

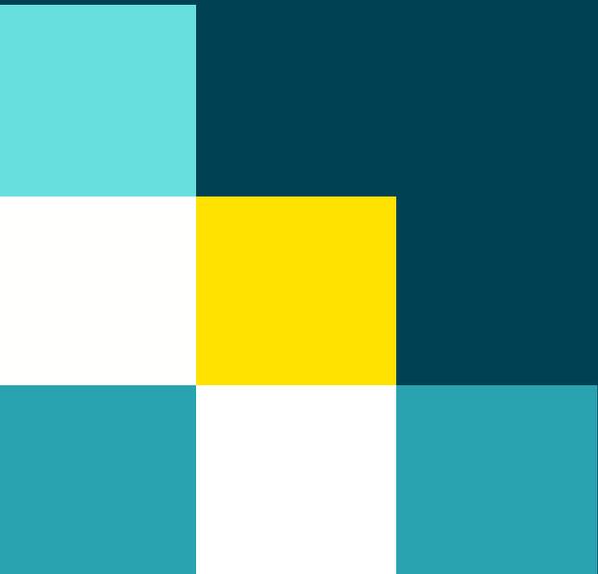


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Public engagement and 'A Healthier Wales'

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Summary

This report considers how commitments on public engagement set out in *A Healthier Wales (AHW)* might be translated into an evidence-informed programme of activity

AHW has a vision of transformed health and social care services, focused on community-based care models, prevention and a national 'offer of involvement' for engagement in decisions about future services.

Defining engagement is not easy; it can mean different things to different audiences and cover a wide spectrum of activities. However, at its core is the enabling of public involvement in decision-making processes.

Engagement in AHW is linked to commitments on:

1. encouraging healthy lifestyles,
2. patient-centred care, and
3. service reconfiguration and wider systems change

The evidence suggests that the role and relative contribution of engagement differs for each:

Healthy lifestyles

- Health behaviours are determined by a wide range of social, environmental and individual factors. Engagement alone is unlikely to address unhealthy lifestyles, but targeted information and support can have positive effects as part of a suite of measures to

bring about changes in health behaviour.

Patient-centred care

- Shared decision making and coproduction, by their very nature, require a patient or user having a greater role in decisions about their care.
- A more collaborative, engaged approach to care can have a real impact in terms of patient satisfaction and potentially health outcomes and service use.
- However, there are challenges in overcoming traditional ways of working, requiring new skills and approaches, and ensuring available, accessible and reliable information.

Service reconfiguration and wider systems change

- There is a wealth of evidence to show the importance and potential value of public engagement in service redesign or reconfiguration.
- While there is no 'blueprint for success', the evidence highlights key elements which support effective engagement on service change:

Transparency: about the nature of the issue, the process for making a decision on it, and the role of the public in that process;

Effective processes: Clearly structured and appropriate engagement processes which engage

with the right audience at the appropriate time;

Clear leadership: a genuine commitment (including among clinicians) to the public playing the defined role; and

Resource and skills: having the right skillsets and appropriate resource to design and implement the process of engagement.

Stakeholder reflections

This review of available evidence was complemented by a series of events with stakeholders, through which the following emerged:

- There is wide-spread belief in the value of engagement and support for greater engagement activity that leads to visible outcomes and action in response.
- However, there is a lack of clarity about the precise role of the public in the transformation agenda – the issues or decisions that they will be engaged on, and the role that they will play in determining the outcome.
- National, regional and local actors all have existing engagement programmes but, beyond legally defined duties, their respective roles in engagement on AHW are unclear.
- Any attempt to (re)define respective roles, should seek to avoid undermining the collaborative working that has been fostered in some regions; and to ensure adequate skills and resources are available.
- Clinical involvement in engagement is seen as key in developing new service models, as ambassadors for change and reshaping the care relationship.
- Improving the availability and accessibility of information is essential; including through optimising the use of digital technology and social media.

Conclusions and Implications

- Service redesign or reconfiguration and wider systems change would sensibly be the focus of a specific programme of engagement for the transformation agenda.
- Such a programme would need to be rooted in a shared understanding and articulation of the role of the public, beyond the commitments in AHW.
- Similarly, a programme of engagement would provide an articulation of the differentiated but coordinated roles of the various bodies; with ‘buy-in’ for the same from leaders across the system.
- It would be important to ensure appropriate resourcing, governance and oversight; with clarity about the role of key bodies, including NHS National Executive, the new patient voice body, Welsh Government, Local Authorities, RPBs and Public Health Wales.
- Such a programme could be supported by development of a suite of accessible and available information and digital technology to support engagement at all levels.

Introduction

The Welsh Government's long term plan for health and social care, *A Healthier Wales* (AHW) (Welsh Government, 2018), identifies public engagement as a key priority – both as a principle for the design of the health and care system, and as a means of achieving a number of desired outcomes. Responding to the Parliamentary Review of Health and Social Care in Wales (2018), AHW commits the NHS and social care system in Wales to the development of new models of health and care, and a reshaping of services which will introduce a different type of relationship between the citizen and the health and care system.

The Wales Centre for Public Policy (WCPP) was asked to consider how these commitments to public engagement can be translated into an evidence-informed programme of activity. Our starting point was to review the evidence on the role of engagement in the three areas to which it is linked in AHW – healthy lifestyles, patient-centred care and service reconfiguration and wider systems change. Using this, we have worked with colleagues at the organisation Involve to facilitate a series of structured discussions with a range of senior leaders and practitioners from across the Welsh health and social care system, as well as academics and experts in the engagement field.¹ The aim of this was to test the resonance of findings from the evidence review and examine those findings in a practical Welsh context, exploring how existing engagement activities might be supplemented or enhanced to support the ambition for public engagement outlined in AHW. From those two inter-linked strands of work a number of observations and conclusions have emerged.

Following a brief outline of the way that AHW conceives of the role of engagement, this report divides into three sections which form a linked narrative:

- A presentation of the findings of our **evidence review**;
- Summary of the discussions with **key stakeholders and experts**;
- An outline of the **policy implications** of, and recommendations from, our findings.

¹ This has included the Welsh Government's *A Healthier Wales* (AHW) Management Team and Advisory Board, Chief Medical Officer and Director of Social Services; Regional Partnership Board (RPB) Engagement Leads; All-Wales Health and Social Care Leadership Group; representatives from Welsh Local Government Association, Board of Community Health Councils; Social Care Wales; Director of Welsh NHS Confederation and Chief Executive, Hywel Dda UHB; experts from Involve, the University of Edinburgh, University College, Cork, The Kings Fund and The Nuffield Trust.

Engagement and *A Healthier Wales*

The Parliamentary Review of Health and Social Care in Wales (2018) assessed the challenges facing the health and social care system, and called for a transformation in the way that services are designed and delivered. It recommended that the primary mechanism for driving this transformation should be the development and testing of new models at the local level with those that are successful being scaled up or spread to the rest of the system. The Review recommended that patients, citizens and other stakeholders should play a central role in the design and development of these new models.

