

Public engagement and NHS Wales

This briefing provides an insight into how successful and effective engagement with the public and patients can lead to positive outcomes for individuals and improved well-being for communities.

Key Points

- There are two key aspects to public engagement in NHS Wales: helping to inform whole system change; and supporting people to stay well and happy.
- Seamless health and care services will only be achieved if people are put at the heart of our services, including the planning and designing of services.
- We need to engage with the public on the future of health and care services so they understand what the NHS can deliver in the future as demand increases and people's needs become more complex.
- It is critical to listen to all voices, adapt continually and be prepared to let go of long-held ideas to truly transform service provision. Engagement is not a one-off exercise. People should be continually involved in shared decision-making and provided with the right tools to make decisions, particularly vulnerable people who often feel excluded from the decision -making process. The goal is to achieve an environment where the public feel 'no decision is taken for me, without me'.

- Successful public engagement is a twoway exercise and benefits patients, clinicians, and the NHS as a whole. Patients get more person-centred and accessible care; clinicians are able to use resources more efficiently with a better understanding of what matters to patients; and the NHS as a whole gets a clearer understanding of what is needed to deliver services in a seamless and integrated way.
- The Parliamentary Review of Health and Social Care recommended that health and social care services need to put patients in control through strengthening individual and community involvement.

Overview

Public support is critical to delivering and securing policy and behaviour change. Achieving effective public engagement requires an effective partnership between those who deliver care and those who receive it.

Programmes that are most successful in establishing a meaningful dialogue between policymakers and the public are those that place the public at the heart of the decisionmaking process and create an environment where they feel they have an influence over the decisions being made. Good examples of this include seatbelt laws, the carrier bag levy, banning smoking in public places and organ donation opt-out laws.

While Health Boards and Trusts are continuously engaging the public, it is vital to recognise that a major change in culture and approach is required to get the public to embrace the different ways of working that the NHS of the future demands. As the Parliamentary Review into Health and Social Care report, published in January 2018, recommended, there is a need to "strengthen individual and community involvement, through voice and control in health and care, and ensuring all ages and communities have equal involvement".

Change is necessary to manage demand and implement new models of service. The benefits of bringing about a shift of care from hospital to home are enormous, and we need to show the public the advantages of health and care being delivered in different ways and within different settings.

However, it is human nature to be emotionally resistant to change, attached to old practices, local institutions and cultures that have been passed down over the years. In light of the Parliamentary Review of Health and Social Care, we now have the opportunity for an open and honest conversation with the public about health and care services in the future and for people to become active participants in their care. All public sector organisations should foster an environment of positive citizen empowerment. There is an opportunity for effective communication and engagement across the whole public service by developing messaging that encourages public acceptance of the need for change. In addition, the language relating to engagement should be framed around the well-being benefits they strive to achieve, particularly patient outcomes.

We believe that there is much to gain from a national approach to public awareness and engagement which involves:

- Reconsidering the relationships we have with the public and the workforce;
- Providing an easily accessible narrative on increasing public understanding of the case for change and the benefits of transforming services;
- Building on existing engagement and communications relationships and channels at all levels;
- Informing, educating and supporting the public to embrace the well-being benefits of self-care leading to changes in behaviour; and
- Proactively working with social movements to raise awareness and deliver change.

For transformation to happen, we need to increase public understanding and acceptance of service redesign, improve people's knowledge of the services they receive and increase public awareness of the impact their choices have on their well-being. This will mean that citizens are equal partners in their health, co-designing services with providers. As the Parliamentary Review highlighted, "Wales must be a listening nation through actively seeking out diverse views and experiences to co-design services with the public if we are to accelerate change and improve quality".

How does NHS Wales engage with the population of Wales?

NHS Wales is founded upon collaboration, co - operation and partnership-working. Engaging with others means working in constructive relationships to ensure best outcome for citizens. Public service providers understand that no-one can operate effectively in isolation and organisations are dependent upon others to support the delivery of services.

