The evidence base for health literacy interventions: Summary Overview

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Executive Summary

This report was commissioned by NHS Education for Scotland, supported by literature searching by Health Scotland.

The purpose of this overview of the evidence base for health literacy interventions is to underpin the National Health Literacy Action Plan and to guide its implementation across NHS Scotland and its partner agencies. It is structured in relation to the two key areas of specific action selected by the National Action Plan to promote the change in practice and culture required:

- The evidence base for health literacy interventions designed to enhance workforce awareness and capabilities.
    - Research on interventions which have addressed the workforce contribution to health literacy is very limited. Some recent approaches (in the US and the UK) have taken a

'whole systems' approach, suggesting the importance of embedding health literacy within culture/organisational change processes.

- There is some limited literature which addresses the impacts of the education of health care staff on health literacy, but little or no evaluation of this.
- A key difficulty in developing the health care workforce contribution to health literacy is the absence of identified 'health literacy competencies'.
- The little research that can be found on health care professional education relating to health literacy is predominantly focused on communication of information: very little literature was to be found relating to interactive (personal empowerment) or critical (community empowerment) literacy. Educational interventions designed to support culture/attitude change tend to promote the self-reflection of the individual practitioner.

- The evidence base for health literacy tools, innovations and technologies.
  - The evidence consistently indicates that the most successful health literacy interventions are multifaceted, including several approaches and techniques as part of a more holistic health literacy approach.
  - Interventions designed to involve people in decisions about their treatment have tended to focus on cancer and cardiovascular disease. Research shows that shared decision-making increases patients' satisfaction with treatment decisions, and improves clinical satisfaction. UK-based work to embed shared decision making in everyday practice indicates that it can create positive change within health care systems and to individual patients.
  - Shared decision making interventions can lead to increased knowledge, self-efficacy, and reduced decisional conflict in disadvantaged patients.
  - Patients are particularly vulnerable following discharge from hospital, for example in relation to changes in medication and new self-care responsibilities. These challenges can be overcome by improving communication between hospital doctors and GPs, supporting patients in managing their medication, and better communication between patients and doctors. This can include approaches which focus on support in people in managing their medication, Teach Back (and similar approaches), and tailored information.
  - There are many interventions designed to help people manage their medication, however few have been systematically evaluated. Similarly, evidence on the efficacy of Teach Back and similar approaches is limited, but these techniques are frequently referred to in 'toolkits' and often part of multifaceted interventions. The literature suggests that these techniques are most successful when they are an integral part of a more holistic health literacy approach.

1 Introduction

Within the Quality Strategy[1], the Scottish Government made a commitment to 'roll out health literacy interventions to support staff to communicate effectively and to ensure people understand what is happening to them'. In May 2014, the Scottish Government published *Making it Easy: A Health Literacy Action Plan for Scotland*[2]. This focuses on improving the healthcare system and workforce capacity and capability to make it easy for people to access and use information about health and wellbeing, rather than seeing health literacy as a gap that needs to be addressed in patient/service user capabilities. The Action Plan:

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

The Health Literacy Action Plan for Scotland comprises:

1. **A workforce awareness and capabilities programme which asks:**
    a. Leadership, management and team leaders to:
        i. Address health literacy as part of their activity to address health inequalities and human rights obligations and in achieving the effective, safe and person centred ambitions
        ii. Take responsibility for staff to be aware of and have access to health literacy tools
        iii. Attend to staff health literacy training needs
        iv. Develop an organisational culture that promotes health literacy
    b. Individual health care staff to:
        i. Recognise people's health literacy needs
        ii. Be aware of appropriate resources
        iii. Employ a range of communication tools

2. **Testing and spreading health literacy innovations, focusing on effective communication – which takes account of people's health literacy needs – particularly at key health care interactions and transitions.** These include:
    - Hospital discharge and clinic visits;
    - Shared decision making and consent for treatments and procedures; and
    - Changes in people's medication

Evidence-based health literacy interventions include:

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

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- The evidence base for health literacy interventions designed to enhance workforce awareness and capabilities.
- The evidence base for health literacy tools, innovations and technologies.

2 Interventions designed to enhance workforce awareness and capabilities

Most health literacy research has focused on patients' health literacy – notably where their health literacy is judged to be 'low' – and interventions to mitigate the impacts of 'low' health literacy. Consequently, the health literacy focus so far has often been on changing/educating patients/service users – notably where their health literacy is judged to be 'poor'. Very little research has been done on the health care workforce contribution to health literacy. A recent BMJ editorial article[3] argues that "it is time to shift our focus [in addressing health literacy] from patient to provider".