The Welsh Government accepted these recommendations and made a commitment to developing new models and the reshaping of services. Alongside a shift to community and home settings, AHW proposed increased centralisation of some hospital services to allow more regionally-based provision which would not just add to, but change and replace existing care models. These new models, and the broader change and transformation agenda, would be informed by ten design principles One of which, 'Voice', was explicitly concerned with public engagement:

...empowering people with the information and support they need to understand and to manage their health and wellbeing, to make decisions about care and treatment based on 'what matters' to them, and to contribute to improving our whole system approach to health and care; simple clear timely communication and co-ordinated engagement appropriate to age and level of understanding. (Welsh Government 2018, p.17)

This definition captures the three key areas to which public engagement is advocated in AHW:

- **Healthy lifestyles:** people taking responsibility for their own health and wellbeing;
- **Patient-centred care:** people being actively involved in decisions about their care;
- **Service reconfiguration and wider systems change:** people being able to contribute to reshaping or improving the health and social care system.

As well as placing 'voice' at the centre of the design of new models of care, AHW commits to developing a national 'offer of involvement' through which the public can participate in decisions about the future of health and social care; underpinned by a programme of engagement.

What is public engagement?

While public engagement is prominent throughout AHW, it is not defined in the strategy. In fact, the term public engagement is used in AHW to cover a broad range of different kinds of activities that provide the opportunity for the public to input into decision-making in some way. The literature on health care, especially related to service change, highlights the difficulties in defining engagement (Abelson et al, 2015; Carman et al., 2013; Djellouli et al, 2019; Foley et al., 2017; Stewart, 2013) but also suggests that it is important to be clear about what kind(s) of engagement are being sought:

Clarity of terminology, and of expectations from all those involved are of paramount importance, with divergence in motivations, aims, goals and expectations of those being engaged and those doing the engaging sometimes reported. (SERIO, 2018)

For the purposes of this work we have adopted (and adapted) the widely used IAP2 framework, which was developed by the International Association for Public Participation and identifies a spectrum of engagement activities ranging from “informing” through to “consulting,” “involving,” “collaborating” and finally “empowering” (IAP2, 2014). These five categories are distinguished by the degree to which they give the public power to make decisions (Table 1).

Table 1: Spectrum of engagement activities

Informing:	Keeping the public up to speed about a specific topic area, but doesn't provide an opportunity for them to feed into decision-making.
Consulting:	Gathering public feedback on governments' decisions.
Involving:	Working directly with the public throughout the decision-making process, to ensure public concerns and aspirations are consistently understood and considered.
Collaborating:	Partnering with the public in each aspect of the decision including developing alternatives and identifying the preferred solution.
Empowering:	Decision making power is handed to the public, who have the final say.

It is important to note that this spectrum is not normative – empowering the public is not 'better' than involving them. The appropriate form of engagement depends on context and the objectives of engagement.

Evidence review

In reviewing the evidence, we sought to examine the issue of public engagement in both health and social care. However, the literature is more extensive for engagement in relation to health, and this review reflects that.

Engagement and healthy lifestyles

As part of working together to achieve our future vision, we need people to take more responsibility, not only for their own health and wellbeing, but also for their family and for people they care for, perhaps even for their friends and neighbours. We will enable this through different forms of engagement, for example using social media and digital platforms, linked to a better understanding of what influences behaviour and the choices we make. *A Healthier Wales.*
(Welsh Government, 2018, p.7)

A Healthier Wales seeks to change the relationship between the public and the health and care service; moving the locus of both agency and responsibility for health from professionals onto members of the public and the communities they live within.

Healthy lifestyles tend to be discussed in terms of key behaviours such as smoking, drinking alcohol, eating healthily and exercise. While it might be argued that these are issues largely of personal responsibility or agency, the evidence shows that social and environmental factors play an important role in shaping individual choices (Johnson et al, 2018). Healthy behaviour, is strongly linked to wider social determinants, including the level of education, income, housing quality and employment (The Health Foundation, 2019). Indeed, the degree of personal and community agency and choice is strongly influenced by the circumstances in which individuals are born, live and work (Marmot, 2017). This has implications for both the role and the design of engagement; but more fundamentally it points to the potential limitations of engagement in effecting changes in behaviour.

Overall, there is a lack of robust evidence on how engagement can support healthy lifestyles. As Coulter (2009) states: “there is no shortage of techniques and case studies but, in general, we lack critical literature and sufficiently rigorous evaluations to provide definitive guidance on which techniques are most appropriate in each and every circumstance.” However, we have identified studies which do shed light on what has worked elsewhere in engaging with individual patients and clients, with communities, and at national level.

Engagement with patients and clients

If engagement is defined very broadly as contact between any part of the health service and the public, then it is already widespread at the individual level. Every day there are countless individual exchanges and discussions between patient and clinician, client or service user and care worker. To avoid stretching the definition of engagement so far that it is rendered meaningless, however, it is helpful to focus on examples of patient/health professional interaction over and above what might be considered routine. As these relate to attempts to change lifestyle behaviours, these are most commonly discussed in behaviour change terms, and include activities ranging from social prescribing to specific programmes such as Making Every Contact Count in Wales.

There is evidence that health-related behaviour change techniques in general may have small but significant effects on public health (Johnson et al., 2018), although NICE (2014) highlights a lack of evidence regarding the most effective means to target multiple unhealthy behaviours. Clusters of behavioural techniques which combine goal setting, self-monitoring and feedback on performance have been associated with larger effects than individual interventions in the context of exercise interventions (Rhodes et al, 2017). Conner and Norman (2017) point to a lack of research into “the maintenance of behaviour change over prolonged periods of time,” stating that “much of the research on the determinants of these behaviours or interventions to change them has been focused on initiation or short-term performance.”

There is stronger evidence of the link between certain behaviour and health outcomes (for activities such as smoking and physical activity) than ones such as binge drinking and diet (Connor and Norman, 2017). However, as Connor and Norman explain: “[for] each health behaviour there is a complex set of relationships to different health outcomes (and one where the mechanisms are only partly understood)” (2017).

The evidence on which forms of engagement work best is mixed. West (2017) found that in-person behavioural support was most likely to be effective in assisting smoking cessation. Access to online medical records has also been shown to improve adherence to lifestyle advice (Imison et al., 2016). In contrast, Rhodes et al (2017) found that the type of engagement had little effect on the effectiveness of exercise interventions.

Social prescribing, an umbrella term for referring patients to non-medical programmes such as gardening, sports or arts activities, often features in case studies of engagement activities. (The Kings Fund, 2018). Although social prescribing initiatives are often discussed positively, there is a lack of robust evidence of its effectiveness as a general approach (Johnson et al., 2018) or the cost effectiveness of individual schemes (Wilson and Booth, 2015). There is also disagreement as to whether the disparate activities grouped under the heading of social prescribing are too heterogeneous to facilitate meaningful study (Kings Fund, 2018).

Engagement with communities

Evidence points to the potential value of community engagement, which focuses on a specific group, defined by common attributes (e.g. a shared location, race, age etc.). According to NICE (2018), “communities that identify and articulate what is most important to them, and agree clear aims for the initiative, are more likely to [...] ‘own’ the initiative and get more benefit from it.” These approaches may be “asset-based” and focus on making best use of communities’ existing resources and tap into communities’ knowledge about their local contexts, whilst also generating support for national policies. NICE (2018) offers advice on operationalising this approach, based on: developing local collaborations and partnerships, involving people in peer and lay roles, and making it as easy as possible for people to get involved. The health inequalities that exist between and across communities make a local focus essential;

What we must not lose sight of is that improving health and wellbeing is far easier for some individuals and communities than others. (Kings Fund, 2018b)

Allender (2018) provides an example of how this can work in practice, focusing on childhood obesity in Australia. His approach involves first working with community “leaders” (such as health service CEOs, local politicians and business executives) to map out the various interdependent aspects of a particular topic. The leaders then recruit over 100 members of the community to generate and prioritise ideas for potential solutions, using the “map” that has been produced. This is a promising experimental approach, with a compelling logical foundation, although research is needed to assess its’ impact on lifestyles.

