

...promoting health and health services improvement in Wales

Redrawing the relationship between the citizen and state

This report represents formal advice from the Bevan Commission to the Minister for Health and Social Care. It is part of a wider programme of work being undertaken by the Bevan Commission.

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Introduction

The core purpose of the state is the protection of its citizens. This involves the protection of citizens' liberty and their security, which includes individual and collective health protection as well as global security. This paper mainly focuses upon the relationship between the citizen and health professionals, expanding upon individual choice and a new kind of citizen; less deferential and appropriately more demanding than in the past with more control over decisions; empowered to affect change through the power of their own actions, shifting away from a paternalistic model of service delivery.

Demand for healthcare services is increasing globally, primarily due to population ageing, increased prevalence of chronic and complex health conditions and growing patient expectations. Although life expectancy in many countries is rising, an ageing population presents health systems with the challenge of balancing increasing demand with reduced expenditure. The NHS in Wales is not alone in needing to address these challenges, providing consistently high quality care in a time of diminishing resources. Governments worldwide are being expected to do more with less which is unsustainable and must change to meet future demand.

We believe that working more closely with the people of Wales to help redraw and rebalance the relationship with the state is key to the future of more successful health outcomes for people and to more sustainable health and social care services in Wales. This paper, identifies some of the key factors involved in achieving this, utilising a prudent approach to health and engaging with people to develop more equitable health and wellbeing to which all in Wales are entitled. The ways of working described in this paper are in sympathy with and enhance the approach described in the Beecham report (Welsh Assembly Government 2006) and subsequent public service and legislative frameworks. These highlight a distinct citizen centred, social model approach to health in Wales which is linked to collective action and where the drivers for this are moral, rather than being driven merely by resource constraints.

Context

Expectations of public services are higher than ever; in part due to the consumer-based, fast-paced environment in which we live, where people expect to be able to receive services and send information instantly (King's Fund 2014). With the rapid progress of digital and medical technology many expect that solutions are available to fix health problems and that the state (as the NHS) has a responsibility to deliver these. Such expectations can be unrealistic and reinforce a medical model of healthcare with the individual as passive receivers of care rather than active participants in their own health and care. Added to this are complex and dynamic governance and accountability structures, where Local Authority, NHS bodies and other regulatory agencies operate alongside each other, but frequently in an unaligned way. (Barnes et al 2008) which can make even simple reform difficult to achieve.

Since devolution in 1997, Wales has progressively engaged in a series of policies which has created a divergence in the way that health and social care services are both commissioned and delivered in comparison to that seen in England. The major difference being that unlike in England, the internal market in the Welsh health service has been dismantled, with the development of all local NHS services now overseen by seven local integrated health boards which aim to build a more collaborative and integrated approach encouraging cooperation and collaboration rather than competition, in delivering public services (WAG 2009).

In response to these challenges and the Welsh policy context, the Bevan Commission was asked to consider how Wales might best achieve sustainable and high quality health and care. The Commission outlined its approach and thinking through Prudent Healthcare defined as 'healthcare which is conceived, managed and delivered in a cautious and wise way characterised by forethought, vigilance and careful budgeting which achieves tangible

benefits and quality outcomes for patients'. This was based upon four prudent healthcare principles, outlined in its Prudent Healthcare Principles paper (Bevan Commission 2015);

- Principle 1 Achieve health and well being with the public, patients and professionals as equal partners through co-production
- Principle 2 Care for those with the greatest health need first, making the most effective use of all skills and resources
- Principle 3 Do only what is needed, no more, no less and do no harm
- Principle 4 Reduce inappropriate variation using evidence based practices consistently and transparently.

Applying the prudent principles in practice will help address the challenges facing health and healthcare in Wales by; focusing upon managing demand; engaging citizen participation and co-production; increasing efficiency of care; and ensuring less inappropriate interventions are used. To empower people to take greater responsibility for their own health and well being and engage them in the planning and delivery or care, we need to move away from the more traditional 'passive acceptance' and top down directed approach to one of 'proactive participation' where rights and responsibilities are also a key consideration .