> *"The ability of patients to understand and access health care depends on both engagement and communication. It is a two way street, with one important focus being a wider drive to improve people's abilities. However, most health professionals and health managers cannot achieve this in their day to day work. What they can do is to consider how they can change the health information and health systems they offer, to make them as easy to understand and interact with as possible. Future research should focus on evaluating attempts by professionals and health systems to remove barriers to understanding and engagement for all patients."*

The World Health Organisation (2013[4]) has noted that there are more than 20 tools for measuring health literacy.

> *"The existing measures of health literacy are still too oriented towards individuals and must be expanded to include the collective level (including communities) and assessing the literacy-friendliness of materials, organizations and environments"*

Some recent (US) research has begun to redress this deficit model by exploring the organisational and health care workforce issues in health literacy.

The US Institute of Medicine (IoM)(2012)[5] noted that addressing health literacy is critical to delivering person- centered randomised controlled trial, and that a wide range of (US) organisations have emphasised the need to tackle system-level factors to ensure that patients can make informed randomised controlled trial decisions.

> *"Although health literacy is commonly defined as an individual trait—the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions —there is a growing appreciation that health literacy does not depend on the skills of individuals alone. Health literacy is the product of individuals' capacities and the health literacy–related demands and complexities of the randomised controlled trial system. System changes are needed to align randomised controlled trial demands better with the public's skills and abilities."*

It presents "an aspirational vision" of a "health literate organization" which enables people to access and benefit optimally from the range of health care services. Such an organisation is characterised by the following attributes:

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

2.1 A whole systems approach

In this section we are concerned particularly with workforce issues, but the IoM paper shows how workforce issues must be addressed within a whole systems approach. The IoM vision is one which asserts that "everyone needs health literacy training" and that this is all about "successful communication". It identifies staff in health promotion roles as requiring specialised health literacy training. The IoM vision for a health literate workforce is one where the organisation:

- *"Hires diverse workforce with expertise in health literacy.*
- *Sets and meets goals for ongoing formal and informal health literacy training for all staff and members of governing bodies.*
- *Evaluates health literacy skills of staff on an on-going basis, provide training to those who do not meet standards of excellence, and evaluate the impact of the training.*

- *Incorporates health literacy into orientation sessions and other types of training (e.g., patient safety, cultural competence, patient-centred care).*
- *Arranges for staff to take advantage of online health literacy training resources.*
- *Supports staff in attending specialized health literacy training outside the organisation.*
- *Brings in outside health literacy professionals to augment in-house training resources.*
- *Develops "expert educators" with cross-cutting educational skills who can serve as role models, mentors, and teachers of health literacy skills to others.*
- *Identifies and implements appropriate new curricula.*
- *Collaborates with patients who can be effective speakers and trainers."*

This whole system approach has parallels with the concept of the Care House developed in the UK during the year of care for Diabetes (2007)[6]. The 'Care House' provides a metaphor for a holistic person-centred care planning process, which emphasised the importance and inter-dependence of each element – if one element is weak or missing the service is not fit for purpose.

The key components are the person with diabetes being engaged and informed, working with randomised controlled trial professionals who are committed to partnership working. The framework shows that that this will only occur in practice if there are sound organisational processes that facilitate their interaction, built on the foundations of robust commissioning processes.

2.2 Health and social care practitioner roles

One significant study of an organisational approach to health literacy was undertaken in the UK[7]. This study evaluated the approach taken by NHS Ashton, Leigh and Wigan in building an infrastructure which aimed to build public health capacity, develop health literacy, and empower people to manage their own health. A Health Improvement Practitioners (HIP) Team was set up, which established a network of Health Champions whose role was to engage with people in their community and help improve their health by providing information and improving knowledge. The Health Champions operated in a variety of community and workplace settings including neighbourhood-based community centres, amateur sports clubs, voluntary organisations, the public sector and private companies. The role of the Health Champion depended on the setting and the interest and skills of the individual. Health Champions were recruited and supported through the offer and delivery of training courses. These included the Royal Society of Public Health Level 2 Award in Understanding Health improvement; the Essential Public Health course and the Connecting Communities to Health programme.