In another example of place-based community engagement, Wigan Council has sought to reformulate the relationship between local state institutions and the public. The Wigan Deal, launched in 2014, is described as an ‘informal arrangement’ between Wigan Council and the public, in which encompasses a wide range of social determinants of health. The Council has made a number of commitments, including keeping council tax low, in return for the public being healthy and active and having their say and “tell[ing] us if we get it wrong” (Wigan Council, 2019). The Wigan Deal is regarded as an innovative example of best practice, and The King’s Fund have now published an evaluation of the work in Wigan, from which a number of key themes emerge (King’s Fund, 2019):

- The Deal is an example of **‘asset-based’ working**, where public services seek to build on the strengths and assets of individuals and communities to improve outcomes;
- Widespread changes are needed in public services’ **culture and work** to realise the full potential of this approach. In Wigan this includes a long-term commitment to a more collaborative style of working with local people and communities;

- **Cross-agency working** between local authority, NHS, the third sector and others has been key;
- It is possible to **achieve savings** while protecting or improving outcomes, but only if services are genuinely transformed and upfront investment is available to help bring about new ways of working;
- The Deal **is not a panacea**, but it does illustrate the kind of work needed to shift to a new model of public service delivery in which patients, service users and communities are involved as active partners.

However, The King's Fund notes that 'The Deal has been at least six years in the making and is still a work in progress' and counsels caution:

The relationship between public services and the people who use them needs to be transformed to allow people to take greater control of their health and wellbeing. Existing ways of delivering services can sometimes disempower the people they are there to help, leaving people feeling unable to make positive changes in their lives and their communities. In the case of health and social care services, changing this means striking a new relationship that puts more power in the hands of patients and service users and emphasises 'working with' rather than 'doing to'... (King's Fund 2019a)

Engagement at national level

The most effective way for governments to encourage healthy lifestyles is to seek to create an environment in which people have the capability, motivation and opportunity to choose to live in way that promote good physical and mental health. The evidence suggests that engagement is not the primary way for governments to achieve this. The determinants of health are strongly influenced by housing conditions, planning decisions, action to tackle poverty and investment in supportive infrastructure (including encouraging walking and cycling and participation in sports).

This points to the importance of taxation and legislation, rather than public engagement. Kuntsche et al (2017) found that increasing alcohol price through legislation or taxation is the most effective means of reducing alcohol consumption at a population level (Conner and Norman, 2017). Research on the international evidence on the impact of tax policy on health behaviour (Public Health Wales, 2019) shows that 'taxation, particularly in the dietary field, can be influential in improving consumer purchasing choices'. Where taxes have been introduced on health-harming food and drinks – most notably in Denmark, Hungary and Mexico – consumption of those goods has reduced. Escobar et al (2013) found that: 'studies suggest that higher prices of SSBs [sugar sweetened beverages] may lead to modest reductions in weight in the population'.

This does not mean that public engagement at national level has no place. There is evidence that it can help to amplify the positive effect of these measures. For example, Hoffman and Tan (2015) found that: “Tobacco product packaging interventions and anti-tobacco mass media campaigns may decrease smoking behaviour, with the latter likely an important part of larger multicomponent programs.”

It can also be used to demonstrate or to generate support for potentially unpopular measures which can encourage healthier lifestyles. There is evidence that structured participation methods such as citizen’s juries change the opinions of those who participate. Researchers found significant changes in participants’ views about the best ways to tackle health inequalities before and after citizen’s juries in Glasgow, Manchester and Liverpool (Smith et al., 2017). Similarly, a citizen’s jury in Brisbane in 2013 reported unanimous support for a sugar tax on soft drinks, with the support “becoming stronger by the time the final vote was cast” despite taxation tending to be a strongly disliked policy lever (Moretto et al., 2014). Public support can play a key factor in ‘emboldening policy makers and politicians to change our environments to improve our health’ (Marteau, 2018) and public acceptance of these interventions can change and grow over time (Bauld, 2011).

At one end of the engagement spectrum, there is evidence that mass media information campaigns can produce positive changes and prevent negative changes in health behaviours across populations, depending on the behaviour being targeted (Wakefield et al., 2010). Evaluations of the national marketing campaign (Change4Life) for the prevention of childhood obesity in England found that it increased awareness of the campaign, but had little impact on attitudes or behaviour mainly because of low levels of public engagement with the intervention (Croker et al., 2012). And a review of television, radio and newspaper campaigns dealing with a wide range of health behaviours found that campaigns are most likely to be successful if the behaviour is one-off, such as a vaccination, rather than habitual, such as diet choices (Wakefield et al., 2010). A review of social media interventions found evidence of improvement in health behaviour, but with small effect sizes (Maher et al., 2014).

Summary

Health behaviours are determined by a wide and complex range of social and environmental as well as individual factors. Seeking to encourage changes in behaviours therefore requires activities that shape the social and environmental context, alongside efforts to provide information and support for individuals. Evidence shows that this kind of engagement – targeted information and support – can have small positive effects as part of a broader suite of coordinated measures.

Experiments with more collaborative forms of engagement at a sub-national level, show that they offer promise as a way of securing buy-in for change and coordinating across organisational divides.

Patient-centred care

Patient-centred care involves health and social care professionals working collaboratively with people who use services:

... Person-centred care supports people to develop the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own health and health care. (The Health Foundation, 2014)

It is a key element of health policy across the UK (The Health Foundation, 2014) and in AHW which contains several key statements about focusing care on the patient including:

As new tools improve diagnosis and treatment, and allow people to manage more of their own care and treatment, professionals will have more scope to lead conversations with people about ‘what matters’ to them, and what they could do themselves to improve their health and wellbeing, or to avoid illness. (Welsh Government, 2018, p.11)

and within the national design principles aimed at driving change and transformation:

- **Voice** – empowering people with the information and support they need to understand and to manage their health and wellbeing, to make decisions about care and treatment based on ‘what matters’ to them, and to contribute to improving our whole system approach to health and care; simple clear timely communication and co-ordinated engagement appropriate to age and level of understanding;
- **Personalised** – health and care services which are tailored to individual needs and preferences including in the language of their choice; precision medicine; involving people in decisions about their care and treatment; supporting people to manage their own care and outcomes. (Welsh Government, 2018, p.16)

There is a significant and growing body of UK and international evidence on patient centred care, much of which examines the role of engagement (Coulter, 2012; NESTA, 2013; The Health Foundation, 2014; Ham et al., 2018:). A majority of the case studies and approaches are specific to particular client groups, clinical settings or communities and also stress the value and sometimes the necessity of tailoring engagement approaches to the needs of individuals, groups, geographies and conditions (Ham et al., 2018). Because of this, the evidence does not offer a list of ‘once-size-fits-all’ interventions that will suit all settings. However, it does help to provide a framework of how engagement can help deliver patient centred care.

Shared decision-making and co-production

Shared decision-making (SDM) is 'an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences' (Elwyn et al., 2012) in order to design person-centred care.