The public is identified as a critical stakeholder in the decision-making process under the Well-being of Future Generations (Wales) Act 2015. Public engagement is also cited as one of four key priorities set out in the Future Generations Commissioner's 2017-2023 draft strategic plan.

NHS Wales' core values are underpinned by a belief that the people of Wales have a key role to play in the provision and delivery of services. We need to support public involvement as much as possible and make it clear what the responsibilities and outcomes of services should be. Partnerships should be kept under review and be prepared to change, adapt or come to an end where they no longer serve a useful purpose.

Mechanisms of public engagement

There are a range of mechanisms that NHS Wales uses to engage the public, including:

- Public meetings;
- Local community groups and forums, such as Community Links groups and Communities First co-ordinators;
- Primary care initiatives like GP patient groups and public surveys;
- Formal consultations;
- Stakeholder Reference Group activity which involves working with partners in local government and the third sector as well as carers and patients;

- Population Needs Assessments under the Well-being of Future Generations (Wales) Act 2015;
- Consultation at public events; and
- Surveys and questionnaires.

The mechanism of public engagement will vary depending on the service area and objectives. When a Health Board wants to gather information about a specific service, they could invite members of the target population to a local forum meeting to share their thoughts and ideas. For broader issues, where a multi-disciplinary approach to the planning, design and delivery of services is required then a stakeholder reference group is likely to be a more effective means of public engagement.

Open board meetings

Health Boards and Trusts across Wales hold formal board meetings monthly. These meetings are open to the public and provide an opportunity for local people to see how the Board operates. Public engagement with these meetings also enables people to see what is expected of the people who make decisions on their behalf, and gain a greater understanding of the pressures they work under. Members of the public can also raise specific issues in writing for discussion at the Board meeting. Agenda items, relevant meeting papers and minutes of previous meetings are available on Health Board and Trust websites and live updates are often shared on social media platforms.

Public board meetings promote the accountability of Health Boards and Trusts to the people they serve and support a workplace culture of openness and transparency. Part of this involves encouraging the public to monitor their Health Board's website for information about the provision of services in their localities and to encourage members of the public to attend and participate in regular board meetings.

Public Service Boards

The Well-being of Future Generations (Wales) Act 2015 introduced Public Service Boards (PSBs) for each Local Authority area in Wales. Each PSB must improve the economic, social, environmental and cultural well-being of its area by working to achieve well-being goals. Through the PSBs, NHS Wales works collaboratively with public sector partners to support citizens within their area to live happy and healthy lives. By leveraging innovative partnerships, NHS Wales can engage more closely with patients and utilise the skills and experiences of local people.

Community Health Councils (CHCs)

There are seven CHCs in Wales, independent bodies representing the interests of patients. Their primary objective is to listen to what local communities have to say about their health services on matters of quality, quantity and suitability and act as the public voice in letting health services know what people want and how things can be improved.

CHCs acknowledge that the NHS in Wales faces significant challenges and that NHS organisations are actively seeking to improve the experiences of patients presenting at Emergency Departments and undertaking public engagement programmes.

The NHS Wales workforce and Making Every Contact Count (MECC)

Every day there are millions of interactions taking place between NHS staff, the public, patients, patient's families and carers. MECC aims to empower staff working within health services to recognise the role they have in promoting healthy lifestyles, supporting behaviour change and contributing to reducing the risk of chronic disease. This recognition extends not only to their interaction with patients, but also to their own health and well-being and that of their friends, families and colleagues. Adopting this approach enables NHS Wales to move to a position where discussing lifestyle and well-being is routine, nonjudgemental and integral to everyone's professional and social responsibility. This will require the development of a healthy, supportive and welcoming culture of employment and effective mechanisms of staff engagement.

Choose Well

The Choose Well campaign was developed in 2011 and aims to help people get the right treatment, in the right place, at the right time through educating patients about the health services available to them and encouraging them to self-care where appropriate. This will reduce inappropriate pressure on NHS services.

In November 2017, the Choose Well campaign launched a new element called My Winter Health Plan. This is a person-centred resource that helps people share key information about their health and support network when health and care staff visit them at home.