Implicit in a prudent approach to health, is the need to redraw the relationship between citizen and the state, so that professionals and the public can work together as equal partners; co-producing new services that best fit their needs and empowering people to gain greater control over their own lives. Explicit within this is the need to now make this relationship change happen in reality.

What do we mean by the relationship between citizen and the state?

The relationship between the individual and the state relies on a compromise between, on the one hand the state having maximum authority while the individual having maximum liberty (Joshi 2012). 'Citizenship' describes this relationship and the need for citizens to understand governmental policy, the economy, laws, rights and responsibilities involved (Institute for Citizenship 2014).

It is becoming increasingly apparent that the more traditional models of service delivery do not help to alleviate social problems (Elvidge 2014) or many of the health problems that can result from them. There has been increased interest by governments and politicians in the concept of 'bottom up' ways of working, where people are more engaged in the process and have greater vested interest and control, particularly over the way that services are designed, developed and delivered. A key part of redrawing the relationship between the citizen and the state in a health context will be to effectively engage the public, patients and carers, in identifying and owning the problems and in helping to find better solutions, redistributing the balance of power and sharing and managing the risks.

There are a wide range of terms and definitions used around patient and public engagement, many of which overlap with the definition of participation. The main difference appears to be that engagement is to attract someone's interest or attention, to involve them and establish a connection, while participation is simply the action of taking part. There can be engagement without participation and vice versa. If aligned however, where engagement leads to participation, the synergy has the potential for considerable change. Co-production has been defined as 'a means of delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours' (New Economics Foundation 2011).

Over time we have seen a gradual shift in responsibility where medical care is increasingly seen as the solution, with a growing assumption that the state will make things right. This leads to a greater imbalance between the

responsibility of state and the individual with increasing emphasis on directing and determining healthcare by those employed within the system. This has resulted in disempowering people, greater dependency and in some cases even causing harm.

Rather than perpetuating a passive approach to health where the individual acts only as a receiver in their relationship with the state, increasing engagement and participation acts as a way of empowering the individual (Figure 1) from cooperation and collaboration to co-production and gradually leading to more equal partnerships between the public, patients and healthcare professionals. This continuum potentially redraws the balance of power and the risk relationship between citizens, professionals and the state.

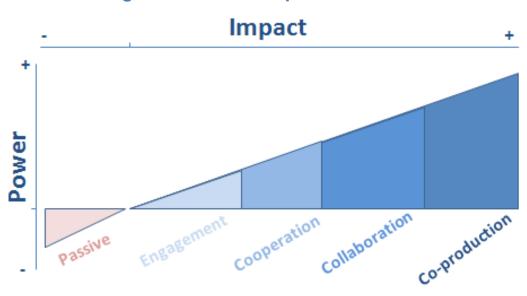


Figure 1: Power - Impact Continuum

Why do we need to redraw the relationship with patients and the public?

- The current system is not working effectively or equitably for all: Although the welfare state has served us well, it fails to meet the needs of many and particularly some disadvantaged minorities. There is evidence to suggest that wellbeing can be best achieved through non medical solutions for example through interaction with friends and family as well as through a new 'enabling state', where individuals and communities are supported and empowered (Elvidge 2014).
- Supporting prudent healthcare principles: Redrawing the relationship with patients and the public is implicit within the principles in supporting the delivery of prudent healthcare in practice. The principles identify the need to develop new, more equal working relationships between patients, the public and professionals; working together as equals and making the most effective use of all skills and resources, particularly those of patients and the public, to deliver better health and wellbeing.
- Improving service performance: Utilising the expertise and experience of those using the services is a powerful tool and rich resource in improving the efficiency of services as well as ensuring that they are best aligned to the needs of patients.
- Designing and delivering better public services: Design and delivery of services will become more customer
 focused, recognising diversity and designing services to best fit needs. It will also help identify other solutions
 that could be provided by others whether patients, carers or the third sector. The solution may not always be
 through a public funded service.
- Improving trust in public services: The process of engaging people in service development becomes more transparent, with organisational commitment to put suggestions into action, proving to the citizen that their input has been valuable and used constructively.