There is a wealth of evidence on the impact of SDM which on balance suggest that it:

- Improves patient satisfaction with their care and the decision-making process involved in that care (Shay and Lafata, 2015), with people reporting more positive experiences of care and attitudes towards recovery, improved self-management, healthier coping strategies and more consistent adherence to medication regimes (Kings Fund, 2014a; Hughes et al, 2018; Montori et al, 2017; Stacy et al, 2017; Khunti et al, 2012);
- Can lead to improved health outcomes, as research across a range of specialties indicates (Ham, et al., 2018; Scottish Government, 2018; The Health Foundation, 2016a: NESTA, 2013; Johnson et al, 2018; Shortell et al, 2016; Hibbard and Greene, 2012; Greene and Hibbard, 2013; Slade, 2017), although some research is more cautious about the direct role engagement plays in outcomes (Tousignant-Laflamme et al, 2017) and
- Can reduce demand for some services in some circumstances (Staveley and Sulilvan). Research in chronic condition has reported lower hospitalisation rates but found no impact on the pattern of service use in primary care (Hibbard and Greene, 2012; Greene and Hibbard, 2013) and some studies have also found no impact on patterns of service use (Lugo-Palacios et al, 2019).

There are parallels between SDM in health and what is co-production in the social care sector which involves a relationship where professionals and citizens engage and share power to plan and deliver support (SCIE, 2013).

The evidence on engagement in social care is much smaller than that for health (Needham, 2009; Needham and Carr, 2013) and some researchers conclude that it the adoption of co-production by local authorities has been patchy and evidence that it has a positive impact is limited (Needham, 2010; Scourfield, 2015). However, Public Health Wales has published a number of case studies - including a Transforming Adult Social Care Team initiative in Carmarthenshire County Council, which aimed to support and empower clients in making more decisions about their care – which suggest that co-production has reduced re-referrals because clients' needs are being met first time around (Public Health Wales, 2015). There are other examples of good practice which have been published by Co-production Wales (2019) and the Social Care Institute for Excellence (SCIE, 2013).

Workforce skills and behaviours

SDM requires a change in attitudes and behaviours of service providers. This is especially true of the relationship between patients and clinicians who have to work more closely together in making decisions about individual care plans, harnessing both clinical expertise and patient knowledge. As Coulter and Mearns (2016, pp.12-13) argue, this 'requires clinicians to rethink the way they work, recognising that the knowledge and experience that the patient brings to the care planning process is as important as the clinical information in the medical record'. It also relies on the patient having the information and capacity to meaningfully participate in SDM (Krist, et al., 2017).

The willingness of professionals to make patient-centred care work is key (Xu et al., 2017). SDM requires them to develop the skills and attributes to understand patient preferences and perspectives, the ability to guide patients through the available information, the sharing of treatment decisions, providing support for self-care and management and using new technology (Coulter et al, 2008). The evidence suggests that, although undergraduate training for doctors, nurses and other healthcare professionals includes communication skills, few will receive specific training in specific SDM competencies and this needs to be addressed (Staveley and Sullivan, 2015; Coulter et al., 2011; Ham et al., 2018; Scottish Government, 2018). Johnson et al., 2018) advocate:

...integrating shared decision making into training courses from the outset, in universities and other programmes, so that by the time a clinician is trained, they are also trained in shared decision making as a normal and good behaviour. (Johnson et al, 2018, p.15)

There are initiatives already underway aimed at reshaping this patient/clinician relationship. Making Choices Together - part of the Choosing Wisely Wales Partnership - is the Welsh arm of an international movement which aims to 'embed a broad culture change in healthcare where clinicians and patients regularly discuss the value of treatments and make shared decisions' (1000 Lives plus, 2019). It has been in place since 2016, but only provides limited information on specific conditions alongside a training programme for staff.

Access to information and health literacy

Alongside support and training for health professionals in communication skills, ensuring effective patient and public access to information on their condition and treatment options is central to effective SDM, while also enabling broader health literacy.

A number of interventions have been shown to be effective in building health literacy, supporting patient involvement in treatment decisions and self-management of chronic conditions (Coulter et al., 2011; Coulter, 2012). These interventions include:

- written information that supplements clinical consultations;

- web sites and other digital information sources;
- personalised computer-based information and virtual support;
- decision aids and coaching and question prompts for patients; and
- self-management education programmes.

Sources of information are extensive and wide-ranging. NHS: Home and NHS Direct provide an online guide to conditions, symptoms and treatments and medication including what to do and when to get help (NHS Direct Wales, 2019). Similarly, there is an extensive range of third sector bodies within Wales and across the UK such as Diabetes UK, Parkinsons UK and Macmillan who provide information and advice on a range of conditions. However, there is little evidence on how effective or well-targeted this information is in helping to support patients (Bull et al., 2014) and, as Krist et al. (2017) note, there is limited data about how the available information is accessed and about the type of information vulnerable and less health literate consumers want and use.

Similarly, the increase in health apps has not been accompanied by rigorous or large scale evaluation of their effects and impact (Coulter and Mearns, 2016), and the NHS is – like most health systems internationally – struggling to develop a consistent regulatory and accreditation framework (Kings Fund, 2016).

There have been calls for quality standards or accreditation schemes, reflecting a growing focus on ensuring the quality of patient information (Patient Information Forum, 2013). NHS England until recently made use of an Information Standard, ensuring that information was evidence-based, tested with users and backed by assessment and accreditation (NHS England, 2019). Research for the Scottish Government has suggested providing a national standardised repository of evidence-based information – in a choice of formats - about a range of treatments (Scottish Government, 2018).

Self-help and structured education programmes have shown to be beneficial in some respects, although the evidence is mixed. The Education Programme for Patients Cymru (EPPC) provides a range of self-management health and well-being courses and workshops for people living with a health conditions or their carers. EPPC is based on the same principles and approach as the Expert Patient Programme and self-management programmes based on this model remain the preferred policy in many countries. However, the evidence base for their efficacy is weak. Some research suggests that the programme can improve patients' confidence in managing their condition, but questions remain about its impact on health in UK patients; the indications are they are unlikely to reduce either hospital admissions or the use of other healthcare resources in the NHS (Greenhalgh, 2009; Griffiths et al., 2007).

There are more positive findings from the DESMOND programme, a UK-based initiative which provides self-management education modules, toolkits and care pathways for people

with, or at risk of, Type 2 diabetes (DESMOND, 2019). The programme was well-received by participants, with evidence of improved confidence in self-management of their condition, but limited evidence of impact on services (Khunti et al., 2012; Chatterjee et al., 2017).

A significant body of **decision aids** are available internationally and there is a solid body of evidence from extensive clinical trials of the beneficial impact of such patient decision aids in terms of improved patient-clinician communication, more informed patient choices and a more active patient role in decision-making about their care (Coulter and Mearns, 2016; Merchant, 2018; Stacey et al., 2017).

There is evidence that use of online information and digital technology can play a useful role in supporting better **self-management** by people with chronic conditions such as diabetes (Huygens et al., 2016; Ham et al., 2018). Equally, for people to have a greater role in self-management, they need access to and understanding of information relating to their health and care. Research by the Kings Fund and Coulter cites the advantages realised by GP practices of online patient access to GP records (Ham et al., 2018; Coulter et al., 2008).

