



# THE LEARNED SOCIETY OF WALES CYMDEITHAS DDYSGEDIG CYMRU

THE NATIONAL ACADEMY – CELEBRATING SCHOLARSHIP AND SERVING THE NATION  
YR ACADEMI GENEDLAETHOL – YN DATHLU YSGOLHEICTOD A GWASANAETHU'R GENEDL

## Submission to the Parliamentary Review of Health and Social Care in Wales

**The Learned Society of Wales (LSW) is an independent, all-Wales, self-governing, pan-discipline educational charity that was established back in 2010. As Wales's first National Academy of science and letters, the Learned Society of Wales, like similar societies in Ireland and Scotland, brings together the most successful and talented Fellows connected with Wales, for the shared purpose and common good of advancing and promoting excellence in all scholarly disciplines across Wales.**

**A.** The Learned Society of Wales welcomes the establishment of a Parliamentary Review into the long-term future of health and social care in Wales, part of the key commitment in the Programme for Government launched in September 2016.

Despite Wales's visionary contribution over the last century to health care provision, on contemporary key indicators it still lags behind England. The purpose of this document is to put before the Welsh Parliamentary Review three proposals that we believe will be of fundamental importance to making step improvements in the quality of health and social care in Wales. The first is the vital necessity to recapture the impetus for prevention using sustainable development principles applied across all policy domains. The second is to recognise and use contemporary understanding of complexity to redesign care pathways. The third is to recognise and foster the role of caring communities and cultural competence in the health and social care system.

The Welsh contribution to the advancement of Health and Social Care has been distinctive and fundamental. Lloyd George and CFG Masterman introduced the National Insurance Scheme in 1911, and in 1948 Aneurin Bevan introduced the National Health Service - the "Tredegarisation" of the whole country - to provide universal provision of health care.

In 1911 the philanthropist David Davies set up the Welsh National Memorial Association in memory of King Edward VII, to combat the scourge of tuberculosis in Wales. From then Wales was prominent in efforts to prevent tuberculosis and the MRC Research Units that were set up in Cardiff made significant contributions both to tuberculosis and to other industrial lung diseases, in particular, pneumoconiosis. In 1917, Lady Emily Talbot endowed the first full time public health chair to be set within an Institute that would "usher in a new type of medicine - Preventive Medicine".

In more recent times, the revolution in Evidence Based Medicine can be traced to the original thinking of Archie Cochrane in Cardiff in 1972 and then the work of Sir Ian Chalmers who established the worldwide Cochrane Collaboration, which is credited with preventing millions of deaths and disabilities. In Primary Care the now world famous Inverse Care Law was the observation of Julian Tudor Hart working in Glyncorrwg.

In 1984, the Secretary of State for Wales established a Health Policy Board and an NHS Directorate in the Welsh Office. Considerable advances were made in establishing a strategic intent and direction for the NHS including advances in the field of health promotion; Heartbeat Wales was renowned internationally for engaging with the media and the public. From the outset, the NHS Directorate in Wales identified clear values and principles that may now seem the norm but at that time were ground breaking - the aims of health gain and improvement in the quality of life, the focus on health and wellbeing outcomes, and patient centred care: "Best practice in Wales even informed the 1996 WHO Ljubljana Charter on reforming healthcare, which reflects aspects of Wales's Strategic Intent and Direction in advocating that health care systems should be:

- Driven by values of human dignity, equity, solidarity and professional ethics
- Targeted at protecting and promoting health
- Centred on people, allowing citizens to influence health services and take responsibility for their own health
- Focused on quality, including cost effectiveness
- Based on sustainable finance to allow universal coverage and equitable access
- Oriented towards primary care.

During this period, NHS Wales pioneered an integrated all-Wales strategy emphasising health improvement, and introduced the principle of measurable outcomes to health policies and management"<sup>1</sup>.

However, as so often in the past, the farsighted thinking coming out of Wales was not translated into implementation strategies that delivered sustainable and equitable improvement in the health of the people of Wales. Despite the vision of Lloyd George and Aneurin Bevan, the Inverse Care Law noted by Tudor Hart persists within the heartlands of Wales<sup>2</sup>; the vision for a new sort of medicine that focused on prevention was soon swallowed up by the more powerful clinical services model; the advances in health promotion were cut short by political decisions of Westminster politicians.