> *"The evaluation report suggests that the HIP role is 'working'. Over three years the HIP team trained over 1000 health champions. General feedback seemed to be very positive."*

The report of the study notes the following learning points:

- Health Champion issues:
    - Continue the provision of behaviour change training. Individuals need help to be able to 'raise the subject' and understand how people's confidence and conviction can be enhanced.

- Review the value of the accreditation process. Whilst it is an essential factor for some people, it is less so for others.
- Learn about mental health and wellbeing. “Sometimes the smallest thing can boost people’s confidence. We need to focus on de-demonising mental health – so it’s not a taboo.”
- Provide high-level support for workplace Health Champions.
- Ensure access to ongoing support from the HIP Team. This will help maintain motivation and provide further learning opportunities among Health Champions.

- NHS issues:
  - Measure the impact of the programme on individual and community health. “The golden question remains – what impact is the programme having?”
  - Recognise the need to extend the reach of the programme. “We need to reach out to organisations we are not working with such as adult social care, care homes and the police.”
  - Develop the Health Champion role and infrastructure. “We need a website to share knowledge, create communities of interest and we need to produce things jointly.”
  - Determine how partner agencies and the public perceive the ‘health offer’. Would a recognisable public-facing identity or brand alongside a wider marketing strategy help? The launch of the website will help.
  - Build resilient communities. “This should be approached in a multi-partner, asset based way, which doesn’t [just] rely on the PCT. Amateur support clubs have been brilliant at this.”
  - ***Embed health literacy approaches into contracts, service specifications and patient/user questionnaires*** (our emphasis).

Dennis et al’s (2012) Australian review[8] aimed to determine how effective primary health care providers are at improving the health literacy of individuals to make lifestyle changes to smoking, nutrition, alcohol, physical activity and weight (SNAPW). Although this review focused on the workforce, it addresses interventions that attempt to cause individuals to change their behaviour; rather than looking at approaches that address the practice of health care staff. This document reviewed 52 papers. Only 33% of interventions provided by doctors were successful in improving health literacy or outcomes; compared to 92% of those provided by nurses, dieticians or health educators. The authors suggest this is because doctors used more low intensity interventions (e.g. smoking cessation brief interventions), which were less likely to be successful. On this basis, they suggest that intensity of intervention, rather than the role of the person that delivers the intervention, is likely to have caused the difference in success. Medium to high intensity programmes may be more effective in part because they take longer, thus enabling the facilitation of shared decision making by allowing trust to develop between patient and practitioner. The review noted that capacity to provide interventions of sufficient intensity is an important condition for effective health literacy support for lifestyle change.

2.3 Health care professional education

The SMCI Associates scoping work on the Current State and Development Priorities to Improve the NHSScotland Workforce Contribution to Health Literacy (June 2013)[9] found that:

> *"The education/training of the NHSScotland workforce in relation to health literacy varies widely, with midwives and doctors being perhaps best prepared to support health literacy at the point of registration. Communication is the main area in which health literacy is addressed, with some focus on other areas such as informed choice (midwives), the social dimensions of care (doctors) and shared decision-making (doctors). There is very little coverage of health inequalities issues. Evidence on the efficacy and impacts of education/training relating to health literacy is very limited indeed, but there are indications that health care workforce development approaches to enhancing health literacy are more successful when they are integrated within more holistic interventions – for example the co-producing health programme in the UK."*

The US Institute of Medicine (2004)[10] noted that "few official requirements or curricula address health literacy in schools of medicine, public health, nursing, dentistry, or pharmacy. Health literacy issues may be addressed under topics such as patient communication, but they are generally not systematically included in these topics"; and that as such "health professionals and staff have limited education, training, continuing education, and practice opportunities to develop skills for improving health literacy (finding 5.3, p 160). This led to their recommendation that

> *"Professional schools and professional continuing education programs in health and related fields, including medicine, dentistry, pharmacy, social work .. nursing, public health .. should incorporate health literacy into their curricula and areas of competence" (recommendation 5.6, p161)*

Despite this, in 2012, researchers were continuing to note the need to include health literacy within pre-registration curricula (Cafiero 2012[11], Horowitz et al 2012[12], Maybury et al 2012[13], Jackson et al 2011[14], Oates & Paasche-Orlow 2010[15], Robertson Jackson & Bullock 2010[16]). Most of the research focus is on developing communication skills as an important part of person-centred care and health improvement.