As Krist et al. (2017) note, however there is limited data about how this information is accessed and about the type of information vulnerable and less health literate consumers want and use. Indeed, some research notes concerns about the impact that low **levels of health literacy** can have on people's ability to manage their own health; there is evidence of lower levels of health literacy amongst patients who were elderly, had a number of co-morbidities or who were from a socio-economically deprived area (Heijmans et al., 2015; Mackey et al., 2016; Carman et al., 2012). Attention needs therefore to be paid to the information needs of people or groups with low health literacy (Coulter et al., 2008; Coulter, 2012). Conversely, there is evidence that patients in more research-active hospitals feel better informed and more confident about their condition and care (Jonker et al., 2019).

Whilst information and tools may be available, efforts are needed to encourage and motivate patients not just to seek health information, but also in navigating what is available. There is a need too for the creation of accessible, user-friendly and appropriate health information, which are appropriate to the individual's lifestyle and cultural context (Krist et al., 2017; Staveley and Sullivan, 2015).

Models of care

As well as attempts to encourage a shift in individual care, there have been moves to develop service models that are more patient-centred, in which engagement and communication play a key role.

Engaging patients in service design

This involves bringing groups of patients into discussions about how a service or care pathway operates. Morrison and Dearden (2013) stress that effective participation relies on

establishing relationships in a way that enables the contribution of knowledge by the public. However, the same research notes the potential pressure for patients and the public to contribute to redesign in a way that is understandable to and 'deemed valid' by health professionals.

Renedo and Marston (2011) note that barriers to effective engagement also includes resistance within organisational cultures, the differing ideas of 'involvement' that may be held by staff and 'involvees' and the challenge of ensuring those 'involvees' have the skills to participate as equal partners. As a result, the ability to participate in detailed service design work sometimes relies on the 'professionalisation' of public participants. Whilst this may be in some ways advantageous, especially when longer-term or more ongoing participation is required, this may restrict involvement to individuals who possess the skills, availability and capacity to fulfil that role; the willingness of patients to engage thus may vary (Filipe et al, 2017; Greenhalgh, 2008; Morrison, 2013). This may serve to limit the range of patient input, and a balance may be needed of 'expert' patients with lived personal experience and the broader public, to ensure a more representative, inclusive and objective voice (Morrison and Dearden, 2013; Martin, 2008; Van de Bovenkamp et al., 2010; Renedo and Marston, 2011).

Nonetheless, there can be very practical reasons for securing more focused and direct patient involvement on specific areas of service redesign work. Locock (2003), advocates mapping the whole patient journey, thinking through the best process to achieve speedy, effective and improved patient care. Redesign of head and neck cancer services in Luton and Dunstable involved the use of interviews with staff and patients and active co-design (Pickles et al., 2007); another case study looking at improving discharge planning involved analysis of the patient journey through the hospital (Samaranayake et al., 2016).

This makes sense because the patient is the only individual who observes and experiences their whole journey across the various care settings. As a result, mapping of the process, informed by the patient and confirmed by data analysis, can be used to improve the process and delivery of healthcare (Ben Tovim et al., 2008; Filipe et al., 2010; Abelson et al., 2018).). Co-led redesign, involving both staff and patients in systems, experience and data analysis has improved service accessibility and efficiency, for example through simpler appointment procedures (Prior and Campbell, 2018).

Designing co-production and collaboration into a service

NHS England has adopted the House of Care model, bringing together personalised and collaborative care planning involving clinicians and patients alongside the commissioning of services for people with long term conditions within a broader population. The model built on the Year of Care programme, which focused on a more collaborative approach to diabetes in primary care and saw improvements in patient experience and self-care. Key parts of this approach are access to the right information for both patient and clinician and continuity of care. At the same time, this is an ambitious and complex model of integrated care, which

also rests on its links to the broader multi-disciplinary team (MDT), providing both care and access to information about available support services (Coulter et al., 2016; NHS England, 2018; Kings Fund, 2013; Ham et al., 2018).

A similar approach can be seen in the Swedish Rheumatology Quality Registry, which involves a shared co-production dashboard to support SDM, recording patient level data on preferences, treatments and outcomes, with the aim of moving the clinicians' role from 'fixer to facilitator' (Lindblad et al., 2017). However, it is worth noting the comments from the Kings Fund report on the House of Care:

The NHS is awash with small-scale improvement initiatives, but care planning and self-management support needs to be implemented across multiple organisations, covering much wider geographical areas of it is to make a real impact. (Kings Fund, 2013, p.18)

Similarly, a recent Wales Audit Office report on the impact of £270 million of Welsh Government spending via the Integrated Care Fund concluded that although the fund has supported better integrated health and social care services, there is little evidence of successful projects yet being mainstreamed into core budgets (WAO, 2019).

Personalised budgets

Allocating budgets to patients or service users enables them to 'purchase' care according to their needs. The evaluation of Personal Health Budgets (PHBs) showed that they are most effective when individuals have full control and flexibility over how to use them. They can result in higher levels of spending on non-NHS providers, which may require freeing up resources tied into contracts with existing providers. Implementing new schemes also requires fundamental cultural changes within the care sector that takes time to be embedded fully into work practices. (Forder et al., 2012; Jones et al., 2018).

An evaluation of Direct Payments in residential care pilots noted the additional work for frontline care managers and the high costs when compared with the 'modest outputs' (Policy Innovation Research Unit, 2017). Research by Reform (2019) on personal budgets across a range of public services indicates the benefits in terms of increased autonomy for service users, but calls for a robust evaluation of outcomes, better assessment processes and ensuring a more developed information and provider framework.

Patient and user experience feedback

Patient and user feedback also has the potential to be an important source of information that can enable service improvement. The NHS has long been collecting a significant amount of data relating to patient experience; NHS England carries out mandatory annual hospital inpatient and other surveys, NHS Scotland runs the Scottish Patient Experience Survey and patient satisfaction in NHS Wales is measured through the National Survey for Wales. As

well as participating in national surveys, many health and social care organisations conduct local patient surveys (Coulter, 2014; NHS England, 2019a; Scottish Government, 2018a; Welsh Government, 2018b; Wellings, 2016). The Board of Community Health Councils in Wales has undertaken reviews of patient experience in Accident and Emergency and ophthalmology services (Board of CHCs, 2016, 2018).

There are limited published examples of this direct patient experience feedback being used to improve services, such as modifying discharge processes (Moore, 2018) and the evidence suggests the NHS has been less than effective in making use of such information to improve or develop services (Coulter, 2014; Moore, 2018; Baldie et al., 2018; Kings Fund, 2015). Sheard et al (2017) argues that healthcare staff often find it difficult to act on feedback and Coulter (2014) observes that 'less effort has gone into how to understand and use the data, and there is little evidence that the information has led to improvements in the quality of healthcare'.

Summary

At the individual level, good patient-centred care and co-production in social care bring patients or users into the decision making process; with professionals 'involving', 'collaborating' or even 'empowering' (see table 1 above) individuals in the decisions over their care. Evidence shows the potential value of these forms of engagement.

At a service level, evidence points to the value of greater involvement of 'expert patients' in the design of specific types of service or care pathways. It would also appear that more use could be made of routine data captured on experiences of care (as a form of 'consulting').