- Changing culture: Engaging citizens alongside professionals will help develop and support a greater understanding of the issues involved, the needs and help generate solutions and support the changes that may be necessary to the ways in which public services and staff currently operate. It should also foster an environment of openness, trust and commitment.
- Increasing sustainability and managing costs: The current model of health and social care delivery is
 unsustainable and must change. Advances in new technologies coupled with public expectations of services
 and the increasing projections of demand will result in increased expenditure. A greater involvement with,
 and shared responsibility for, the way in which services are designed and delivered will help to mange and
 prioritise expectations with future demand.
- Supporting patient care: There is evidence to suggest that people derive benefit from the support of others, especially those who have had similar personal experiences (Elvidge 2014). Volunteering has also been shown to have a positive impact upon well being of those who volunteer and in supporting professionals to improve patient care.
- **Reducing re-admissions:** Evidence suggests that the role of the public in supporting vulnerable patients could help reduce re-admissions (Jones 2004).
- **Technology** will inevitably help redistribute the balance of power whereby access to information, other tools and resources will enable and empower the patient to take greater control over their own health and care.
- **Greater Value** for both the patient and the professional in having conversations which lead to better outcomes for the individual and their families through choices which are most fitting to the needs of the patient and which may involve less invasive or non medical interventions.

The responsibility of co-ownership

With increased involvement and power comes greater accountability and shared responsibly which will need to be fully considered and addressed by all. We can learn from other devolved nations in the UK such as Scotland which have explicitly set out notions of mutuality, reinforcing the public ownership of the NHS where 'the people of Scotland (are) not just consumers - with only rights - but as owners with both rights and responsibilities' (Scottish Government 2007).

International examples of shared ownership exist such as the relationship-based, customer-owned Nuka System of Care. This has outperformed many known health care systems and its customer-owners recognize that future generations of their families will continue to own, manage and benefit from these services (Gotleib 2013). It also recognises that to achieve this has taken considerable time and effort. However with such ownership, comes a sense of shared responsibility and achievement for the health care system's success. Wales must look more carefully at how it can apply the learning from the Nuka. In particular the following four aspects should provide a useful guide:

- 1. Identifying opportunities to strengthen patient and public engagement and accountability at local and national levels.
- 2. Finding ways to give the patient's voice more weight: centrally, in acute and primary care discussions about services.
- 3. Using community health councils more effectively to involve people in planning, delivery and accountability of health services.
- 4. Engaging the communities and patients in service design and delivery and securing ownership as customer-owners.

Where are we now?

There is a growing consensus that individuals need to take greater control of, and responsibility for, their own health and well being. Evidence suggests that people want more control of their lives to maintain and improve

wellbeing and independence (Hairon 2008). The Wanless Report(2002) argued that to address the challenges in health, patients must become independent agents, fully engaged in their own health and healthcare and in 2009 the NHS Constitution was updated to include a set of responsibilities for patients (NHS 2013) (see also Coulter et al 2008; Higgs 2005; King's Fund 2015).

Whilst some progress has been made by Health Boards and Trusts across Wales to place greater emphasis on public engagement, there appears to be little evidence that this empowerment of individuals is either being prioritised or delivered at scale or pace that would have the capacity to overcome many of the issues facing service delivery already outlined. We are not seeing public and patient engagement and participation taken seriously enough as a core function and therefore to the levels necessary to have a significant impact. Achieving this is complex and requires strong leadership and the cooperation of both professionals and the public if it is to succeed.

How much of this is down to individual attitudes is unclear but studies of health perceptions (PwC 2010) show that whilst 81% of respondents thought that individuals should be responsible for getting fit, 94% believe that national or local government or public service providers should be mainly responsible for providing healthcare. However, shifting this attitude into action has not yet been achieved. Another barrier is the perception gap, where people rate public services locally as better than services that are run nationally, suggesting that the public do not associate local experiences with national political decisions (2020 Public Services Trust 2010).