US research has shown that health professionals often underuse best practice communication strategies (Schwartzberg et al 2007[17]; Turner et al 2009[18]; Rozier et al 2011[19]). Training, however, can increase randomised controlled trial professionals' intentions to use clear communication techniques (Mackert et al 2011[20]); and health professionals who have attended health literacy training have succeeded in learning communication skills (Kripalani et al 2006[21]; Martin et al 2009[22]; Blake et al 2010[23]). Furthermore, interventions that involve training for randomised controlled trial professionals in health literacy have reported improvements in cancer screening rates and better patient satisfaction ratings (Clark et al 1998[24]; Ferreira et al 2005[25]). While research has not yet established direct links between training and improving health outcomes, health literacy training has been shown to achieve desirable educational outcomes (Coleman, 2011[26]).

Coleman (2011)[27] concludes that there is evidence to indicate that randomised controlled trial professionals of all types "lack adequate training in health literacy principles" (p. 76). Further,

Coleman argued that there needs to be more research on which approaches (e.g. Teach Back or other methods such as avoiding jargon or general education about the importance of health literacy) should be taught to health care staff, as well as which approaches would be most effective in improving patient outcomes.

Coleman suggests that more work should be done on assessing and evaluating the teaching of health literacy approaches to nurses and other allied health professionals. Coleman refers to recent and on-going work in the US to establish an "*as yet unidentified*" 'core set of measurable competencies' in health literacy that would apply to all health care staff[28].

The little research that can be found on health care professional education relating to health literacy is predominantly focused on communication of information: very little literature was to be found relating to interactive (personal empowerment) or critical (community empowerment) literacy. There is however, a growing body of evidence that the provision of culturally sensitive care can improve health outcomes and patient satisfaction (Brach and Fraser, 2000[29]; Way et al 2002[30]), and the need to train health professionals with the ability to provide quality care for a diverse population (Crandall et al 2003[31]).

2.4 Conclusions

- Research on interventions which have addressed the workforce contribution to health literacy is very limited. Some recent approaches (in the US and the UK) have taken a 'whole systems' approach, suggesting the importance of embedding health literacy within culture/organisational change processes.
- There is some limited literature which addresses the impacts of the education of health care staff on health literacy, but little or no evaluation of this.
- A key difficulty in developing the health care workforce contribution to health literacy is the absence of identified 'health literacy competencies'.
- The little research that can be found on health care professional education relating to health literacy is predominantly focused on communication of information: very little literature was to be found relating to interactive (personal empowerment) or critical (community empowerment) literacy. Educational interventions designed to support culture/attitude change tend to promote the self-reflection of the individual practitioner.

3 Interventions focused on health literacy tools and approaches

There is relatively little evidence on the efficacy of health literacy interventions (Berkman et al 2011[32]; Dennis et al 2012[33]), partly because of the relative novelty of health literacy as a research area, meaning that in some of the large clinical literature databases (i.e. CINAHL) the term does not exist as a pre-determined search/term (see appendix A). Furthermore, health literacy is defined and operationalized in different ways, and it is relatively common for research purporting to examine approaches to health literacy to focus on functional literacy alone, conflating 'low' functional literacy with 'low' health literacy. The focus is generally on people with 'low' (health) literacy, although the

challenges in defining health literacy are clearly recognised (for example, Nutbeam[34] 2000; Manafo & Wong[35] 2012; Berkman et al 2011[36]).

The vast majority of work identified originates and was carried out in the US. This does raise questions as to transferability to UK (Scottish) contexts. Nevertheless, there are some useful and potentially fruitful findings from US studies that should not be dismissed on this basis.

The SMCI Associates scoping work on the Current State and Development Priorities to Improve the NHSScotland Workforce Contribution to Health Literacy (June 2013)[37] concluded that:

- *The evidence on the efficacy of health literacy approaches is limited; and those that demonstrate clearest effects are intensive and long term, and focus on changing **patients' behaviour**. We identified no studies addressing real impact on health outcomes.*
- *Most health literacy interventions reported on focus on issues related to patients with 'low' health literacy, and interventions to mitigate the impact of this on health behaviours.*
- *US approaches, in particular, often focus on methods of measuring patients' 'health literacy', in order that the healthcare practitioner can respond appropriately. The definition of 'health literacy' is a particular issue here, as is whether a patient's 'health literacy' can be changed or improved.*
- *There is much focus on making information accessible – through developing different approaches to written information (e.g. developing pictorial approaches), and supporting patients to use the internet.*
- *Most health literacy interventions relate to issues of functional literacy (communication of information) than of interactive (personal empowerment) or critical (community empowerment) literacy.*
- *Health literacy interventions usually relate to supporting patients self-management of health conditions, and medication management.*
- *The development of trust between patient and practitioner is important, and it is this that facilitates shared decision-making.*

3.1 A holistic approach

The evidence consistently indicates that the most successful health literacy interventions are multifaceted, including several approaches and techniques as part of a more holistic health literacy approach.