At national and regional level this requires action on a number of fronts including:

- **The care relationship:** New care approaches will require overcoming traditional ways of professional working and clear incentives to change, supporting the shift in individual patient/clinician or client/provider relationships to a more collaborative approach. There are practical barriers to be overcome, including the challenges of freeing time for more complex consultations and the development of new skills. There are substantial policy, workforce and training implications for the development of the professional curriculum, the approach to continuing professional development (CPD) and professional regulation;
- **Resources:** a more engagement-focused approach to care can in time free up resource if, for example, patients with a chronic condition become more confident in managing their care. At the same time, a more shared approach can be demanding and time-consuming if done well, especially in the initial stages. This can pose a real and practical challenge (Keating and Pace, 2018; Merchant et al, 2018; Shortell et al., 2017; Policy Innovation Research Unit, 2017);

- **Information:** The evidence supports the value of improved clinical information for enabling joint decision-making. However, there are particular challenges in the rapidly emerging field of digital technology and the framework for effective assurance and dissemination. Policy levers in this respect could be similar to that suggested in research for the Scottish Government, including enhanced governmental or national leadership in assurance processes or the creation of a standardised information repository (Scottish Government, 2018);
- **Supporting service users:** Strategies for promoting an active role for patients need to pay attention to health literacy, shared decision-making and self-management. Equally, explicit standards could be set requiring health care providers to show evidence of how they involve patients (Coulter et al, 2008).

Service reconfiguration and wider systems change

Systems change spans large-scale service reconfiguration at a national or regional level as well as smaller scale redesign of local services or care pathways. It may involve:

- Changing or improving an individual service or care pathway;
- Local/regional service restructuring;
- National efforts at system change (including the rebalancing of responsibility between citizen/patient and the health and social care system).

The evidence on the impact of public engagement on systems change is mixed. Many of the case studies and approaches are very specific to client group, clinical service or place. There is a particular focus in much of the evidence on specific clinical areas such as stroke or A&E services, and with a focus also on major urban settings. There are some lessons to be drawn from this evidence, but there is no consensus about the direct impact or benefits of engagement (Dalton et al., 2016; Fulop et al., 2012; Barratt and Raine, 2012).

Some forms of impact were relatively easy to demonstrate such as the impact on leaflet design; however, the effect on others of receiving the literature was unknown. Other forms of impact were difficult to demonstrate such as the impact of service users on strategic decision-making. (Mockford et al., 2012)

And Abelson et al (2018) note that evaluations of public engagement often focus on process – how well engagement activity was planned, executed and implemented - rather than outcomes.

There is existing Welsh Government guidance on engagement and consultation for service change, to which LHBs and Trusts are required to adhere (Welsh Government, 2011). Local authorities have statutory consultation requirements on major service changes and some aspects of their planning, across all their functions. The evidence suggests many include their own engagement/consultation processes on social care under the auspices of the Public Service Boards. However, there is limited published evidence on engagement in social care systems change.

Barratt et al. (2015) argue there is no 'magic bullet' that will lead to the smooth acceptance of service change. Proposals on reconfiguration are frequently contentious. At the same time, there is clear evidence from the literature of factors associated with positive public engagement on service redesign, as well as potential barriers (Foley et al., 2017). There is nonetheless little evidence on the potential negative impact of patient engagement, unless consultation is done badly (Dalton et al., 2016). The literature does not enable a definitive menu of activities that will suit all settings and cases, but does help to provide a framework of how engagement can help deliver service change through redesign and reconfiguration.

Engaging early and throughout

Existing Welsh Government engagement and consultation guidance requires public engagement at an early stage of any proposed change, stating that NHS bodies must:

...engage with citizens, staff, staff representative and professional bodies, stakeholders, third sector and partner organisations at the earliest opportunity when it is considering service change. (Welsh Government, 2011)

Likewise, the NHS Transformation Unit (2018) emphasizes that clinical redesign must ensure staff and service user involvement from the very start and throughout the process. NHS England has statutory guidance on patient and public participation in commissioning healthcare; this sets out clear requirements for engagement in a range of areas, including the preparation of annual reports, commissioning and business plans and any proposal for new service models or service change (NHS England, 2019c)

A number of researchers emphasise the role of engagement at both an early stage and throughout any redesign process as a key success factor (Dalton et al., 2017; The Kings Fund (2011). Three case studies from Ireland examining reconfiguration of urgent care argue that engagement in the early stages of planning was a central factor in the more successful processes (Foley et al., 2017). Conversely, Foley cites Kings Fund research on the development of sustainability and transformation plans (STP) in NHS England which highlights the resistance to STPs from many communities and stakeholders due to the absence of any early involvement. The Independent Review Panel (IRP) in England reports that inadequate community and stakeholder involvement in the early stages of planning

change was one of the reasons why reconfiguration proposals had been referred to them for decision (IRP, 2010). In short, genuine interaction with the public and other stakeholders at the formative stage of change was a feature of successful engagement processes (Foley et al., 2017; Turner et al., 2016).

Making engagement meaningful

The evidence indicates that engagement needs to be meaningful and demonstrate tangible evidence that the views and concerns of patients and the public have been listened to, taken into account and have real ability to impact on the decision-making (Morrison and Dearden, 2013; Barratt and Raine, 2012; Barratt et al., 2015). It is not sufficient to collect data from patients; the data needs also to be made use of (Coulter, 2014). There is also a practical danger of paying insufficient attention to the views of patients and public about 'matter of fact' issues such as transport links to new services (IRP, 2010; Barratt and Raine, 2012; Barratt et al., 2015). Research on proposals for centralisation of stroke services on Manchester shows that the need to achieve a more consensus-driven solution resulted ultimately in a less radical transformation of services (Turner et al., 2016).

Good quality engagement will have a clear purpose, linked to a decision-making process which is informed by the feedback received from those engaged, whether patients, public or others (Foley et al., 2017; Turner et al., 2016; Dalton et al., 2016; Kings Fund, 2018a).

Research also highlights concerns about consultation processes which appear designed to overcome opposition to proposals or focus largely on disseminating information, rather than seeking to actively involve the public in dialogue and decision-making (Foley et al., 2017; Fulop et al., 2012). Similarly, Ocloo and Matthews (2016) point to the tendency for some involvement processes to engage tokenistically with a narrow range of groups and interests, and focus on top-down consultation rather than real collaboration and power-sharing.

The importance of transparency

Engagement also needs to be based on trust and transparency about the drivers for any service redesign and the fact that any reconfiguration is likely to involve some trade-offs and conflicting interests (Kings Fund, 2011). Hence, the way in which the need for change was explained and communicated to the public had an impact (Fulop et al., 2012). One of the case studies from Ireland was less successful partly because of public concern that the changes were driven by an undeclared desire for cost savings and service centralisation (Foley et al., 2017). Research relating to proposed centralisation in emergency services in two separate sites in England indicates that the public opposition was rooted in a belief that proposed changes were a cover for cuts (Barratt et al., 2015). The IPR (2010) stresses the need for proposals to be clear about what can and cannot be delivered through change.

Case study

The Social Services and Well-being (Wales) Act 2014

The National Social Services Citizen Panel for Wales was set up to enable service users, citizens and carers to provide independent perspectives which would inform the implementation of the 2014 Act. There was positive feedback from Panel members, who reported that they felt genuinely involved at a strategic level. The 2014 Act also established a requirement for Regional Citizens Panels, designed to provide views of service users to Regional Partnership Boards.