There is also the important consideration that in theory, the public may want to have more say over services, but in practice few actually get involved (Public Services Trust 2010). It is often only in a crisis situation such as the threat of hospital closures that mobilises large scale public involvement. The challenge will be to identify how best we can encourage, whether through social media, PR campaigns or other means, the public to be motivated to give their time and become actively involved. Ultimately to recognise their ownership of their NHS in Wales.

Where do we want to be?

The concept of an 'adult to adult' relationship model for redrawing the relationship between the citizen and the state (Public Services Trust 2010) recognises that whilst everyone may not want a significant role in development or delivery of public services, the public should be encouraged to take responsibility and to help inform and change attitudes and behaviours to support public service. This can be helped through a number of strategies utilising existing social networks and digital technology, incentives and tools to support the state taking a more supportive role, tailoring levels of engagement and involvement to the individual.

The Wellbeing of Future Generations (Wales) Bill (Welsh Government 2015) recognises that to give future generations a good quality of life we must work together to tackle the challenges of today and tomorrow to improve the social, economic, environmental and cultural well-being of Wales. This will involve overcoming many of the issues we currently face (summarised in Figure 2).

We need a real commitment to concerted action and a co-ordinated response by both those using services and providing them to achieve real change in the relationship between citizens and the state. Patients, carers, the public and professionals will all need to recognise and sign up to this with access to the relevant training, tools and skills to effectively work as equal partners. This will require strong leadership at all levels throughout the organisation and the recognition that this will lead to better outcomes for patients based upon what they need not what the services have available.

Figure 2: Where do we want to be?

Now	Future
Unaware & not responsible	Awareness and responsible use of health resources
Passive acceptance	Active participation
Health care receivers	Co producing health and health services as equal partners with healthcare professionals
High levels of chronic disease and long term conditions	Reduced burden of avoidable disease and mortality
Deprivation driven variations in health; e.g. life expectancy; obesity; cancer incidence; and emergency admissions	Greater equity and reduced health variation
Inefficient use of skills and resources	Prudent use of all skills, assets and resources
Risk averse culture	Embrace managed risk and uncertainty
Low levels of health literacy	Supported and improved health literacy

Co-production enables citizens and professionals to share power and work together in equal partnership, to create opportunities for people to access support when they need it and to contribute to social change. Co-production will truly be in place when we can see the 5 co-production principles enacted in normal practice:

- 1. Value all participants & take an asset-based approach.
- 2. Develop peer-support networks & social capital.
- 3. Focus on personal outcomes what matters to the individual.
- 4. Build relationships of equality & reciprocity.
- 5. Work in partnership with the people who use our services, as catalysts for change.

Prudent Health Principle 1 states that we should; 'Achieve health and wellbeing with the public, patients and professionals as equal partners through co-production' (Bevan Commission 2015). This principle sets out three aims:

- 1. To avoid illness and treatment by keeping healthy through self-care and prevention interventions
- 2. For individuals to gain more control over their health and wellbeing by working with professionals to make joint decisions about care and treatment
- 3. For the public to support professionals to design and deliver new and better services through coproduction.

Prudent principle 2 identified the need to 'care for those with greatest need first, making the most effective use of all skills and resources' To deliver a prudent approach to health, all skills and resources should be used to best effect, including those of patients, the public and professionals. The public should be aware of their role, their rights and their responsibilities in supporting health and well being of themselves, for those around them and the wider community, whilst understanding and recognising the limitations of the healthcare system. Professionals should ensure that they have appropriate and evidence-based information and decision making tools available to become involved in decision making which best suit their needs.

Embedding Prudent Health Principles across Wales will achieve tangible benefits and quality outcomes for patients. It will help to redraw the relationship between the citizen and the state and through collective action

will fundamentally change the culture, professional and public views. For patients and the public to participate as equal partners, there must first be engagement, to energise and inspire people to want to deliver change. It will be necessary to act in an equal and reciprocal way by building people's confidence over time, ensuring that opportunities are created and that people are truly given agency.

