to services which can help sustain health.

(Note that these categories span both the narrower definitions of ‘functional’ literacy / health literacy and the broader – more public health type definitions as described in Annex 3.)

6.43 The above paragraphs summarise the responses to the questions about ‘What Next?’. However, it is important to emphasise that there was no appetite for the development of a ‘Health Literacy Strategy’. This was mainly because – as described earlier - the ideas underpinning health literacy are seen as being very diffuse.

6.44 For some respondents, this led them to ask the question ‘What is the ‘added value’ of taking a health literacy approach? How – in practical terms – does it help to see these diffuse issues through the ‘prism’ of health literacy?’

6.45 More specifically, one respondent asked ‘How is health literacy different - or anything more than – providing those things listed in the Partnerships for Access to Health (PATH) project ‘What do people with multiple and complex needs want from services?’ [The list on Page 5 of the report covers: simple, quick access to services at the time they are needed; a single point of access or one service that will respond to all needs and thus avoiding repeated assessments; respect from staff; staff behaviour that is culturally sensitive, equal, fair, and non-judgemental; consistent and positive relationships with staff offering long-term support with handovers of casework when staffing changes; effective joint working and communication between services; information about the services available, their remit and how to access them; a flexible approach to each client, as what works for one client may not work for another; support with the practicalities of everyday life; peer support; and involvement in decision making.] The respondent felt that this list covered all the aspects which should be thought about in the context of providing a service that was sensitive to the issue of health literacy.

6.46 However, other respondents were emphatic that there was an extra dimension which was not covered by the list in Paragraph 6.43 above; this related to the education and empowerment of individuals through building knowledge, skills and confidence, leading to changes in health behaviours (50, 51, 52).

6.47 It was suggested by a few respondents that without a strong conceptual framework to guide the activities and development of a health literacy perspective, to identify exactly what this ‘added value’ could be over and above the current range of existing or planned projects, and to identify gaps in the coverage of the current approaches, there was a risk of a lack of intellectual
clarity. This was seen to be important given the multiple conceptualisations and vocabularies that already exist and which sometimes cause confusion and misunderstanding. (It is not clear where the development of this conceptual framework might come from; an attempt by the National Social Marketing Centre to set up a health literacy network had not been successful and no respondents expressed enthusiasm for the setting up of such a network.) Others, however, thought that the conceptual issues were secondary to focusing on the more practical aspects of increasing awareness of current activities, sharing knowledge and understanding, and focusing on learning from current practice.

6.48 There was a corresponding lack of clarity about whether there should be a single focal point for work on health literacy in the Health Directorates. Respondents are of the view that health literacy is delivered through joint working and that it relies on a partnership approach. However, it was said by more than one respondent that the responsibility for health literacy ‘falls between Community Learning and Development in the Local Authority and the NHS’ or ‘it falls between the NHS and the Local Authorities’. Another respondent commented that ‘overall responsibility for health literacy is unclear; is this a shared responsibility or does one organisation have the lead? And if so, which organisation is leading?’

6.49 Overall then, on the whole respondents favoured taking an integrated approach, and adopting the ideas of health literacy into mainstream policy, practice and planning. This type of approach was thought to represent the most effective and efficient way to progress this important agenda. It was suggested that this integration is already happening to some degree and should be further encouraged.

Tensions and Challenges

6.50 The main issue that respondents identified was the scale of the agenda. Developing a NHS which is sensitive to the widespread issues of low or inadequate health literacy and which is able to respond to each individual’s needs was thought to be a huge task.

6.51 Respondents thought that the extent to which the NHS was able to deliver a service which both recognised and responded adequately to problems of low health literacy had improved; but there was a very long way to go on every aspect of this work.

6.52 Specific practical difficulties which were raised were: the inadequacy of short term project funding to deliver these aims; the lack of recognition of how very labour intensive the work is and how much it depends on working in a long term one-to-one relationship with individual patients and carers; the clash between the aspiration for the NHS to deal adequately with problems of low health literacy and the harsh realities of the practical constraints of the NHS; the lack of commitment to the literacies / health literacies / wider literacies agenda within senior levels of the NHS.

6.53 These practical issues echo the sentiments of one of the main writers in this area, Ilona Kickbush who has written recently that ‘To be a health literate society need a health literate public, health care professionals, politicians and policy makers…..Several initiatives remain at grassroots level. Lessons learned are not transposed to other contexts or communities, nor do they feed into policies being developed. The gap between policy and practice needs to be bridged in both directions.’

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15 Navigating Health: The role of health literacy. Ilona Kickbush, Suzanne Wait and Daniela Maag (February 2009)
6.54 The launch of the National Health Information Support Service, heralded in Better Health Better Care as a service which will have ‘a key role to play in supporting initiatives which build people’s capacity to improve their health and wellbeing’ is also highly relevant.

6.55 The National Health Information Support Service is underpinned by a detailed ‘Information Literacy’ framework and an ‘Information Literacy’ cycle, which uses many of the ideas and concepts which underpin health literacy. Thus, the information literacy cycle covers a number of steps: defining questions, sourcing information, checking credibility of sources, sharing information, applying information to decision making, and transforming knowledge into practice; this takes the concept far beyond the domain of information and into the realms of citizenship and empowerment. Respondents agreed that this work – and the underlying ideas - must be fully aligned with other initiatives within the literacy / health literacy area.

7. CONCLUSIONS

7.1 There is no universally agreed conceptualisation or definition of health literacy. Authors from a wide range of backgrounds, disciplines, and perspectives have contributed to the debate about health literacy. The field is currently in a dynamic and developing state.

7.2 Earlier definitions concentrated on what is generally referred to as ‘functional’ health literacy; this is quite a narrow concept in which health literacy is seen as the ability to read and comprehend written medical information and instructions. Later definitions of health literacy have become broader, more nuanced, and more contextualised; they have emphasised empowerment and citizenship aspects, and they resonate with a public health orientation – rather than simply a clinical orientation – to health literacy.

7.3 Interviewees related strongly to the ideas underpinning the various conceptualisations of health literacy; however only a minority actually used the language and vocabulary of health literacy. There was no clear or shared view of the exact meaning of the term ‘health literacy’ amongst those who used it; usage varied across the spectrum from something fairly close to ‘functional’ health literacy to something much broader.