In addition to the Choose Well campaign, the Welsh Government introduced Choose Pharmacy in 2016, which sees pharmacists take responsibility for managing and treating minor ailments, such as coughs, colds and hay fever, instead of the patient going to their GP. Choose Pharmacy has improved patient access, has made better use of pharmacists' skills and resources, and improved public understanding of the support available at their local pharmacy.

NHS organisations are sharing common public messages through social and conventional media to ensure that the public is aware of all available health services, including those available digitally - for example, the advice on the NHS Direct Wales website.

How public involvement with health and care services contributes to well-being

Creating the right environment

It is important that those working in the NHS create an environment where patients feel a sense of ownership and control over the care they receive. Achieving this sense of ownership and control is key to having an informed public – a public that is aware of the risks of unhealthy behaviours and makes the most of every day in good health.

Our focus should be on helping patients to become knowledgeable partners in managing and improving their health. Understanding what matters to people will help health and social care practitioners to engage people to see how looking after themselves can help them achieve their goals. This will benefit not just themselves, but all those who rely on the NHS today and in future, including NHS staff.

Informing a patient, their carers and the public about health and treatment options provides an opportunity for engagement and a chance for patients to play a leading role in the management of their well-being. When patients are well-informed, they make different choices about treatments and what patients want often differs from what doctors think the patient wants. Increasing engagement so that people can feel involved in their care and treatment plans therefore is ultimately about providing greater choice.

Furthermore, when people are involved in the decisions that directly affect their lives, their self-esteem and self-confidence increases. This improves health and well-being and supports strong social networks, which also has a positive effect on individual and population well-being. Involvement in discussions about health and health services also supports social cohesion within communities.

Putting the citizen first

We are a society with immediate needs. As consumers, we are digitally aware and have high expectations of access, personalisation and the ability to retrieve information 24/7. We make informed choices and expect service delivery where and when it is convenient to us. The same level of service is expected from our health services.

The term 'citizen' has a number of definitions, but broadly refers to anyone who receives, or is affected by, public services. In NHS Wales, patients are the obvious citizens but we have to consider lots of other groups beyond patients when planning and delivering services including NHS staff, patients' families and loved ones, and carers. Organisations may define this in different ways – patient, service user, carer or service recipients, but what matters is the attitude and organisational culture.

Putting the citizen first is not about giving citizens everything they want – different people want different things. It is about adopting a mindset that places the interests of patients before those of the organisation and tailoring what the organisation does to meet the needs of service users.

Providing high quality information

The provision of information to service users is increasingly recognised as a central part of health systems across the world. It is a vital tool in engaging and informing individuals about their health. High-quality patient information should form an integral part of providing patient-centred care which focuses on the needs of the individual.

Research shows that effective engagement supports patients to play a leading role in the management of their health and well-being. It improves patient knowledge, experience and satisfaction, reduces costs through greater self-care and self-management, and results in more appropriate use of services. The results are improved health behaviours and better adherence to treatment plans. High quality information encourages patients to take responsibility for their own well-being which prevents over reliance on services.

Improving health literacy

Health literacy is the degree to which individuals have the capacity to obtain, process and understand health information in a way that supports them to make informed decisions about their well-being. Low health literacy means a person may not be able to understand their health needs and may have difficulty in navigating complex healthcare systems, with consequences on their wellbeing.

People with low health literacy have poorer health status, are less likely to make healthy living choices, experience higher rates of hospitalisation and emergency admissions and incur substantially higher health service costs.

Service providers must appreciate that people have different levels of literacy when it comes to their health and well-being. Improving health literacy is just about producing information – it is about engaging the public so they have a good understanding of their needs and treatment.

The King's Fund emphasise the risk faced by service providers when caring for patients with low health literacy: *"The temptation for clinicians faced with someone who has little knowledge of health matters and is not confident about asserting their views is to make the decision for them, thus further reinforcing their passive role and the tendency towards poorer health in the long term."*

By tailoring health information to each patient, medical practitioners can provide a chance for people to learn about their health and their responsibility to maintain it. It is possible to inform and engage patients from all walks of life and educational backgrounds if they are provided with effective materials and support by well-trained staff.