Sheridan et al's (2011)[38] systematic review concluded that the most effective interventions were intensive, multifaceted interventions that involved a lot of time, often over a period of weeks or months. In particular, mixed-strategy interventions focusing on self-management were deemed most effective in terms of reducing severe health outcomes among individuals who might otherwise have to use emergency departments or inpatient hospital stays (e.g. in heart failure or asthma).

Berkman et al's (2011) [39] detailed systematic review of health literacy interventions concluded that:

- Evidence for interventions is limited.

- Those interventions that demonstrate clearest effect on health outcomes are those that are intensive, involve a lot of time and focus on changing behaviour i.e. improving patient self-management of specific conditions (e.g. diabetes, chronic heart disease) through structured educational interventions over several weeks or months.

In England, the 'Skilled for Health' programme[40] was a government funded programme which ran from 2003 to 2009. It aimed to address both the functional literacy needs and health inequalities prevalent within traditionally disadvantaged communities by promoting positive attitudes, and reduce stigma and shame. It embedded language, literacy and numeracy skills learning into a wide range of health topics. A number of positive outcomes (Berry & Baker 2012[41]) were reported, including increased health knowledge, positive changes in health behaviours including healthier eating, increased physical activity and weight loss, and increased self-esteem and confidence. This embedded learning approach helped to empower participants by ensuring they had the skills and information they need to make informed choices about their wellbeing in the future (Berry & Baker 2012[42]).

'Teach to Goal' is a US-based intervention which includes a several approaches to support people with heart disease to develop self-care skills. It is currently being is currently being tested in a Randomised controlled trial in order to determine whether it is more effective than a single-session brief intervention for increasing knowledge, skills and self-management behaviours. This study aims to provide an evidence base for the relative benefits of different educational strategies in improving heart failure self-management skills (Baker et al 2011[43]).

3.2 Shared decision-making and consent

The Decision Navigator (DN) intervention (Bekora et al 2008)[44] aims to help people with cancer to weigh up the risks and benefits of each treatment choice, whilst taking account of their own personal objectives for treatment and quality of life. Patients meet with a 'Patient Information Navigator' (member of staff trained in DN) prior to four key doctor appointments - initial appointment, treatment planning appointment, treatment review, follow up appointment. These meetings are designed to prepare questions for the consultation using specific structure (SCOPED[45]). SCOPED was developed in the US as a form of critical reflection that is used to help people to think, talk, read and write about decisions.

- Situation: clarifying known facts about my condition
- Choices: clarifying which options are available
- Objectives: clarifying my goals and priorities
- People: clarifying roles and responsibilities
- Evaluation: clarifying how my choices affect my objectives
- Decisions: clarifying which choice is best and next steps

The Patient Information Navigator works with the patient to enable them to generate their own list of questions for the consultation. The list is then given to the patient's doctor for them to review before the appointment. The navigator goes together with the patient to the appointment and audio-records the consultation whilst also noting down the key points. The patient will take away a

CD of the consultation on the day, and be sent a typed summary of what was discussed, which is copied and also sent to the hospital consultant – it can also be sent to the GP so that they are kept up to date with the patients hospital care.

US research[46] has shown that receiving Decision Navigation increased patient participation and satisfaction with treatment decisions, and improves clinical satisfaction with cancer health care consultations.

The Edinburgh Cancer Centre piloted the Decision Navigator (DN) as a randomised controlled trial[47] (patients receiving DN or usual care) from 2008-10, with 123 newly diagnosed prostate cancer patients, to find out whether DN increased patients' confidence and certainty in treatment decisions, while reducing regret associated with decisions made. Patients who received DN were more confident in making decisions about cancer treatment than those that received usual care. They were also more certain they had made the right decision after the consultation, and had less regret about their decision 6 months later. DN was found to be feasible, acceptable and effective for use with this patient group in Scotland. The same research team have explored DN with breast cancer patients, but found no significant impacts within this group, possible due to a small sample size. They are also studying the long term impact of DN with brain tumour and bowel cancer patients[48].