7.4 Moreover, interviewees used other frameworks and paradigms of more direct relevance to their own work when discussing the ideas of health literacy including risk management; information literacy; equality and diversity; patient centredness.

7.5 Measuring the extent of low or inadequate literacy, given the diffuse nature of the underlying concepts is not straightforward, and estimates of the extent of the problem of low health literacy in countries where this has been attempted vary widely. Efforts to improve the measurement of (low) health literacy are ongoing.

7.6 Despite the lack of definitive estimates, which is due in part to the complexity of developing good measures, there is agreement that there is a substantial and widespread problem of poor health literacy.

7.7 The impact of inadequate or low health literacy has both health and financial consequences. Research evidence shows that that patients with low health literacy: have poorer health status and poorer self reported health; enter the system when sicker; are at a greater risk of hospitalisation and have longer hospital visits; have higher rates of admission to emergency services and require more avoidable hospitalisation; are less likely to adhere to prescribed treatments and self care plans; have more medication and treatment errors; have less knowledge of disease management.
and health-promoting behaviours; are less able to self manage; have decreased ability to communicate with healthcare professionals and share in decision-making; are less able to make appropriate health decisions; make less use of preventive services; suffer stigma and shame; have poorer health outcomes including knowledge, intermediate disease markers, measures of morbidity; and will incur substantially higher healthcare costs.

7.8 Over the past 5-10 years a number of countries have adopted targets and objectives for improving health literacy within their strategic policy processes. In addition, there has been a focus over a similar timescale on international reviews of research evidence to examine what initiatives in health literacy have been tried and what the impact of these have been.

7.9 The most relevant, comprehensive and recent review (1) of the research evidence has concluded that ‘initiatives designed to specifically target low literacy groups have had mixed results, with some studies showing beneficial effects on knowledge and behaviour, but there have been relatively few attempts to test the effects of these initiatives on reducing health inequalities.’ The review comments that most often low literacy initiatives have involved designing or revising patient information or educational materials in order to enhance comprehension among people with health literacy problems; and in relation to written information, the review’s main conclusion is that ‘written information (e.g. leaflets) used as an adjunct to professional consultation and advice has been shown to improve health knowledge and recall, particularly when it is personalised to the individual. But few other beneficial effects have been demonstrated and there is no evidence of improvement in health behaviour or health status’.

7.10 Health literacy is strongly linked to current policy within NHS Scotland and more widely within the Scottish Government. The key policy links are to health inequalities; patients rights; patient safety; self care; anticipatory care; shifting the balance of care; eHealth; mental health and wellbeing; adult literacy and numeracy; and workforce planning. Health literacy is also linked closely to the six dimensions of quality / improved care: patient centred, safe, effective, efficient, equitable and timely.

7.11 Interview respondents believe there is a widespread lack of awareness within the NHS about the extent of low or inadequate health literacy (and general literacy), and that there are insufficient resources devoted to addressing low health literacy. The inadequate communication of skills of NHS staff and health care professionals, together with the large amount of poor quality written information circulating in the NHS were thought to be the main contributory factors.

7.12 Many ongoing initiatives and projects relevant to improving health literacy are ongoing in Scotland. These cover aspects such as training on literacy, numeracy and health literacy; improving communications; improving written materials; improving access to services; eHealth; knowledge management; management of multiple morbidities and long term conditions.

7.13 Respondents would like the capacity of the NHS to respond to people with literacy and health literacy to be built. There are a range of ways in which this could be done including raising the awareness of all health care professionals of the widespread problem of low or inadequate health literacy; better training for all health care professionals in communication skills, in listening skills, and in responding to difference; improvements to the quality of written materials circulating in the NHS; more support for identifying those with low health literacy; more capacity to build personal and tailored solutions for those with low health literacy; better awareness by health care professionals of what support is available and how to access it.
7.14 Respondents regard the topic of health literacy – and the improvement of health literacy – as vital for the development of the wealthier and fairer; healthier; safer and stronger; smarter; and greener Scotland as set out by the current administration. Respondents have many ideas for new initiatives which could be pursued. However, there is also a recognition that this is a large and daunting agenda, and that it will be important to focus on a limited set of priorities in the first instance.

7.15 Respondents favoured taking an integrated approach, and adopting the ideas of health literacy into mainstream policy, practice and planning. It was suggested that this integration is already happening to some degree and should be further encouraged.

8. RECOMMENDATIONS

8.1 Recommendation 1 There is no appetite for, or requirement for a ‘health literacy strategy’ for Scotland. This is mainly because the ideas underpinning health literacy are complex and diffuse. Pursuing a separate policy on health literacy would be counterproductive, and would not achieve the aim of improving health literacy across the population of Scotland. No ‘policy lead’ for health literacy is required.

8.2 Recommendation 2 There should instead be a focus on the practical integration of the ideas underpinning health literacy into existing programmes, projects and initiatives. This will involve the setting up of coordinating arrangements to ensure that learning is shared across the range of stakeholders, and that significant developments are tracked. The coordination will extend beyond the Health Directorates to include, for example, the work on adult literacy and numeracy.

8.3 Recommendation 3 There are a number of ongoing initiatives which will make important contributions to the development of the conceptual framework and the empirical landscape, and these should be tracked. The group referred to in Paragraph 6.14 above are undertaking an international study of health literacy which will run from 2009-2011 and it will be important to follow the development and delivery of this study. Second, the National Social Marketing Centre has commissioned a study to assess the costs of poor health literacy both to individuals and society; the results of this study should be followed up. Third, a new government funded baseline study of adult numeracy and literacy in Scotland is currently being undertaken by Glasgow University and this will provide evidence of the scale of the more general problems of low literacy and numeracy in Scotland.

8.4 Recommendation 4 Given the wide range of ongoing relevant projects and programmes ongoing in this area, an exploratory external event on the topic of health literacy should be held. The purpose of such an event would be to increase awareness of the topic, to identify current activities, to assist with the integration of the ideas of health literacy into policy development, and to share knowledge and expertise. Such an exploratory event might usefully be preceded by an internal meeting to coordinate, share, and build understanding of the current range of activity in this area.