Prudent healthcare

Prudent healthcare focuses on engaging the public to think differently about the health and care services they receive. This means changing ways of working, but also ways of thinking, so that we can focus on what the people who use and deliver NHS services value.

The four prudent principles are:

- Achieve health and well-being with the public, patients and professionals as equal partners through coproduction;
- Care for those with the greatest health need first, making the most effective use of all skills and resources;
- **Do only what is needed**, no more, no less, and do no harm; and
- **Reduce inappropriate variation** using evidence-based practices consistently and transparently.

Following these principles empowers the public, NHS professionals and public service leaders by promoting prevention, encouraging a joined-up approach to treatment and creating the necessary conditions to support a system-wide focus on value and outcomes.

The Public Health Wales report 'Achieving Prudent Healthcare in NHS Wales' says that patient and citizen engagement lies at the centre of delivering the prudent healthcare agenda.

Without the constructive, informed environment that successful public engagement brings, it becomes increasingly difficult for the benefits of prudent healthcare principles to be realised.

Engagement from elsewhere

As Wales' largest employer, NHS Wales must continue to seek sustained improvement and learn from other sectors about how they have introduced mechanisms for engaging with the public.

Participation Cymru

Participation Cymru, hosted by the Wales Council for Voluntary Action (WCVA), works with organisations in the public, private and third sectors to achieve improved public engagement in the design, development and delivery of citizen-centred services.

In addition to its comprehensive training programme for organisations that want to develop their skills in public engagement, Participation Cymru facilitate meetings and events; undertake practical engagement work of their own; develop evaluation methodologies; and support organisations in the writing and design of effective engagement strategies.

Participation Cymru have established the 10 National Principles for Public Engagement.

The 10 principles are:

- Ask 'Will it make a difference?';
- Ask the right people;
- Give everyone a fair and equal chance to participate;
- Work with other organisations;
- Speak and write simply and clearly;
- Make it easy for people to take part;
- Support and encourage people to learn and develop;
- Consider time and money;

- Encourage people to be honest and clear about their ideas; and
- Do it better next time.

Abertawe Bro Morgannwg University Health Board (UHB), Betsi Cadwaladr UHB, Hywel Dda UHB, Powys Teaching Health Board, the Welsh Ambulance Service NHS Trust and Velindre NHS Trust have endorsed the principles, as well as Aneurin Bevan CHC, Cwm Taf CHC and the Welsh Government.

Health and Care Research Wales

Health and Care Research Wales provides an infrastructure to support and increase capacity in research and development (R&D), runs a range of responsive funding schemes, and manages the R&D funding allocation of NHS Wales. Health and Care Research Wales pledges to secure excellent standards of public engagement in health and care research projects.

Health and Care Research Wales has established the Involving People Network to engage the public in research projects. The Network is comprised of members of the public across Wales who work with researchers to improve treatments and care. The Network goes beyond just consulting or engaging people in informing policymaking – it is a means of getting direct patient involvement in the processes of planning, delivering, supporting and disseminating the findings of research projects to maximise impact. There are currently around 200 members of the Network.

In 2017, Health and Care Research Wales announced a partnership with the National Institute for Health Research, the Chief Scientist Office in Scotland and the Public Health Agency in Northern Ireland. The partnership has produced a set of national, self-assessment standards for public involvement in research in Wales and Scotland. Having a set of core standards can help everyone to improve the quality and consistency of public involvement in research by working towards, delivering or exceeding current good practice.

Local Authorities

Local Authorities have recognised the importance of working with the public, stakeholders and other delivery partners to design and deliver vital services.