How best to engage patients, carers and the public

For Prudent Healthcare to be embedded across Wales, the public must become co-producers of health and supported in becoming fully engaged in the process of improving and designing services. Professionals will also need to recognise the importance of this and develop their own skills and techniques to support patient engagement. This in turn will help patients become proactive in keeping healthy through better self-care, work in equal partnership to make decisions that best suit their particular needs about their own personal care and treatment and support professionals in designing and developing services (Bower et al 2009).

The following, while not a conclusive list, provide a platform from which further developments and local action can help translate this into action. It will need concerted action across all aspects, not just one or two, to achieve a significant change in balancing the relationship supporting a more prudent approach to health:

- 1. Capture the passion that people feel for the NHS. People highly value the NHS (King's Fund 2014) and in Wales feel particularly passionate towards its origins and its core principles of comprehensive, widely accessibility and free at the point of delivery. We must find ways to capture this passion and protectiveness for our National Health Service, in a positive and constructive way, whilst also providing an evidence-based understanding of the problems.
- 2. We need to put Prudent Health on the public agenda. To do this we should deliver a national campaign to remind the public that the NHS belongs to us all, is paid for by us all and that we all have the opportunity to get involved and improve services. Examples include:
 - Introducing a monthly day for health, where the public can share ideas and thoughts about the health service to stimulate debate, discussion and action. NHS Change Day is an example of how this can be achieved with professionals.
 - Using social networks to create a wider social movement for change.
 - Engaging the public in developing a public charter that sets out clearly the expectations of the public and the NHS and creates discussion and debate.
 - Spending time understanding how and where the public have discussions about health. We should then
 use these channels to deliver a national campaign and a 'national conversation' e.g. through Facebook
 Twitter and other digital opportunities.
 - Engaging the media, with the public, to develop a Prudent Health campaign.
- 3. Fish where the fish are. We must consider the channels that are being used by patients and the public when discussing health, and become active in these channels. People will use a wide range of channels when looking for health information and support, including online, telephone, face-to-face and support groups. Increasingly, patients are using mobile devices and apps to monitor and manage their health. We must understand the journey that the person takes from awareness of the problem to advocacy and participation to be able to provide tailored and specific information for that individual, across all of these channels.
- **4. Consider the demographic.** Use targeted messaging and content in a multichannel approach to ensure that there is wide coverage of consistent and specific messaging, whilst also considering how we can ensure we address inequality. Targeting messages and engaging people at schools, colleges and through third sector organisations.
- 5. Shared decision making as an integral part of professional practice. Decision making should involve patients and the public in all aspects of health (King's Fund 2014). However, this relies on patients having the

confidence to play an active role. It also requires skilled healthcare professionals who are able to use shared decision making tools and approaches (Health Foundation 2014). All professionals will require training and support to ensure that they are fully participating in shared decision making. This should be included at all levels and across a range of training opportunities whether as part of undergraduate, post graduate/ CPD or induction training and held accountable through annual reviews.