This was followed in 2015 by consultation on the second tranche of regulations, codes of practice and guidance relating to the Act, including a number of public events; there were a number of consequent changes made to the regulations as a result. (Practice Solutions, Undated; Welsh Government, 2015; Kaehne and Taylor, 2016)

In 2018, Welsh Government also funded a Citizen's Jury – including service users and carers - to examine the question '*What really matters in social care to individuals in Wales?*', designed to test whether the 2014 Act was making a difference to social care delivery within Wales. The subsequent report identified recommendations around several areas, including the need for key workers, more support for carers, and the embedding into care of co-production and individual care planning. (Welsh Government, 2019)

Leadership of the engagement process

The evidence highlights the importance of clear leadership in delivering effective engagement on service redesign, especially given the potential complexity of larger scale redesign or reconfiguration. Turner et al (2016) stress the value of clear leadership in managing engagement on stroke service redesign in London, as this was needed to co-ordinate the input of multiple stakeholders. Whilst the same research acknowledges that this may have resulted in a much more top-down driven process, the need for strong managerial leadership of engagement is noted elsewhere (Dalton et al., 2016; Kings Fund, 2011).

Three case studies from the English NHS (Fulop et al, 2012) found that more cohesive and stable senior management teams were associated with more successful consultation on and implementation of service change, compared with less success in a rural Trust that saw considerable turnover in senior leadership. Coulter (2009, 2012) stresses also the need for robust leadership if engagement and change is to be effective, and notes the value of strong Board-level support for a distributed and empowered leadership model in achieving this.

Clinical engagement and leadership

There was strong evidence also of the value of clinical involvement and leadership in engagement on service redesign. Research by the Kings Fund (2011, 2014) stresses the importance of strengthened clinical advice to and leadership of reconfiguration processes and since much service reconfiguration may involve a number of different service providers this enhances the case for clinical leadership at a strategic and cross-organisational level.

The evidence also suggests that a strong clinical voice on leading and supporting proposals, backed by a clearly articulated clinical case for change, can give engagement and proposals an enhanced legitimacy for the public (Dalton et al., 2016; Foley et al., 2017; Barratt et al., 2015; Turner et al., 2016). Senior clinical staff were heavily involved in making the case for the reshaping of stroke services in the Manchester case study; indeed, clinical staff provided much of the impetus for the proposals for change and worked with the local stroke network to lead the engagement and implementation. Likewise, in the London case study, clinical staff were involved in planning the new stroke service model, drawing up quality standards for the service and working with stakeholders during the consultation process (Turner et al., 2016). The proposals for reshaping of hospital services undertaken through the South Wales Programme were driven strongly by clinical views and advice, with clinical staff playing a leading role in the subsequent consultation (South Wales Programme, 2014).

At the same time, there is evidence that, while necessary, the use of expert clinical advice is not in itself sufficient to make a persuasive case for change. The public will not remain passive consumers of information but will actively question, challenge and oppose proposals for change (Foley et al., 2017; Kings Fund, 2011). This is sometimes even despite clinical concerns about the safety of services, as one case study demonstrates (Fulop et al., 2012).

As other research notes, 'engaging clinicians to pursue a clinical case for change may have implications for involving the public in service design, as their views may not coincide' (Turner et al., 2016, p.163). Indeed, engagement may fail if service commissioners or leaders 'continue to regard medical or clinical knowledge as pre-eminent and fail to acknowledge residents' local knowledge and perspectives' (Barratt et al., 2015, p.1216). However, a small scale study of engagement with lung cancer patients and clinicians showed the value a more positive clinical attitude towards involvement (Forbat et al., 2009).

Clear communication

The literature stresses the importance of effective communication, with the need for:

- Good quality information about any case for change and shared effectively;
- A clear decision-making process and purpose for engagement;
- Clear and open channels of communication;

- Wide distribution of consultation literature, supported by extensive public engagement events (Barratt et al., 2015).

There are also strong arguments that accessible and detailed workforce, financial and service improvement plans must underpin reconfiguration proposals (Kings Fund, 2011, 2014). The literature is certainly clear that any case for change needs to be sufficient yet understandable and appropriate, receptive to public views and provide the opportunity to challenge professional views (Barratt et al., 2015; Morrison and Dearden, 2013). Findings from the IRP (2010) indicate that limited communication methods and important content missing from reconfiguration plans featured in a number of unsuccessful consultations.

Summary

There is a wealth of evidence to show the importance of public engagement in service redesign or reconfiguration (Laurance et al., 2014; Prior and Campbell, 2018; Coulter, 2014; Ben Tovim et al., 2008; Davis et al., 2016; The Kings Fund, 2014). What comes through from this is a preference for a greater role for the public (for 'involving' or 'collaborating' with them on change).

Nonetheless, there is no single model of effective engagement which delivers such service or systems change (Dalton et al., 2016). Many factors will have an impact; the make-up and scale of the communities involved, the type and extent of the services being discussed and how complex or controversial are the changes being considered. From the evidence reviewed, there does emerge several clear features of effective engagement on systems change;

- **Transparency:** A real commitment to engage and clarity about both the questions being asked and the potential for public influence. An offer to the public of genuine and visible interaction and influence appears to be key; ensuring that risks, opportunities, options and challenges are shared openly and fully.
- **Effective processes:** Clearly structured and appropriate engagement processes which engage with the right audience early and throughout the whole engagement cycle;
- **Clear leadership;** Including professional clinical leadership;
- **Clarity:** Effective communication of the case for change, the options and the issues that are being engaged on and the decision-making process. Striking the balance between being comprehensive and detailed but clear and understandable;
- **Inclusion and organisational resistance:** Ensuring key stakeholders (including professional or clinical groups) are part of the process. And where the public play a greater role in the decision, ensuring balance between 'service' and 'public' views.;
- **Resource and skills:** engagement can be very demanding and time consuming if done well; having the right skillsets to determine and implement appropriate methods to deliver a programme of work that delivers against the aims and objectives;

- **Commitment and outcomes:** ensuring there is a clear response to and action on the feedback and outcomes of engagement.

These elements of effective engagement for systems change are consistent with the approach developed by Involve (Involve, 2005, 2019). Recognising that all forms of engagement are valuable – from informing through to empowering – they argue that the starting point for designing any engagement activity should be to determine its scope and purpose:

- Why engage with the public?
- What decision are people being invited to participate in?
- What is genuinely ‘open’ and available to influence about the decision being considered?

Answering these questions can then support the development of an effective process, which may (for example) focus on effectively ‘informing’ people in a transparent and open way; or it may lead to the ‘empowering’ one or more groups to make a decision on a particular issue.