Every year Local Authorities are required to submit a balanced budget by the end of March for the financial year ahead, and to share that budget, as well as the process through which it was produced, with the Welsh Government. This gives the public an insight into the rationale behind the difficult decisions being made on their behalf and provides an opportunity to contribute to the decision-making process. The following list summarises three examples of successful public engagement by Local Authorities across Wales:

- Carmarthenshire County Council set up a dedicated project group comprising more than 40 stakeholders, 30 third sector organisations and delivery partners to gather views about budget proposals ahead of the new financial year. The Council supported this by delivering public roadshows and stakeholder events with representatives from Equality Carmarthenshire (an umbrella grouping of diversity groups, including the Youth Council, 50+ Forum, Disability Coalition, and the Multicultural Network), businesses and Town and Community Councils. There was also a separate seminar held for third sector organisations in relation to social care and housing;
- Wrexham County Borough Council used an online budget simulator tool called YouChoose. The tool was used to engage with participants and ask them to achieve a £34m savings target over five years. Use of this tool made up phase 1 of the engagement process, and phase 2 involved using a consultation booklet to present the full package of budget proposals to meet the funding shortfall for the forthcoming financial year. Over 300 people engaged with phase 1 of the process, and more than 600 people engaged with phase 2. The key messages from participants were summarised and analysis on the results was provided;

The City and County of Swansea have launched an extensive and longterm 'Sustainable Swansea: Fit for the Future' initiative. The initiative focuses on the transformation of services and the methods of service delivery; collaboration with other councils and organisations; and the delivery of sustainable solutions that have prevention at their heart. It was implemented to agree the services the Council should provide in future, what they should stop doing; and looking at what communities are prepared to do for themselves and how the Council can help and support this. The initiative involved staff, communities, organisations and council partners and enabled residents to understand that the programme was not just about money but about a new way of doing things in the Council area. Through the initiative, the Council is continuing the conversation to develop services that are fit for the future.

Beacons for Public Engagement, National Co-Ordinating Centre for Public Engagement

In 2008, the Beacons for Public Engagement initiative was launched. Its aim was to inspire a culture change in how Universities engage with the public. The Beacon for Wales was a partnership between Cardiff University, University of Glamorgan, Amgueddfa Cymru - National Museum Wales, Techniquest, and BBC Wales. It worked to develop the skills and confidence of University staff and students in listening to and learning from publics across Wales. Six Beacon partnerships and a National Co-ordinating Centre for Public Engagement (NCCPE) were funded.

The six Beacons were University-based collaborative centres that were set up to support, recognise, reward and build capacity for public engagement, with a lifespan of four years. Their partners included further education colleges, museums, galleries, businesses, charities, TV and press, and public bodies.

Engagement in action

The following section provides best practice examples of successful public engagement from Wales and beyond.

Making Choices Together, Academy of Medical Royal Colleges

Making Choices Together is a clinician-led initiative, promoted by the Academy of Medical Royal Colleges in Wales in partnership with the Board of Community Health Councils, and Public Health Wales NHS Trust.

Making Choices Together aims to:

- Embed a broad culture change in healthcare where clinicians and patients regularly discuss the value of treatments and make shared decisions;
- Ensure reliable and valid information is available for patients and clinicians regarding agreed interventions of low value, such as where there is a minimal chance of a beneficial outcome;
- Enable participating professional health organisations such as the health professional colleges and societies, to produce lists with patients of commonly used treatments/ interventions whose necessity should be questioned;
- Encourage local clinical teams to use shared decision-making skills in consultations, and to adopt or select, locally relevant interventions of low value; and
- Reduce harm to patients caused by inappropriate use of tests or interventions.

As part of Making Choices Together, patients are encouraged to ask their clinician four questions:

- What are my options?
- What are their risks and benefits?
- Do I really need this?
- What can I do to help myself?

Grow Rhondda, Rhondda Primary Care and Treorchy Men's Sheds

Grow Rhondda is the result of collaborative working between Rhondda Primary Care, Ysbyty George Thomas Hospital and the community group Treorchy Men's Sheds. The programme is a therapeutic gardening group for people with mild anxiety, low mood, low self-esteem or those experiencing social isolation. It consists of eight weekly sessions where patients get involved in all aspects of gardening. The project brings the local hospital into the community and engages local community groups.