8.5 Recommendation 5 Given the wide ranging nature of this topic, it will be important to prioritise areas for further development, and not to attempt to tackle all aspects simultaneously.
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ANNEX 1 – Topic Guide for Interviews

1. Is your organisation involved in the issue / topic of health literacy?
   - If Yes to Q1 Can you tell me in what ways your organisation is involved? [Go to Q2]
   - If No to Q1 Does your organisation have any plans to become involved in the issue of health literacy?
     - If Yes Ask respondent to describe plans and Go to Q2
     - If No Can you tell me the reasons for that? (Ask whether the organisation is involved in issues relating to general literacy and tease out whether any of these relate to health literacy.)

2. What is your understanding of the term ‘health literacy’? What is your understanding based on?

3. What is your understanding of the scale of the problem of inadequate health literacy? How important do you think it is to have a clear idea of the scale of the problem?

4. What do you see as the main links between health literacy and government (health) policy? What do you see as the main links between health literacy and the policy position of your organisation?

5. What do you see as the main problems / issues relating to health literacy in Scotland?

6. Is your organisation / the community within which you are a stakeholder involved in any specific initiatives / policies / programs to improve health literacy?
   - If Yes to Q6 Can you tell me about this / these? What have been the objectives of these initiatives / policies / programs? What outcomes have been specified for the initiatives / policies programs? Have these outcomes been measured? Over what timeframe? What has been learned / concluded?
   - If No to Q6 Are any initiatives / policies / programs under development or being planned? What are these? What objectives will be set for these initiatives / policies / programs? What outcomes will be specified? How will the outcomes be measured?

7. What kinds of policies, programmes, initiatives or efforts to increase health literacy would you like to see developed in Scotland? Why do you say that?

8. Any Other Issues?
ANNEX 2 – Key Informant Interviews at Stage 2

1. *Catriona Carson, Senior Development Officer for Literacies and Health, NHS Greater Glasgow & Clyde. Catriona.carson@ggc.scot.nhs.uk. 0141 232 0163
2. John Cowie, Workforce Directorate, Scottish Government, 0131 244 3329
3. *Adam Crosier, National Social Marketing Centre, 20 Grosvenor Gardens, London, SW1W ODH
4. *Dr Martin Donaghy, Director, Health Protection Scotland, Clifton House, 1-7 Clifton Pl, Glasgow
5. Deirdre Evans, Director, National Services Division, ISD, Gyle Square, 1 South Gyle Crescent, EDINBURGH, EH12 9EB
6. Kevin Geddes, Director, Long Term Conditions Alliance Scotland. 0141 404 0231. Kevin.geddes@ltcase.org.uk
7. Dr Gail Gilbert, Scottish Medicines Consortium, Delta House (8th floor), 50 West Nile Street, Glasgow, G1 2NP, 0141 225 6874
8. Moira Hamilton, Adult Literacies Development Coordinator, Learning Connections, Education and Lifelong Learning Directorate, Scottish Government 01224 332974
9. Emma Hogg, Mental Health and Wellbeing Directorate, Scottish Government, 0131 244 5640
10. Elspeth Hosie, Health and Literacy Project Worker, CLAN Health & Literacy Project. Elspeth@clanedinburgh.org. 0131 537 4230
11. Christine Hoy, Long Term Conditions Unit, Scottish Government 0131 244 2946.
13. *Suzanne Macaulay, Health and Literacy Project Worker, Aberdeen, Smacaulay@aberdeencity.gov.uk. 01224 896156.
14. Liz McDonald, Director, Consumer Focus Scotland Royal Exchange House, 100 Queen St, Glasgow, G1 3DN 0141 226 5261 / 0141 227 6451 (direct) Liz.macdonald@consumerfocus.org.uk
15. *Susan McKinlay, Head of Media and Communications, NHS 24 Clyde Contact Centre, Golden Jubilee National Hospital, Beardmore Street, Clydebank, G81 4HX 07768 557498
16. Professor Stewart Mercer, Department of General Practice and Primary Care, University of Glasgow 1 Horseclethill Road, Glasgow G12 9LX
17. *Pat O’Connor, Patient Safety Programme, Tayside Patient Safety Initiative
18. Alistair Pringle, Patint Focus and Public Involvement, Scottish Government, 0131 244 3028
19. Lesley Reid, Community Learning and Development Partnership, NHS Lothian, 536 3508
20. Graham Robertson, Chief Executive, NHS Health Scotland. 536 5515.
21. Des Ryan, Chief Executive, Edinburgh Cyrenians Trust - 0131 475 2354 des@cyrenians.org.uk
22. Carol Sinclair, Director, Patient Experience Project, Scottish Government. 0131 244 2378
23. Dr Ann Wales, NHS Education for Scotland, Thistle House 91 Haymarket Terrace EDINBURGH EH12 5HD
25. June Wylie, CNO Directorate 0131 244 3329 (Nominated by Paul Martin.)

(*) Denotes a telephone interview

Note that despite repeated attempts, it proved impossible to undertake an interview with a representative of the Association of Community Health Partnerships.

16 Nominated by Paul Martin, Chief Nursing Officer
17 Nominated by Professor Kenneth Paterson, Director, Scottish Medicines Consortium
18 The interviews was with both Graham Robertson and Cath Denholm
19 The initial list of interviewees suggested Audrey Taylor from NHS Education for Scotland. However, Audrey Taylor did not feel qualified to comment and referred me to Dr Ann Wales.
20 Nominated by Paul Martin, Chief Nursing Officer
ANNEX 3 FINDINGS – STAGE 1

1. The findings of Stage 1 of the scoping exercise are organised in 6 sections as follows:
   - Definitions of Health Literacy
   - The Measurement of Health Literacy
   - The Impact of Inadequate or Low Health Literacy
   - Policy and Practice Initiatives to Improve Health Literacy and their Impact
   - The Nature and Extent of Links between Health Literacy and Scottish Government Policy
   - Possible Options for Development

2. Note that early on in the development of the material for Stage 1, a highly relevant – and recent – publication was unearthed (1). The Picker Institute was commissioned by the Health Foundation, under their Quest for Quality and Improved Performance (QQUIP) initiative to produce an overview of the research evidence on the ‘effectiveness of patient-focused interventions’. Seven areas – one of which was improving health literacy – were identified for review. Chapter 1 of the review report, which was published in August 2006, is entitled ‘Improving health literacy’, and this material has been drawn on in what follows, especially in the section which sets out the findings in relation to ‘Policy and Practice Initiatives to Improve Health Literacy and their Impact’.