A randomised controlled trial is currently underway in Australia to examine the ability of an e-health-assisted strategy in people at highest risk of a cardiovascular event to lower their risk, through receiving and adhering to best practice recommendations (Redfern et al 2014[49]). The impact of this e-health strategy, the Consumer Navigation of Electronic Cardiovascular Tools (CONNECT) on health literacy levels is also being examined. Two thousand participants are taking part in this study, and they will be followed up over an 18 month period.

Durnand et al (2013[50]) sought to verify "the assumption that shared decision making would be most beneficial to disadvantaged groups and may reduce health inequalities" and evaluate the impact of Shared Decision Making interventions on patients from disadvantaged groups. Their systematic review concluded that shared decision making interventions led to increased knowledge, self-efficacy, and reduced decisional conflict in disadvantaged patients. Their analysis suggests that these interventions, when adapted, may be most beneficial to lower literacy groups, which in turn, may reduce health inequalities. They warned, however, that "these results could not be pulled into the meta-analysis and should be interpreted with caution".

The Health Foundation's MAGIC (making good decisions in collaboration) Programme[51] tested an approach to embedding shared decision making in everyday practice. The programme began in August 2010 and ended in October 2013. Its aims were:

- To demonstrate that shared decision making can feasibly, affordably and sustainably become a core characteristic of routine clinical care, both within primary and secondary care and at large scale.
- To build practical and transferable knowledge about how this can be achieved and what the conditions for success are.

The MAGIC programme was delivered through activities including:

- Skills development and engagement.
- Development workshops for participating health care staff.
- Guidance on developing, adapting and implementing decision support tools.
- Facilitation and peer support for clinical teams.
- Support in involving patients, including setting up patient forums and implementing a campaign (Ask 3 Questions) to increase patient's awareness of shared decision making.

The evaluation (The Health Foundation 2013[52]) of the first phase of the MAGIC programme showed that, while there are challenges to making shared decision making a reality, and it can be difficult and slow to do so, it can also create positive change within health systems and to individual patients. In March 2012, NHS East Midlands commissioned Picker Institute Europe to design and deliver a shared decision-making project (Walsh et al 2012[53]). The work aimed to:

- Build on and contribute to the evidence base for understanding and supporting shared decision-making.
- Develop recommendations for advancing shared decision-making within local health services.

Key themes were identified and explored in-depth in a series of focus groups with young people, parents and carers, and through individual interviews, a discussion group and a hands-on workshop with health professionals. Taking all the project elements together, five key priorities emerged for driving and developing shared decision-making in the East Midlands. These were:

- Communicating and defining shared decision-making.
- Securing senior level direction, leadership and support.
- Developing multi-disciplinary and multi-agency ways of working.
- Preparing and equipping people for shared decision making.
- Showing that shared decision making works.

3.3 Hospital discharge and clinic visits

The period following discharge from hospital is a vulnerable time for patients, with about half of adults (Kripalani et al 2007[54]) experiencing a medical error following discharge, and 19-23% suffering an adverse, often drug-related event. There are several important challenges to providing high quality care as patients leave hospital, including changes to medication, new self-care responsibilities, and complex discharge instructions. These challenges can be overcome by improving communication between hospital doctors and GPs, supporting patients in managing their medication, and better communication between patients and doctors (Kripalani et al 2007[55]). This can include approaches which focus on support in people in managing their medication, Teach Back (and similar approaches), and tailored information.

3.4 Medication changes

The Scottish Government has developed a DVD[56] highlighting the importance of good communications between patients and health care staff with regard to medicines management, and

the dangers associated with miscommunications which could easily be avoided. It highlights the need for clear communication at all times, and the importance of checking patients' understanding of instructions and asking them to repeat them back. It also points to the role that carers and/or family members can play in medicines management.

The Brown Bag Medication Review[57] is a common practice in the US, designed to help pharmacists and GP practices improve communications about medications between patients and health care staff. This involves inviting patients to bring in all of their medication and explain to them how they take it, when and in what quantities. It allows checks to be made on understanding and adherence, as well as providing opportunities to reduce prescriptions. Few studies have evaluated the effects of patient participation in medication reviews. A recent (Willboordse et al 2014[58]) systematic review conducted in the Netherlands looked at the outcomes of 37 articles and concluded that involving patients can improve their knowledge, satisfaction and the identification of drug-related problems.