Dave Harris from Treorchy Men's Sheds said: "The benefit you will get from any gardening project is the fact that you are outside. You can share that experience with other people and enjoy the aspect of the garden through the changes in the seasons, what you can plan or plant. Within a few weeks you have something growing and that's a rewarding experience."

Studies have found that the mental health benefits of gardening are extensive. Not only can regular gardening reduce mental health problems such as depression and anxiety, but it can also reduce stress and combat high blood pressure, as well as increasing rates of physical activity.

Kafka Brigade, Rhondda Cynon Taf (RCT) Local Service Board

The Kafka Brigade model focuses on creating action in response to the case of a representative citizen experiencing a common "wicked" issue - where problems have proved persistent - like substance misuse, truancy or domestic violence. The model incorporates six steps:

- Explorative research and case selection;
- Case research;
- Expert critique;
- Collective performance review;
- Action plan; and
- Follow up.

In 2008, RCT Local Service Board commissioned the Kafka Brigade to apply its methodology locally to domestic abuse and identified an individual who represented the profile of a 'typical' victim of domestic abuse. In RCT, the individual was Emma, who matched the characteristics and represented approximately 2,000 victims of domestic abuse in RCT. Emma and the practitioners who worked with her on the ground shared their experience in detail.

The next stage of the research brought together the experts in the field of domestic abuse service delivery and local and national decision makers. At this meeting, Emma talked about her experience with local services - identifying both good and poor practice across and between all agencies. It culminated in a commitment by each agency to a shared vision to make things better for Emma, her family and others experiencing a similar situation.

Collectively, the key issues for improvement were drawn together into one action plan; each action being assigned to senior decision makers within the agencies concerned. The action plan changed the way services were provided in the local area and an attributable drop of 12% in minor violent incidents during the quarter following the completion of the project.

The Welsh NHS Confederation Memorandum of Understanding with the Arts Council of Wales

The Welsh NHS Confederation has recognised the value of the arts to health, well-being and active participation by signing a Memorandum of Understanding (MOU) with the Arts Council for Wales. The three-year agreement, signed in September 2017, aims to promote the benefits that the arts can bring to the population's health and well-being and encourages people to engage more closely with their local communities.

Arts and health is all about mobilising patients to engage in relaxed, enjoyable activity that ultimately has a positive effect on their physical and/or mental health. Such activities, particularly when they are delivered in welcoming, non-clinical settings, provide opportunities for people to engage with each other and their own creativity, directly improving their sense of well-being and improving knowledge.

As highlighted in the Arts Council of Wales' mapping report, 'A Mapping Study of Current Activity', arts can increase social engagement, provide opportunities for self-expression, reduce feelings of loneliness, decrease a person's perception of pain and aid the healing and treatment process. Health Boards across Wales are realising the positive benefits of heightened patient engagement brought about by innovative arts interventions.

Person-centred leadership programme 2017-18, Public Health Wales NHS Trust, Velindre Cancer Centre NHS Trust and the Centre for Patient Leadership

Public Health Wales and Velindre NHS Trust have been working with the Centre for Patient Leadership to develop effective and successful patient and community leaders who can influence and contribute to the decision-making process and support the shaping of local healthcare services.

The programme's focus is on building new relationships between citizens and health and care professionals within local communities, fostering collaboration and partnerships in order that citizens and communities are involved directly in decisions about the future of health and care services. The programme consisted of a combination of workshops, action learning, and coaching support over a period of eight weeks. Programme outcomes for the organisations involved include:

- A self-sustaining network of local patient leaders acting as mentors for newly emerging patient and community leaders;
- Confident and competent patients who engage with the system and health care
 professionals to support culture change and work in partnership on service redesign and
 delivery;
- Conduits between health organisations and the wider system and the local community, able to 'represent' the health organisation in the community, particularly with marginalised and 'seldom heard' groups;
- Conduits between the community and the health organisations, providing data, information and feedback that is defined by the community and so reflective of 'real' and often hidden needs; and
- Active, motivated individuals prepared to facilitate health initiatives and projects in their local community.