Definitions of Health Literacy

i) Background

3. The term ‘health literacy’ was first used in 1974 (1), and the field of health literacy emerged properly in the 1980s and 1990s (2). Issues in the conceptualisation and definition of health literacy have been developed, summarised and synthesised by a range of authors (1-11).

4. This is a complex field, and there is no universally agreed conceptualisation or definition of health literacy. Authors from a wide range of backgrounds, disciplines, and perspectives have contributed to the debate about health literacy. Moreover, the debate is highly topical, and a number of substantial contributions to the development of ideas in this field have been made in the last few years. Thus the field is currently in a dynamic and developing state.

5. Whilst acknowledging this complexity, this report attempts to clarify (and to simplify) these ongoing debates in order to provide a framework within which – in the context of current Scottish Government thinking – progress towards a policy response can be made. Paragraphs 6-21 below therefore summarise – in simplified form - the ways in which the topic of health literacy has been conceptualised and defined.

ii) Early Definitions

6. Earlier definitions concentrated on what is generally referred to as ‘functional’ health literacy; this was a quite a narrow concept in which health literacy was seen as the ability to read and comprehend written medical information and instructions.

7. It is important to recognise that functional health literacy does not – in any definition – equate simply with the ability to read. Functional health literacy is not necessarily related to years of

21 ‘patient focused’ interventions implies or suggests a clinical consultation focus; in fact the interventions covered in the overview are much broader and include public health type interventions.
education or to general reading ability; a person who functions adequately at home or work may have marginal or inadequate functional literacy in a health care environment.

8. To be more specific, as articulated by Pleasant and Kuruvilla (2), functional health literacy has usually been defined and articulated within the context of the specific, individual, clinical encounter. The authors say ‘... This clinical approach to health literacy developed mainly within the US to help physicians better communicate their prescriptions and to help patients better understand and comply with treatment regimes. This work tends to characterise health literacy as a problem that patients have and physicians need to overcome’.

9. The US Department of Health and Human Services (DHHS) definition of health literacy also fits fairly well with this idea of functional health literacy, although by referring to patient decision making the concept is already starting to be extended. The US DHHS definition is ‘the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions’ (12).

iii) Broader Definitions

10. More recently, definitions of health literacy have become broader, more nuanced, and more contextualised. For example, the Institute of Medicine (13) divides health literacy into functional skills (such as speaking and listening), print literacy, and cultural and conceptual knowledge. Health literacy is seen as the ‘bridge’ or ‘mediator’ between individuals and health contexts, the health care system, the education system, and broad social and cultural factors at home, at work, and in the community.

11. The World Health Organisation (WHO) definition (7) emphasises the empowerment aspects of health literacy using the definition ‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health’. The WHO also says that health literacy ‘means more than being able to read pamphlets and make appointments’ but rather ‘implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions.’

12. A similar definition is used by the Australian Bureau of Statistics when it defines health literacy as ‘the knowledge and skills required to understand and use information relating to health issues such as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy’ (14).

13. The National Social Marketing Centre (NSMC) (www.nsms.org.uk) vision of health literacy takes a broadly similar approach. The NSMC view is that health literacy is ‘part of a set of ideas that considers the interests of the citizen to be paramount, that empowers consumers and that enables ordinary people to take greater control over the factors that influence their health and wellbeing’.

14. This broader definition of health literacy and the role of health information and education in bringing about improved health literacy is emphasised by Nutbeam, one of the most longstanding and influential writers in the field of health literacy, who proposes that there are three levels of health literacy (15): functional (basic skills in reading and writing to be able to function in a health context); interactive or communicative (more advanced cognitive, literacy and social skills to actively participate in health care); and critical (the ability to critically analyse and use information to participate in action to overcome structural barriers to health).
15. These definitions extend to their broadest when they enter the political realm. For example, Kickbush (16) gives a definition of health literacy which involves understanding peoples’ rights as patients, acting as informed consumers, and acting individually or collectively to improve health through the political system. This more overtly political analysis is also illustrated by Maddox (17) who discusses how many people, rather than acting on their own, share (health) literacy tasks with others. She therefore hypothesises that (health) literacy skills don’t only reside in individuals but in groups of people, for example families. (And in that sense, a person’s (health) literacy can be seen to go beyond his or her own skills.)

16. This idea is taken even further by Papen and Walters (18) who describe a study in which the relationships between literacy, learning and health were examined in the context of adults for whom English was a second language and / or adults who were attending literacy courses. They found that writing things down in preparation for consultations, taking dictionaries on visits to the doctor, reading leaflets whilst drawing on prior experience and knowledge, checking family medical books, and doing research on the internet were used by students as strategies to cope with difficulties they faced when engaging with the health-care system. Some of the demands of reading and understanding were resolved through using other people who were better able to read and understand [English] texts, who had an understanding of certain diseases, or who were more familiar with the working processes and structures of the health system. (Note that this process is known as brokering or mediation; brokers or mediators might be friends, family, key workers or health professionals.)

17. Two further broader definitions which are fairly up-to-date and which have currency and influence are included here to help further the overall understanding of the concept of health literacy and how this has developed through time. First, Zarcadoolas et al (19) define health literacy as ‘the wide range of skills and competencies that people develop to seek out, comprehend, evaluate and use health information and concepts to make informed choices, reduce health risks, and increase quality of life’. Second Kickbush and Maag (20) use the definition of ‘the ability to make sound health decision(s) in the context of everyday life – at home, in the community, at the workplace, the health-care system, the market place and the political arena. It is a critical empowerment strategy to increase people’s control over their health, their ability to seek out information and their ability to take responsibility’.

iv) The ‘Public Health’ definition / conceptualisation of Health Literacy

18. These broader definitions resonate with a public health orientation – rather than simply a clinical orientation – to health literacy. The public health approach explicitly connects health literacy with health promotion and the social marketing of public health interventions, and connects health literacy as an issue equally important in the public sphere as in health care settings.

19. This broader approach also makes clear that to understand health literacy requires an understanding of context: this includes the individual’s personal background, the social and institutional practices of health care (including the relationship between doctor and patient), the cultural practices of looking after one’s health, as well as the emotional aspects of dealing with ill health.