Kalichman et al. (2013)[59] conducted a randomised controlled trial to test the efficacy of a pictograph-aided medication adherence skills-based counselling intervention with 446 adults living with HIV with marginal and low levels of health literacy in the US. Participants were randomly allocated to one of three groups: pictograph-guided adherence counselling; standard adherence counselling; or general health improvement counselling. Participants were followed for 9 months after the intervention, and those with marginal literacy skills were found to benefit from adherence counselling regardless of pictographic tailoring. Individuals with lower literacy skills demonstrated greater adherence in the general health improvement counselling condition, suggesting that this group might require more intensive of provider-directed interventions.

In their US-based systematic review of the relationship between adherence to cardiovascular or diabetes medication and health literacy in older adults, Loke et al (2012[60]) concluded that the current evidence does not show a definite association between health literacy and medication adherence in older adults with cardiovascular disease or diabetes. In the absence of a definite link, they suggest that efforts to develop interventions to improve health literacy might not necessarily improve adherence to medications.

The AHRQ Universal Precautions Toolkit outlines a range of additional approaches that health care staff can use to help people manage their medication and improve medication adherence, including the use of Pill cards, Pill charts and Med cards[61].

3.5 Teach-back

Research suggests that patients remember and understand less than half of what health care staff explain to them and the more information given, the more information is forgotten[62]. Teach-back is a communication technique which health care staff can use to check that patients correctly understand the information or instructions they have been given. Within the United States, teach-back is endorsed by the Agency for Health care Research & Quality[63] who consider it "one of the 11 most highly rated patient safety practices".

Within Scotland, the Government has produced 'teach-back' postcards and several DVDs demonstrating teach-back in practice, see figure 1.

Figure 1: NHS Scotland Teach-back postcard

On the back, the postcards say:

> *Teach-back is a really simple way to check patient's understanding.*
> *It involves asking patients to explain or demonstrate, in their own words, what you've discussed with them – for example:*
> *'To be sure I've explained this consent form clearly, can you tell me what you are agreeing to?''*
> *Or*
> *'Please show me how you will use the asthma inhaler, so I can be sure I have given you clear instructions.'*
> *Or*
> *'We discussed a lot today. Can you tell me what you found most important?'*
>
> - *If patients do not restate the information correctly, then try explaining again using different words, drawing a diagram or simplifying instructions, then use teach back again.*
> - *If, after two or three attempts, the patient still does not "get it," then ask a colleague for help or look for another explanation such as the need for an interpreter.*

Teach Back involves asking people to restate information that has been presented to them (White et al 2013[64]). Teach Back is used as a strategy to review and eliminate gaps in communication between healthcare providers and service users (Dosch 2013[65]). US research (Schillinger et al 2003[66]) has shown that Teach-back is successful regardless of patients' health literacy abilities, and has been shown to improve health outcomes. The *Health literacy: Best of Scottish* conference in March 2013[67] heard one example of how Teach-Back was being incorporated into improvement methodology, for example through the Scottish Patient Safety Programme.

Berkman *et al*[68] (2011), noted that there was little peer reviewed published research on Teach Back, and suggested that Teach Back may not need specific investigation in relation to health literacy as it has been well studied in other fields (i.e. psycholinguistics). Despite a lack of robust evaluations of the Teach Back method, it is widely suggested as a potential way in which health care staff might address low health literacy among service users[69].
There is, however, some recent research which addresses the efficacy of Teach Back.

A Randomised controlled trial (Negarandeh et al 2013[70]) has been conducted in Iran, examining the impact of Teach Back in conjunction with pictorial image education strategies on knowledge about Type 2 diabetes and medication/dietary adherence. One hundred and twenty-seven people with Type 2 diabetes and low health literacy were randomly allocated into three groups: two groups receiving an intervention: pictorial image or Teach Back; and a control group. The two groups receiving an intervention had education sessions within three weekly sessions, each lasting 20 minutes. Level of functional health literacy, diabetes knowledge, and adherence to medication and diet were measured and compared in the three groups before and six weeks after the interventions. Both Teach Back and pictorial images increased knowledge, as well as adherence to medications and diet among people with type 2 diabetes and low health literacy. On this basis, the authors concluded that both educational strategies seem to be effective for use with individuals with diabetes and low health literacy.

A systematic review is currently underway in Vietnam to assess the effectiveness of health education using Teach Back on adherence and self-management in chronic disease, and to determine how the Teach Back method is best delivered (Thi Thuy Ha Dinh 2013[71]). No results have yet been published, and timescales for publication are not available online.