Connected Health Cities, North of England

Connected Health Cities unites local health data and advanced technology to improve health services for patients across the North of England and has used the citizens' jury method to include the wider community in decision-making. It involves briefing citizens in detail on a particular issue and asking them to produce a report with recommendations. The method can be used to complement other forms of consultation.

The Connected Health Cities programme carried out two citizens' juries to explore whether its planned and potential uses of health data were acceptable to the public. Each jury was made up of 18 citizens and ran over four days. The citizens were asked to address a set of questions about how the programme should protect and use health data, and to judge what was acceptable. Citizens heard from and asked questions of expert witnesses, and carried out group exercises. They reached conclusions together and were polled on their individual views at the start and end of the process. Findings from the citizens' juries will impact on the way data is used across the programme.

Developing interventions to raise awareness of rabies in rural Africa, Glasgow University and Ifakara Health Institute, Tanzania

Rabies kills around 25,000 people in Africa every year. Many of these deaths could be avoided through vaccination of individuals after a suspected rabies exposure, but vaccination costs are high and often beyond the financial reach of poor rural communities. This project, led by researchers from the University of Glasgow and Ifakara Health Institute, worked with some of Tanzania's poorest communities to find the best way of getting the prevention message through to change lives.

In addition to delivering public health lectures in schools in the most at-risk areas, interactive resources included Ketso mats - large, felt grid mats with coloured "leaves" on which participants share ideas and see them come to life in a visual way. This helped participants from a range of backgrounds express their views anonymously, without fear of criticism. Young people were also engaged through a rabies song competition, supported by professional musicians and informed by the work of Feliciano dos Santos who uses music to mobilise communities in Africa. Music is a vital tool for awareness in Africa, and radio is accessible to most people, even in remote areas.

Workshops also identified health, veterinary and dispensary staff who could help overcome barriers to prevention in young people. The project also engaged local motorcycle taxi companies who could not only help to coordinate emergency transport so rabies victims could access health services, but whose drivers were themselves some of the young people the project wished to engage. Teachers also attended a workshop where they were trained to deliver and evaluate rabies information in classrooms, so that they themselves could raise awareness and provide part of the evaluation data.

Ebola, West Africa

The West African Ebola epidemic of 2013/14 was the most widespread in history. Over 28,600 cases were confirmed, mainly in Guinea, Sierra Leone and Liberia, resulting in at least 11,000 deaths. The WHO did not declare all areas of West Africa to be Ebola-free until June 2016.

Humanitarian aid workers, volunteers and the local authorities used a variety of communication and engagement approaches during the Ebola response, including social media chat groups, community radio and door-to-door canvassing.

Engagement was also achieved by setting up dedicated phone lines, community gatherings in urban areas, and the implementation of the 'Wash Ebola Away' strategy. Wash Ebola Away focused on house-to-house hygiene promotion and distribution of hygiene kits. Other examples of public engagement during the outbreak included the work of Mercy Corps (a prominent non-governmental organisation), who collaborated with 76 local partner organisations to hire 830 public health trainers and train over 15,000 community educators in Liberia.

IMPACT DC, Washington and Project Dulce, San Diego

Research shows that patients remember significantly more information when presented with a printed aid and verbal instruction, rather than receiving verbal instruction only. The best materials are short documents that patients can easily read and understand. IMPACT DC, a programme of Children's National Medical Centre in Washington, designed a one-page guide to help providers more effectively educate patients and caregivers about living with asthma. Using a familiar traffic light colour scheme, the document demonstrates how to recognise and treat symptoms they can safely manage themselves and those which require immediate medical care.

In San Diego, Scripps Health developed Project Dulce, a skills-based education programme for patients newly diagnosed with diabetes. The project provides practical guidance on daily activities such as testing blood sugar levels and making healthy lifestyle changes. The programme also directly addresses issues of health literacy, teaching patients the meaning and application of the key terms necessary to manage diabetes. For example, one lesson focuses on nutrition and explains how to read food labels to make healthy decisions at home. Part of Project Dulce's success comes from its low cost, self-sustaining model. Former patients receive in-depth training to become instructors, offering peer support in addition to subject matter expertise.