20. An alternative narrative on the trajectory for these definitions is given in the Institute of Medicine’s report (13) where the development is described as being from the 1970s when the
The concept of health literacy had a focus on the individual (functional health literacy), through to the year 2000 where the focus shifts to health systems (and the tripartite model of functional, interactive and critical health literacy especially as articulated by Nutbeam), through to 2006 when the concept moves to a more community focus through the multiple literacies models promoted by for example Zarcadoolas (19).

21. Finally, a very recent article by Nutbeam (21) sets out the two different roots of the concept of health literacy – the concept in clinical care, and the concept in public health. The paper describes the two distinctive concepts that reflect health literacy, respectively as a clinical ‘risk’ or a personal ‘asset’.

The Measurement of Health Literacy

i) Background

22. It is clear that the broad range of definitions of health literacy as summarised above create some challenges when it comes to measuring levels of health literacy. This is because the varying definitions arise from different conceptualisations of health literacy; and the ways in which health literacy is both conceptualised and defined have implications for its measurement. If health literacy is defined narrowly as the kind of ‘functional health literacy’ then one set of measures are appropriate; however, if a broader view of health literacy is taken then the measurement will be required to reflect these broader skills and aspects.

23. A helpful discussion of these measurement issues is contained in the 2006 paper by Baker (22). In essence it is argued that if the definition of health literacy adopted focuses on individual capacity only (aspects such as reading fluency and prior knowledge in the form of vocabulary and conceptual knowledge of health and health care), then there are measures available which can be used. However, if the definition adopted is broader, then information about the individual’s environment (e.g. the health care system and context, the complexity of spoken and written messages, public health messages) as well as information about culture and social norms would also need to be captured and measured. The development of measures to capture these broader aspects is a new field and no consensus yet exists as to how this should be done.

24. The National Social Marketing Centre reports on its website that they are currently undertaking an EU supported research study to assess levels of health literacy in a number of European states. The website states that ‘... The survey will seek to define and measure for the first time, levels of health literacy across nation states in Europe’.

ii) Measuring Functional Health Literacy

25. There are a variety of tools available to measure functional health literacy, although most of the work in this area has been undertaken in the US and the tools do not necessarily translate effectively into a UK context.

26. For example Jochelson (3) lists four tests which are / have been used frequently to measure functional literacy, numeracy skills, and health literacy: The Rapid Estimate of Adult Literacy in Medicine (REALM) is a 3-5 minute test that is used in health care settings to estimate adult literacy; The Test of Functional Health Literacy in Adults (TOFHLA) which takes 22 minutes to administer and the short version S-TOFHLA which takes 7-10 minutes; The (US) Health Activities Literacy Scale (HALS) based on the National Activities Literacy Scale; and the Newest Vital Sign which is a three minute test (23).
27. The scale of the problem – even on this fairly narrow definition - as estimated in the US and elsewhere is sobering. Jochelson’s review states that ‘the US National Adult Literacy Survey of 1992 found that 51% of the adult population had serious problems with reading or basic arithmetic or very basic functional literacy and numeracy skills (24). In Canada 48% of adults fell into the two lowest literacy levels of marginal and inadequate literacy (25).’ The US Department of Health and Human Services (26) estimates that only 12% of US adults have proficient health literacy.

28. The Australian Bureau of Statistics (27) reports that in 2006 60% of adults aged 15-74 do not have adequate health literacy.

29. A recent survey in England showed that about 16% of adults have literacy skills lower than that of an average 11 year old and 47% of adults have similarly low levels of numeracy (28), whilst an estimated 800,000 adults in Scotland are thought to have difficulties with reading, writing and numeracy22. These Scottish figures will be updated later in 2009 when the Scottish Government reports the results of a baseline study currently being undertaken by Glasgow University. A UK study of health literacy which reported in 2007 (29) found that 11% of participants had marginal or inadequate health literacy; and that the older participants were disproportionately affected.

30. As has been illustrated in Paragraphs 5.26-5.29 above, quantifying the extent of the problem – even on a fairly narrow definition of health literacy – is not straightforward, and estimates of the extent of the problem in the countries where this has been attempted vary widely. Nonetheless, even on the most conservative estimate, it can be seen that there is a substantial problem to be addressed.

iii) Measuring Broader Aspects of Health Literacy

31. The work on measuring wider aspects of health literacy is in its infancy. Jochelson’s 2008 review (3) states that ‘no tools that go beyond this [functional health literacy] to lifestyle behaviour exist. No published studies were found that attempt to develop criteria to test the conceptual and empowerment definitions of literacy.’

32. The searches undertaken for this review have uncovered a small number of emerging programmes of work in this area. For example in 2007, when the initial results from the International Adult Literacy and Skills Survey was published by the Canadian Council on Learning (30), it identified 5 distinct dimensions of health literacy which reflected improved methods for measuring broader aspects of health literacy. These were:

a. health promotion measures (to capture an individual’s ability to enhance and maintain health by locating and using health information);

b. health protection measures (to capture an individual’s ability to safeguard individual or community health by reading information or participating in referenda);

c. disease prevention measures (the ability to take preventive measures and engage in early detection);

d. health-care maintenance measures (the ability to seek and form a partnership with health care providers to follow directions or discuss alternative treatments); and

22 Adult Literacy and Numeracy in Scotland, Scottish Executive, 2001
e. *system navigation measures* (the ability to understand and to access needed health services).

However, as pointed out by Baker (11) this type of scale takes 30-40 minutes to administer and is not always straightforward to interpret.

33. Moreover, Pleasant and Kuruvilla (2) have recently (January 2008) reported an initial attempt to create a measure of the ‘public health approach’ to health literacy. A scale of 16 statements, each of which is either True of False (e.g. overall, vaccination has more risks than benefits; using condoms when having sex can prevent the spread of AIDS; exercise helps prevent heart disease) was developed to test out this public health approach to health literacy. The initial findings from this work were surprising (health professionals scored lower than lay people) and more work is required to produce a reliable, valid scale. However, there is an appetite to do this and the substantial measurement challenge is very much ‘work in progress’.

iv) Measuring Health Literacy in Scotland

34. It is clear from the discussion above that there are no easily available ‘off the shelf measures’ which can be applied in Scotland. General literacy is of course vital for all aspects of life, and indeed, one of the Performance Indicators in the Government’s Performance Management Framework is to reduce the number of adults of working age with low levels of literacy and numeracy (31). However, whilst comparisons on general literacy may be interesting they do not necessarily translate in a straightforward way to the broader concepts. It is very likely that the levels of inadequate health literacy in Scotland are high.