There are several techniques which are similar to Teach-Back, for example Ask Me 3[72] and Time to Talk[73], which are designed to improve communication and engagement between service users and randomised controlled trial providers. They work by providing 'permission' to the patient to ask, and a structure for the interaction. The use of these approaches is based on studies which have shown that people who understand health instructions make fewer mistakes when they take their medicine or prepare for a medical procedure, and may also get well sooner or be able to better manage a chronic health condition[74].

US research (Wisconsin Collaborative for Health care Quality 2010[75]; Galliher et al 2010[76]) indicates that these techniques can increase patient satisfaction with each visit, help to decrease the number of missed visits, reduce the number of call-backs (patient calls for clarification or more information) and do not add significant time to the length of patient visits.
However, because the onus is on the patient, these techniques rely upon the confidence and skills of the patient.

There is minimal published literature on the Ask Me 3 approach, and no Randomised controlled trial data or systematic review outcomes to draw conclusions from. Despite so little in the way of evaluation data, its use has been advocated in several papers (Abrams et al 2009[77]; Evangelista 2010[78]; Ferguson & Pawlak 2011[79]; Johnson et al 2013[80]).

3.6 Tailoring information to people's needs

A US based systematic review (Mafano & Wong 2012[81]) of health literacy programmes focussing on access to, understanding and use of heath information noted a lack of published research on tailoring information to people's need. They identified nine articles which demonstrated positive outcomes, with participants feeling more confident in their ability to find and apply online health information, and retrieve online information independently. However, the authors noted limitations in generalizability due to reduced quantity and quality of evidence available. On this basis, they support previous calls for the development of evidence-based interventions that meet the needs of specific populations, including older adults (Schaefer 2008[82]; Schaffer 2007[83]).

A recent Swedish study (McInnes & Haglund 2011[84]) looked at the accessibility of online health information and implications for health literacy. The names of 22 conditions were entered into five search engines, and the readability of the first 10 results was evaluated. Government and health service provider websites were found to be most readable, whilst higher education websites were the hardest to read. It was also found that some of the most frequent search results (such as Wikipedia pages) were amongst the hardest to read. On this basis, the study concluded that health professionals, with the help of public and specialised libraries, need to create and direct patients towards high-quality, plain language health information in multiple languages.

The My Diabetes My Way (MDMW) website[85] was launched by the Scottish Diabetes Group in October 2008. It is the official NHS Scotland patient and carer information portal on diabetes. It contains validated educational materials in a variety of formats (leaflets, videos, interactive tools), for people with diabetes. The aims of this information resource are to improve patients' knowledge of the disease, their self- management and ultimately to improve their health outcomes. It also enables people with diabetes from across Scotland to access their own medical information online. The evaluation of the first year (Cunningham 2012[86]) showed that the system is a useful additional component for the self-management of diabetes in Scotland. Users report that it helps them in their self-management, with 98% also indicating that it leads to a more productive consultation with health care staff. Despite these important benefits, it is acknowledged that the project only reaches a small proportion of the wider diabetic population (~250,000), many of whom are likely to benefit from this initiative.

3.7 Conclusions

- The evidence consistently indicates that the most successful health literacy interventions are multifaceted, including several approaches and techniques as part of a more holistic health literacy approach.
- Interventions designed to involve people in decisions about their treatment have tended to focus on cancer and cardiovascular disease. Research shows that shared decision-making increases patients' satisfaction with treatment decisions, and improves clinical satisfaction. UK-based work to embed shared decision making in everyday practice indicates that it can create positive change within health care systems and to individual patients.

- Shared decision making interventions can lead to increased knowledge, self-efficacy, and reduced decisional conflict in disadvantaged patients.
- Patients are particularly vulnerable following discharge from hospital, for example in relation to changes in medication and new self-care responsibilities. These challenges can be overcome by improving communication between hospital doctors and GPs, supporting patients in managing their medication, and better communication between patients and doctors. This can include approaches which focus on support in people in managing their medication, Teach Back (and similar approaches), and tailored information.
- There are many interventions designed to help people manage their medication, however few have been systematically evaluated. Similarly, evidence on the efficacy of Teach Back and similar approaches is limited, but these techniques are frequently referred to in 'toolkits' and often part of multifaceted interventions. The literature suggests that these techniques are most successful when they are an integral part of a more holistic health literacy approach.

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