Call and Check Programme, Jersey Postal Service

The number of Jersey residents aged over 65 is set to double between 2015 and 2040. Such a demographic change represents a significant public health challenge. In an apparently unrelated development, the postal service in Jersey carried out a questionnaire among its staff members to ask them what additional services they felt the Jersey postal service could provide – the result was the 'Call and Check' programme.

Staff identified the increasing number of frail and elderly people, particularly those living alone, as a gap in service monitoring. Under the Call and Check programme, postal workers visit these patients twice each week, for approximately five minutes each visit. They deliver prescriptions and provide appointment reminders, while also checking on patients to look for warning signs of deterioration.

Postal workers participating in the programme are required to undertake training before engaging with patients and are provided with an overview of how the programme is implemented and a checklist of 'things to look out for'. While no formal medical care is provided, these checklists allow postal workers to make recommendations to local primary care services should they feel that a patient requires medical attention.

An informal evaluation programme found that *all* elderly patients who had received home visits from local postal workers felt that they had benefited from the programme. Postal workers who participated in the delivery of the programme reported greater job satisfaction and a feeling they were making a real difference to the local community.

The Kitchen Table, Oregon, USA

The Kitchen Table is the creation of a group of non-partisan, non-profit community organisations dedicated to helping the population to have a voice, to share their ideas, opinions, beliefs, and resources in improving Oregon and its communities.

The Kitchen Table is a space to empower individuals to contribute feedback, ideas, and resources to decision-makers, public projects and initiatives. After signing up, contact is made periodically by email to asking for opinions on Oregon's latest public policy issues, requesting participation in a public project, or investing in the local community.

Oregon's Kitchen Table strives to:

- Create simple, easy-to-use platforms (online and in person) for state-wide public engagement;
- Promote in-depth public engagement with the tough trade-offs and challenges decision makers confront in governing our state;
- Provide leaders with high-quality feedback on issues that matter to Oregonians;
- Increase Oregonians' interest in participating in local, regional, and state-wide decision making; and
- Empower citizens and decision-makers to communicate and work together in a fact-based, civil, and creative way.

Barbershop Outreach Programme, New York City, USA

Founded in 2007, The Black Barbershop Health Outreach Programme was born out of the need to address health disparities among African American men. African American men die disproportionately more than any other segment from preventable diseases.

Over the past decade, the Black Barbershop Health Outreach Programme has found success in its three-pronged approach to community engagement:

- **Screen:** Screening men for diabetes and high blood pressure.
- Educate: Educating men about making healthy lifestyle choices.
- **Refer:** Referring men to local services where support is available.

The programme has screened over 30,000 African American men in 800 black-owned barbershops to date. The goal of the Programme is to screen and educate 500,000 African American men for cardiovascular diseases by 2020. Organisers of the Programme are actively seeking additional barbershops across the USA as well as other stakeholders such as fraternities, sororities and churches to support this effort and increase public awareness.

Conclusion

As highlighted within the Parliamentary Review of Health and Social Care, engagement with the public and the patient is critical to the acceptance and success of transformational change needed in NHS Wales.

Providing information and communicating with patients and the public are key elements of engagement. However, they must be combined with meaningful opportunities for individuals and local populations to participate in service development, planning and evaluation, along with the service actively listening to what matters.

A health and care service should be organised around the needs of those who use it and strengthening engagement and participation with patients and the public may be the best way to enable the service to become sustainable in the future.

How can the Welsh NHS Confederation help you?

Please get in touch if you want further details on any of the issues raised in this briefing. Please contact **Nesta Lloyd-Jones**, **Policy and Public Affairs Manager at <u>Nesta.Lloyd-Jones@welshconfed.org</u>**

The Welsh NHS Confederation is the only national membership body which represents all the organisations that make up the NHS in Wales: the seven Local Health Boards and three NHS Trusts.

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