35. The recently commissioned (by the Health Analytical Services Division) ‘Better Together - Inpatient Survey’ asks a few questions about ease of access to services and satisfaction with services23, but the questions have not been designed specifically to test health literacy.

v) Which Groups have Low or Inadequate Health Literacy?

36. A range of groups have been identified as experiencing disproportionately low or inadequate health literacy. These are people with chronic physical or mental health problems (32), those with lower levels of educational attainment – especially those who are older and whose parents had lower educational attainment, (33, 34). Although health literacy does not straightforwardly correlate with other inequalities in health, low health literacy appears to be particularly prevalent among lower socioeconomic groups, ethnic minorities, the elderly and those with chronic conditions or disabilities (1).

vi) Is there a Good Screening Test for Health Literacy?

37. One possible policy approach to the issue of health literacy – especially in the clinical rather than the public health context – would be to look at the evidence about whether it is possible to screen for health literacy – and thence to offer support to those who have inadequate or low health literacy.

38. As might be expected, on this as on so many questions in this complex field, there are differing views on whether a good screening test has been, or could be developed. According to Nutbeam (8), ‘*a strong science is developing to support screening for poor literacy skills in*
clinical care and this is leading to a range of changes to clinical practice and organization’. [Note that Nutbeam is talking about general literacy skills here, not health literacy.]

39. However, by contrast, according to Baker (11) ‘….. It remains unclear whether it is possible to develop an accurate, practical ‘screening’ test to identify individuals with limited health literacy.’ He goes on to say that ‘… Even if this goal is achieved it remains unclear whether it is better to screen patients or to adopt a ‘universal precautions’ to avoid miscommunication by using plain language in all oral and written communication and confirming understanding with all patients by having them repeat back their understanding of their diagnosis and treatment plan.’

40. In Scotland currently the introduction of the Keep Well24 initiative (formerly known as ‘Prevention 2010’) has provided an opportunity to include literacy screening and referrals within a mainstream service. A recent evaluation of this has been commissioned by NHS Greater Glasgow and Clyde (NHSGGC) to provide NHS GG&C staff baseline information for the development of literacy awareness, screening and referrals within the area.25

The Impact of Inadequate or Low Health Literacy

41. A range of studies have looked at the impact of inadequate or low health literacy in terms of both health and financial consequences (1, 3, 12, 26, 33, 34, 35, 36, 37, 38). This research has reported that patients with low health literacy: have poorer health status and poorer self reported health; enter the system when sicker; are at a greater risk of hospitalisation and have longer hospital visits; have higher rates of admission to emergency services and require more avoidable hospitalisation; are less likely to adhere to prescribed treatments and self care plans; have more medication and treatment errors; have less knowledge of disease management and health-promoting behaviours; are less able to self manage; have decreased ability to communicate with healthcare professionals and share in decision-making; are less able to make appropriate health decisions; make less use of preventive services; suffer stigma and shame; have poorer health outcomes including knowledge, intermediate disease markers, measures of morbidity; and will incur substantially higher healthcare costs. As reported by DeWalt et al (37) patients with low literacy were generally 1.5 to 3 times more likely to experience a given poor outcome.

42. The National Social Marketing Centre is currently conducting a study to assess the costs of poor health literacy both to individuals and society. [Note that the only financial costings which have been found to date have been produced from within US. The figures run into billions of dollars.]

Policy and Practice Initiatives in Health Literacy and their Impact

i) Background

43. A number of strategic policy documents emanating from the USA and Canada, have focused on improving health literacy both by setting targets and objectives for improvements in health

24 http://www.keepwellscotland.com/
literacy and also by pursuing policy, programme, and practice initiatives which seek to improve health literacy, especially amongst those with low health literacy. In addition four recent reviews (1, 33, 37, 39) have been undertaken to examine what initiatives in health literacy have been tried, and what the impact of these have been.

ii) Policy Reports and Policy Objectives

44. For example, in their report *Healthy People 2010: Understanding and Improving Health*, the U.S. Department of Health and Human Services included improved consumer health literacy as a (developmental) objective (32). Other US examples include the American Medical Association which has adopted a policy on health literacy, and the National Institutes of Health and Agency for Healthcare Research and Quality which introduced a grants programme entitled ‘Understanding and Promoting Health Literacy’ in 2004.

45. Still in the US, the Institute of Medicine’s 2004 report (13), contains recommendations set out under three main headings: make effective communications an organisational priority to protect patient safety (actions such as raising awareness, training staff, using interpreters, creating patient centred environments, measuring and monitoring patient safety); address patients’ communication needs across the continuum of care (actions such as signing at entry points, appropriate language, approaches to discharge, and recommendations about the health care encounter itself such as not giving too much information and encouraging questioning); and pursue policy changes that promote improved practitioner-patient communications (actions such as expand the range of patient centred educational materials, and policies on insurance and financial incentives).

46. Another example comes from the Canadian Public Health Association (CPHA) which has identified the achievement of health literacy as one of its nine major goals.

47. According to Coulter and Ellins (1) ‘Within the UK, the ‘Skilled for Health’ campaign was jointly launched in 2003 by the Department of Health and the Department for Education and Skills. The campaign aims to demonstrate the links between better basic skills and improved health and to develop health-related learning materials for use with key groups: teenage parents, people with long term medical conditions, the elderly and ethnic minorities. Six local projects were launched in 2004 for phase two of the initiative.’

iii) Reviews of Evidence of Health Literacy Interventions and Their Impact

a. Coulter and Ellins

48. In their book chapter on improving health literacy published in 2006, referred to earlier, Coulter and Ellins (1) conclude that ‘initiatives designed to specifically target low literacy groups have had mixed results, with some studies showing beneficial effects on knowledge and behaviour, but there have been relatively few attempts to test the effects of these initiatives on reducing health inequalities.’