- **6. Readdress the message "what can I do for you?"** We should be moving away from a 'doctor knows best attitude' towards a shared and equal partnership in determining treatment and care decisions, "what can we do together to address the problem that you have?" Professionals will need to be supported in having these discussions with patients through training.
- 7. Use the influence of family and friends. Friends and family have one of the biggest influences on a person's health (Edelman Health Barometer, 2011). An example of this is vaccination (Takahashi *et al*, 2002). Social interaction is therefore key to spreading good health. We should utilise social networks (both virtual and real) to begin peer-to-peer driven engagement in health and healthcare.
- **8. Create an open dialogue.** There should be easy flow of dialogue between the public and professionals, from front line staff to policy leaders. The third sector will also have a key role to play in supporting this and wider engagement of specific groups. Mechanisms such as the Bevan Advocates will also help support this open dialogue and an opportunity to contribute to more innovative solutions.
- 9. Education and Training Tools and support for patients and professionals. Ensure a comprehensive programme of education and training in both the current workforce and those currently in training as an integral part of CPD, induction and core training. Make the most of the tools and training already developed and proven to be successful and address the gaps in need, making them appropriate and easily accessible to all. Where there are gaps make sure tools and training programmes to support this are developed for example a resource pack to support the discussion.
- **10. Build on our strengths** Schemes which already aim to develop and build confidence and skills of patients to self manage their own health conditions such as the Education for Patients Programme should be further developed and expanded. Where appropriate they should be updated and adapted to meet the needs of a range of patients and to fully engage volunteer patient support.
- **11. Measures of success.** Health Boards should be held to account by monitoring and measuring the impact of engagement with the public, particularly those in greatest need.
- **12. Reward and Recognition.** There should be recognition when patients, the public and professionals work together to co-produce new services or solutions that are prudent. This should be through the media as well as through local events and award ceremonies.
- **13. Using big data.** We are currently in a technology and information age where citizens are considered as data subjects (Tucker 2012). The role of data can redefine the relationship between the citizen and the state; provided that we collect, analyse and exploit data effectively (Manocha 2011). We should ensure that privacy is not breached and that personal information is not shared inappropriately (Hogge 2007).
- **14. Community Health Councils.** CHC's should build on their statutory position as independent advocates for the patients and act as enablers for coproduction. They should play a key and active role in supporting the redrawing of the relationship and the wider engagement of local communities in the local health and care services.

Conclusions

There is a long standing ambition by Welsh Ministers of creating world-class health and social services in Wales, 'services best suited to Wales but comparable with the best anywhere' (Welsh Government 2011). To achieve this against the backdrop of increasing demand and austerity will require a very different approach and culture than is evident to date. This is a considerable challenge and will require strong collective leadership and commitment by

all those providing services as well as those using services, to make a real difference and achieve a more prudent approach to health across Wales.

Concerted effort, with targeted training, interventions and media/ PR campaigns to reinforce this message, will help to raise awareness and create wider conversations around prudent health. Actively supporting innovation, trying out and testing new ways to engage with others and then sharing and adopting good practice consistently across Wales will support this further.

This can only be done if it is seen as an important priority by everyone; the public, patients and professionals; and by the national and local organisations responsible for providing and monitoring health and care services across Wales, who should all be held to account. There is a need to use the skills of professionals and the public better to help find solutions together, openly addressing the issues of rights and responsibilities and the sharing of power alongside that of sharing and managing risk. This will be an essential prerequisite for the future sustainability of health and well being in Wales. We need to change the balance of power between people and the state for as Aneurin Bevan states "The purpose of getting power is to be able to give it away"."

Whilst we may not have all the answers as to how best to achieve this, there is a need to start somewhere, stimulating people in conversations around this and in finding new ideas and solutions with them, sharing and learning from each other along the way. Doing so will help not only develop better services, it will also help develop a more trusting and rebalanced relationship with the very people we are trying to help.

Recommendations

Such changes will take time to be achieved, but it is essential to start to make changes now. It will be vital that leaders set the scene, act to embed the shift of power and drive the change in culture. The change relates to both the relationship with the individual patient or carer, staff at all levels and with the wider public. The Bevan Commission therefore recommends that;

- 1. Co-production principles are embedded into every aspect of the work of health and social care at national and local levels as a fundamental prerequisite of all working practices, aligning resources, targets and incentives accordingly.
- 2. Training and support for health and care professionals at all levels will need to be revised to support the change of emphasis and shift of power. Professional bodies, training and education organisations, audit and inspection bodies will all need to reflect this change. We recommend that all practitioners in health and social care use the phrase 'what can we do together' in place of 'what can I do for you?'
- 3. A national conversation and campaign are initiated to ensure everyone understands and are able to fully participate, drawing from evidence in health literacy, behaviour change and social movements for change.
- 4. Key organisations in Wales such as; Community Health Councils; Wales Audit Office; Healthcare Inspectorate Wales; Care and Social Services Inspectorate Wales; and professional representative bodies should all take full account of their role and responsibility in redrawing the relationship between the citizen and the state.

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¹ This quote widely attributed to Bevan was made during a speech and is referenced within Michael Foots biography of Bevan.

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