Discussions with stakeholders

Alongside the review of the existing evidence, we worked with colleagues at the organisation Involve to facilitate a series of structured conversations with senior leaders from across the governmental, health and social care system in Wales.² Our intention was to use these discussions to test our findings, and to build a picture of how engagement is, and may be, used to realise the aims of AHW. The feedback and comments - which are summarised below – reflected and echoed many of the themes emerging from the literature. At the same time, it also raised additional and some Wales-specific issues:

- **Clarity on the role of engagement in transformation:** At present there is not a shared understanding of the role of the public or patients in the transformation process. The vision articulated in AHW of a more patient-centred service appears to have wide spread support. As does the idea that engagement should be central to the transformation agenda. But in our interactions, there was no consistent, clear articulation of the role of engagement, particularly in relation to service reconfiguration. As an indication of this, stakeholders offered a diverse range of potential measures for ‘success’; these included:
 - The public recognise and feel they’re being involved and feel ownership of the process. Engagement is seen as ‘the norm’;
 - There’s visible action on public/patient feedback;
 - Public acceptance of engagement outcomes, even challenging ones;
 - There is tangible change and improvement to services. Services are being replaced, not just added onto;
 - Improved population health and wellbeing, with individuals and communities taking increased responsibility for their own health;
 - New models of care are developed and driven by a partnership between populations, communities, families, individuals and staff.
- **Clear governance and leadership:** The evidence points to the importance of clear ownership of the engagement challenge and top-level leadership; including political leadership and ‘buy-in’. Responsibility in Wales for engagement on health and social

² Including Welsh Government’s *A Healthier Wales* (AHW) Management Team and Advisory Board, Chief Medical Officer and Director of Social Services; Regional Partnership Board (RPB) Engagement Leads; All-Wales Health and Social Care Leadership Group; representatives from Welsh Local Government Association, Board of Community Health Councils; Social Care Wales; Director of Welsh NHS Confederation and Chief Executive, Hywel Dda UHB. We also spoke with policy and engagement experts and academics from across the UK.

care and the transformation agenda is shared across Welsh Government, the NHS Executive, LHBs, RPBs, and Local Authorities, with a lack of clarity on distinctive roles that each might play.

- **Shared working and collaboration:** We heard concerns about limited integration and the complex nature of joint planning architecture in Wales, especially in health and social care. Some areas report good partnership working, but the AHW engagement agenda is challenging and limited resources need to be used efficiently and effectively.
- **There must be clarity on the questions being asked and their purpose:** the transformation agenda articulated in AHW has the potential to generate a multiplicity of issues that might benefit from public engagement. As outlined above any engagement activity should be rooted in clarity about why public views are being sought and where they might realistically expect to have an impact. Effective communication of the case for change must also underpin the questions being asked about that proposed change.
- **Locus of the engagement:** depending on the nature of the issue or question being considered, engagement might happen at local, regional or national level. There appears to be a degree of consensus that engagement on service change should happen at a local or regional level, with some arguing for national communication activity to support this. A focus on engagement at the individual level (shared decision making and patient-centred care) is also seen as central to achieving AHW. Finally, there was support for the idea that there should be national engagement activity on some issues (e.g. funding for social care).
- **Defining the audience:** The discussions emphasised the need for the audience to be defined by the purpose of each individual engagement – who needs to be involved? Alongside a desire to ensure ‘fresh thinking’, engaging widely and beyond ‘the usual suspects’, there was at the same time a recognition of the value of the ‘expert patient’, who could bring a deeper experience of services, especially to the development or redesign of individual services or clinical pathways.
- **Enabling a more informed debate:** The feedback we heard pointed to the importance of health literacy and information frameworks – for both public and clinicians - to support new, engaged and rebalanced care relationships. There was a recognition of the value of targeting particular priority areas, for example those services relating to chronic conditions such as diabetes, chronic pain or COPD.
- **Building on existing success:** We heard the view that there is already strong engagement work going on in LHBs and social care, with good policies and practice. However, it is inconsistent and not being shared in any structured or meaningful way. There would be value in greater structured learning and convergence of practice, and some efforts to initiate this have already begun.

However, we also heard concerns about the risk of ‘engagement fatigue’ and available engagement capacity, whether individual, communities or organisations: the engagement programme needs to be manageable for all involved.

- **Involving clinicians:** There needs to be clear demonstration in national, regional and local plans for how clinicians are involved in engagement, especially around service redesign or reconfiguration. Alongside this, the evidence reviewed has highlighted the need to focus on clinical skills and behaviours if the aim is to rebalance the relationship between professional and service user or patient – a potentially enormous training and development agenda.
- **Prevention:** Some argued that a real shift to prevention needs large-scale behavioural change, with a combination of national activity on shaping the broader environment alongside individual interventions. There are some regional approaches to place-based working (such as the Wigan Deal discussed above), which have attracted significant interest and are showing some promise.

Conclusions and policy implications

A number of themes emerged from the literature which were given a strong practical and often very specific Welsh context or focus as a result of discussions with stakeholders. From this, it is possible to draw out reflections on how to progress the engagement agenda in AHW.

The development of a national 'offer of involvement' and the associated programme of engagement should be based on a shared vision for the role of engagement in the transformation agenda. Our work points to the need to consider the three areas linked to engagement in AHW separately:

- **Encouraging healthy behaviours** is not primarily an issue of engagement, although targeted information and support can complement wider efforts to change the social and environmental factors that influence behaviours. Placed-based approaches to involving or collaborating with the public also show some promise as a way of securing buy-in for change and coordinating across organisational divides. The Welsh Government's obesity strategy – Healthy Weight: Healthy Wales – seems to incorporate these elements (Welsh Government, 2019).
- **Patient-centred care** is a form of engagement – done well, it leads to people taking a greater role in the decision making on their care. To achieve this, the public need to have accurate and accessible information, and support to use it. But without changes in clinical and professional behaviours, this will be insufficient. There are some efforts in Wales to ensure that information, support and training are in place, but it is not clear that these are commensurate to the stated ambition.
- Evidence supports patients playing a greater role in understanding and improving care pathways, and any associated changes in **service design**. This suggests that the new models of care that are currently being developed, and which are intended to form the basis of the future patterns of provision, should draw on the evidence of effective engagement for service design.
- **Wider service reconfiguration**, to the extent that it will result in certain forms of provision in certain areas being changed or withdrawn, will always face resistance. Effective engagement can play a part in mitigating that risk and addressing peoples' concerns. And there is evidence – including from experience in Wales – that those forms of engagement that give the public a greater role in decisions ('involving' or 'collaborating') can help to reinforce the transformation agenda.

- The **broader 'systems change' agenda** appears to be concerned with changing the attitudes and behaviours that define the relationship between citizen and state, or service and service user. Achieving patient-centred care, and greater involvement of patients and public in service design or reconfiguration would contribute to this; but it is not clear from discussions with stakeholders what, beyond this, would constitute 'success'.

There does seem to be the potential for increasing the national effort to raise awareness of the need for change in the health and care system, which could in part 'frame' the programme for engagement as an effort to change the relationship between citizen and state. Alongside this, there could be scope for nationally-led involvement, collaboration or empowerment of the public on specific issues or decisions; for example, by using a citizen jury or assembly to look at future funding of social care. Both would require leaders to focus on and prioritise this within the transformation agenda.

Based on all of the above, it would appear that service redesign or reconfiguration and wider systems change would sensibly be the focus of a specific programme of engagement for the transformation agenda.

In addition to substantive decisions about the role of engagement in transformation, any programme for engagement for AHW will need to resolve some of the questions around **governance and resourcing**. At the moment, RPBs, PSBs, LHBs, Local Authorities, and Welsh Government all undertake forms of public engagement. It is widely accepted that this could be better coordinated, and some regions have made progress in achieving this. It will be important not to undermine local and regional success when developing a national approach to the resourcing and coordination of engagement. The wider transformation agenda is being driven by the RPBs, and it will be important to align engagement activity with this, and ensure appropriate resourcing and capacity. At the national level, robust and visible monitoring of performance on engagement is essential, and should be combined with support, including an effort to ensure the availability and dissemination of good practice. Clarity on the respective roles of a new patient voice body, the NHS National Executive, Welsh Government and Public Health Wales will be important.

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