49. Given the saliency of the Coulter and Ellins review to this report, it is worth recapping the main findings in some detail. The authors identified three key objectives of health literacy interventions that had been introduced. These were: to provide patients with timely and appropriate health information materials to enhance health knowledge, skills and behaviours, and to enable informed health decisions; to encourage the appropriate and effective use of healthcare services, including greater uptake of preventive and screening services; and to
tackle inequalities in health and healthcare access by targeting information and education at low literacy, hard-to-reach and disadvantaged groups.

50. Given this range of types of objectives, Coulter and Ellins grouped the range of outcomes that had been specified for the interventions that had been tested into four categories: patients’ knowledge and information recall; patients’ experience, including communication and psychological outcomes; health services utilisation and cost; and health behaviour and health status.

51. Coulter and Ellins classified the interventions which they uncovered in their review into four types: written health information, alternative format resources (including internet and digitally based patient information and support systems); targeted mass media campaigns; and low literacy initiatives. The top level findings in each of these areas are reproduced below.

52. As far as written information is concerned, Coulter and Ellins conclude that ‘written information (e.g. leaflets) used as an adjunct to professional consultation and advice has been shown to improve health knowledge and recall, particularly when it is personalised to the individual. But few other beneficial effects have been demonstrated and there is no evidence of improvement in health behaviour or health status’.

53. As for alternative format resources, the review states that ‘alternative format resources, such as websites, can also improve knowledge and studies have demonstrated high user satisfaction and beneficial effects on self efficacy and health behaviour. There is some evidence of greater health benefit for disadvantaged groups when access barriers are overcome. Harm arising from unreliable websites may be under-reported.’

54. As far as targeted mass media campaigns are concerned, they say that ‘targeted mass media campaigns have been shown to increase awareness, but the effects may be short-lived. There is some evidence of impact on utilisation of services, but little evidence of beneficial effect on health behaviour, although two studies showed that the mass media could be effective in influencing smoking behaviour among young people’.

55. In relation to low literacy initiatives they comment that ‘low literacy initiatives may employ any of the strategies described in the three other categories. Where low literacy initiatives differ is in specifically targeting such strategies towards groups who lack adequate health literacy skills. Most often low literacy initiatives have involved designing or revising patient information or educational materials in order to enhance comprehension among people with health literacy problem.’ [Note though that elsewhere they comment that improving readability does not of itself improve necessarily improve comprehension.]

56. Most of the evidence for low literacy initiatives currently comes from North America. Overall they conclude – as set out above - that ‘initiatives designed to specifically target low literacy groups have had mixed results, with some studies showing beneficial effects on knowledge and behaviour, but there have been relatively few attempts to test the effects of these initiatives on reducing health inequalities.’


57. The report of an expert panel on the topic of health literacy in Canada (33) which was published in 2008 concluded that ‘there are very few rigorous evaluations of the effectiveness of health literacy interventions in Canada or in other countries’ and also that ‘there is some evidence that community-based and participatory approaches hold some promise in addressing
health literacy issues’. Whilst the expert group considered that there were potentially valuable initiatives throughout Canada to address health literacy issues, many of these were short-term and without sustained funding, and there are no ongoing mechanisms for sharing best practices across the country.

c. Pignone et al

58. The 2005 systematic review by Pignone et al (39) examined interventions designed to improve health outcomes for persons with low literacy skills. Twenty articles examining interventions designed to improve health among people with low literacy were found. The most common outcome studied was health knowledge; fewer studies examined health behaviours, intermediate markers, or measures of disease prevalence or severity. According to the authors, the effectiveness of interventions appeared mixed and the review concludes that drawing conclusions about effectiveness is difficult and that further research is required.

d. De Walt et al

59. The review by DeWalt et al (37) in 2004 reviewed 3015 titles and abstracts from the period 1980-2003, and found 29 literacy (NOT health literacy) interventions. They concluded that ‘These studies did not provide a good evidence base: no studies looked at the impact of literacy interventions on health care costs, reducing health inequalities or reducing health care access disparities; most studies of health outcomes focused on improvements to knowledge and the interventions did demonstrate increased knowledge, at least in the short term.’

iv) Other Contributions

60. The 2008 article by Nutbeam (8) emphasises the importance of more general strategies to promote literacy, numeracy and language skills in populations.

The Nature and Extent of Links between Health Literacy and Scottish Government Policy

61. It is clear from the foregoing that health literacy – and the improvement of health literacy – is crucial to the delivery of Scottish Government policy. An increase in health literacy is necessary for, and congruent with, the aspiration expressed in ‘Better Health, Better Care’ (40) for ‘mutuality’ – that is a greater sense of ownership and involvement of the public in service design. However, in general up until now, public debate and policy in the UK has been more strongly focused on the provision of health information than on health literacy. (Indeed, the drive to deliver high quality consumer information is a central component of Government policy for the NHS (41). Initiatives such as NHS24 and the National Electronic Library Health illustrate how significant a policy driver this has been.)

62. At a more detailed level, the key policy areas which link to an improvement in health literacy relate to reducing health inequalities (including a focus on wider determinants), to improved public health, to patient and public engagement, to patient safety, to service redesign, to self care and to the self management of long term conditions, to the encouragement of personal responsibility, and to policy on adult literacy and numeracy more generally.

63. Some of these policy drivers can be described as ‘enduring’ whilst others have been given particular emphasis by the current administration. As regards ‘enduring’ policy drivers, policy...
highlighting the focus on patient and public engagement in the development and delivery of healthcare was first developed in the late 1990s (42, 43). Government policy ever since (both in the UK and in Scotland) has continued to reinforce this as an underlying value in the development and delivery of all healthcare services and as a way to ensure that the research agenda is relevant to the needs of patients. As argued by Coulter and Ellins (1) ‘Health literacy is fundamental to patient engagement. If individuals do not have the capacity to obtain, process and understand basic health information, they will not be able to look after themselves effectively or make appropriate health decisions.’

64. A paramount focus on patient safety has been at the heart of government health policy for decades, and has been highlighted in a range of policy documents (31, 40, 41, 42, 43). The same is true for service redesign, which recognises that service delivery is not a static function (31, 40, 41, 42, 43).

65. Self care is ‘what people do to care for themselves, their children, other family members and their communities. In relation to health and health care, it is all that people do to maintain health, prevent illness, seek treatment, manage symptoms, treatments and side effects, accomplish recovery and rehabilitation and manage the impact of chronic illness and disability’ (44). Supporting self care is a major part of Scottish Government programmes to improve health and to make best use of health care resources (31).

66. The current administration has focused very clearly on the reduction of health inequalities (45) and on the improvement to public health through policy initiatives and programmes to reduce obesity, smoking, alcohol and drug consumption, to improve sexual health, and to improve mental health and wellbeing. A strong focus on Early Years Interventions has characterised much of government policy (40, 46). These policy objectives are completely congruent with a requirement to invest in improving health literacy.

67. In their 2006 review of interventions to improve health literacy (1), Coulter and Ellins say ‘Achieving greater health literacy in the population is, therefore, integral to improving the health of disadvantaged populations and to tackling health inequalities’. In their 2007 article, (47), they go one step further and argue that ‘any strategy to reduce health inequalities must promote health literacy’. They say that ‘because health literacy is central to enhancing involvement of patients in their care, all strategies to strengthen patient engagement should aim to improve health literacy.’

68. They continue ‘Many people will have difficulty taking advantage of these (sic) new opportunities if the problem of health literacy is not dealt with. This could widen health inequalities, or even create new ones.’

69. According to Coulter and Ellins (47), health information materials, decision aids, self management action plans, and other “technologies” of patient engagement are most effective when they supplement or augment, rather than replace, interactions between patients and professionals. They argue that as patients take on new health roles, ongoing support from health professionals may become even more important. In addition, they argue that health professionals must be given the opportunity to develop their competencies in patient centred care—particularly their communication skills; and that clinicians must also be given the resources needed to work collaboratively with their patients, to help them access and
understand health information, and to offer support in making choices to those who need (that support).

Possible Options for Development

70. The above summary and the scan of the relevant literature suggest there will be no ‘magic bullet’ as regards a solution to the problems created by low health literacy. The research evidence provides a few ‘leads’ but no decisive template for action. As identified in this literature scan, policy responses could cover any / all of the following: improvements to written materials; service redesign; building on the adult literacy and numeracy strategy (52); developments to / support for health professionals to develop their competencies; brokering and / or mediation.

71. There is substantial evidence (over 800 studies according to the Institute of Medicine) that most health materials are poorly written and poorly designed. Although this is only a small part of the overall approach to health literacy, initiatives to make improvements to written materials are important, and there is a large literature on how this can be achieved, and a number of checklists / tools which are available to assess readability, cultural appropriateness etc (1, 48). Literacies projects in Scotland have also produced guidelines on clear communication.27

72. Some individual studies have highlighted initiatives around practice redesign to help improve outcomes with for individuals with low literacy (e.g. Institute of Medicine Roundtable on Health Literacy held on 19 November 2008. The full report of this meeting is not yet available). Specific ideas are about walking through the health care experience from the perspective of a patient and making improvements to signage, etc.

73. According to Nutbeam (8) any strategies to promote (general) literacy, numeracy and language skills in populations, will have a positive impact on health literacy. Given that improvement to general literacy and numeracy is set out as an objective within the Government’s performance management framework (31) , the policy response within the Education Directorates should be linked to the overall policy response on health literacy.

74. Coulter and Ellin’s recent article (47) found that ‘... developing professionals’ communication skills was also an effective way to improve patient participation in clinical decision making and their knowledge and information recall of their condition and treatment. Clinicians needed to learn to communicate risk and elicit and respect patient preferences, and to coach and use question prompts. The involvement of health professionals in educational and self help programmes appeared more effective for disadvantaged populations.’ Elsewhere (1) they have made the case that support for health professionals, particularly in developing their competencies – particularly their communication skills – may be helpful in addressing low health literacy.

75. As described by Papen and Walters (18) and set out in Paragraph 23 above, there may be a role to be developed which can be described as ‘brokering’ or ‘mediation’ to support those

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with low health literacy. (Note that the ‘brokers’ or ‘mediators’ may be either formally or informally connected to the person who is receiving support.)

76. Many other possibly promising interventions are suggested by Coulter and Ellins (1), which may be promising for those with low health literacy. For example, internet based educational programmes; information and advice services supplied through digital interactive television; the use of visual aids and particularly pictograms; and ‘information therapy’ where it is argued that information should be prescribed to patients at every point along the healthcare continuum (49).
ANNEX 4 – A Selection of Ongoing Initiatives in Scotland

1. Training on Literacy / Health Literacy
   - Awareness Training with NHS staff on literacy / health literacy funded through Adult Literacy initiatives
   - Improving the literacy and numeracy of the population (including the NHS workforce)
   - Development of learning pathways for improving literacy / health literacy
   - Referring patients to courses etc if have poor health literacy
   - Training Pack on Literacy awareness for the health sector
   - Improving Screening for low Literacy / low Health Literacy (including Keep Well)
   - Induction of NHS24 staff using the language that patients use
   - Publicity material and follow up in health clinics

2. Improving Communication
   - Development of communication and translation strategy by NHS HS
   - SBAR in patient safety (Start, Background, Assessment, Recommendation)
   - Emergency Care Survey
   - Service contracts on communications standards etc
   - Developing the Confidence of Patients

3. Improving Written Materials
   - User Testing of Written Materials
   - Personalising Information
   - More use of Visual Information

4. Improving Access to Services
   - Improving Referral pathways
   - DVD aimed at asylum seekers re access to services
   - Improving Links between Primary Care and the Voluntary Sector in Mental Health
   - Improving Access to Information

5. eHealth
   - Logging on to own personal record
   - Electronic record demo
   - NHS Scotland ELibrary
   - Health Information Plus portal
   - Project to have ‘stories’ available on USB pens etc

6. Knowledge Management
   - Consultation on ‘Enabling Partnerships: Sharing Knowledge for a Mutual NHS’, which covers social networking etc
   - Development of Knowledge Worker role
   - Information prescription, information therapy in Ayrshire and Arran

7. Management of Multiple Morbidities and Management of Long Term Conditions / Self Help for Well Being and Health
   - Programme of research on Living Well with Multiple Morbidities
   - Call for proposals by LTCAS on self management by voluntary sector
   - Focus groups on managing LTCS
   - Self help for Wellbeing and Health (particularly within Mental Health Improvement)