Today, Wales still lags behind England in key health and wellbeing measures, and it is also reported in the media that the Welsh public is less satisfied with the NHS and is significantly less confident than England and Scotland in the ability of the NHS to provide a high standard of care<sup>3</sup>. Therefore the Learned Society of Wales welcomes the opportunity to contribute to this review with a view to the Welsh Government setting out a

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<sup>1</sup> Pamela Michael, Public Health in Wales (1800-2000) A brief history, Welsh Government, 2008

<sup>2</sup> The Inverse Care Law Programme, <http://www.wales.nhs.uk/sitesplus/888/news/40984>

<sup>3</sup> <https://yougov.co.uk/news/2015/02/04/welsh-confidence-nhs-significantly-lower-england/>

distinctive Welsh vision and ambitious goals for translating farsighted evidence-based thinking into real and sustainable generational improvements in the health and wellbeing of the people of Wales. We note that the Welsh Government now has an obligation under the Wellbeing of Future Generations (Wales) 2015 to report on progress to these goals.

Globally, all health care systems are under pressure because of the impact of increasing populations and increased longevity,<sup>4</sup> resulting in more people with multiple complex needs that span health and social care. The Learned Society for Wales agrees that the future funding model for health and social care in Wales is critical for any sustainable system that aspires to deliver continuous improvements in wellbeing and health expected of advanced economies, given there is mounting evidence of “failures in the health and social care system”<sup>5</sup>. We do not here seek to reiterate the points made by the House of Lords report on the “Long Term Sustainability of the NHS and Adult Social Care”<sup>6</sup>, but instead draw the attention of the Welsh Parliamentary Review to an important aspect of funding identified in the OECD’s forthcoming report on “Tackling Wasteful Spending on Health”<sup>7</sup>. The OECD observes that “around one-fifth of health expenditure makes no or minimal contribution to good health outcomes”. Not only so but data from many countries including Wales show that about one in ten patients are harmed by hospital admission<sup>8</sup>.

We are also concerned that the public has growing and sometimes unrealistic expectations of the ability of health systems to stave off the inevitability of mortality, which in turn drives health and social care services to focus on “rescue reactions ” rather than ensuring the quality of life and “a good death”. We therefore advocate that any future system changes to health and social care in Wales must take into account not only the levels of future funding, but also the Prudent Health Care principles embraced by Welsh Government that acknowledge the importance of reduction of waste. We also argue that funding should be linked to outcomes that are measured in terms of patient acceptability of services, health gain, and improvements in or safeguarding of the quality of life.

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<sup>4</sup> We also recognise the significant contribution older people make to the economy through caregiving as well as volunteering.

<sup>5</sup> in 2015 UK population mortality rates increased. Hiam L, Dorling D, Harrison D, McKee M. What caused the spike in mortality in England and Wales in January 2015?

*J R Soc Med.* 2017 Apr;110(4):131-137. doi: 10.1177/0141076817693600. Epub 2017 Feb 16.

<sup>6</sup> <https://www.publications.parliament.uk/pa/ld201617/ldselect/ldnhssus/151/151.pdf>

<sup>7</sup> <http://www.oecd.org/health/tackling-wasteful-spending-on-health-9789264266414-en.htm>

<sup>8</sup> Sharon Mayor, Elizabeth Baines, Charles Vincent, Annette Lankshear, Adrian Edwards, Mansel Aylward, Helen Hogan, Paul Harper, Jan Davies, Ameet Mamtora, Emily Brockbank, and Jonathon Gray. Measuring harm and informing quality improvement in the Welsh NHS: the longitudinal Welsh national adverse events study, Health Services and Delivery Research, No. 5.9, NIHR Journals Library; 2017 Feb.

## B. The Priority for Prevention

The urgent need to focus on prevention was identified by Wanless in the early 2000s<sup>9</sup>. This report identified trends that would ultimately put enormous pressure on the sustainability of the NHS. Unfortunately, whilst his report was greatly admired the health system did not move beyond dealing with short-term demands. The consequence has been that the most pessimistic scenario Wanless put forward has turned out to be reality - *“no change in the level of public engagement. Life expectancy rises, but by the smallest amount ... The health status of the population is constant or deteriorates. The health service is relatively unresponsive with low rates of technology uptake and low productivity”*. The Welsh Government’s review offers a new opportunity to redress this glaring deficiency.

Since 1990, the Global Burden of Diseases Study has tracked incidence, prevalence, mortality, healthy life expectancy and disability adjusted life years for most countries in the world and has reported large increases in life expectancy but no evidence for the expected compression of morbidity. The study concluded, “Health is improving globally, but this means more populations are spending more time with functional health loss, an absolute expansion of morbidity”<sup>10</sup>.

Across the UK the pressure is reflected in regular headlines of a dramatic rise in unscheduled care, long waiting times in Emergency Departments, bed crises through the winter, cancellation of appointments, overloaded services, and extended hospital stays because of lack of social care places. As the population ages the demand also increases for elective services, outstripping supply and consequent extended waiting times. There is a tendency to cancel elective operations to deal with emergency pressures, storing up greater long-term problems.

The following figure, produced by the Prudent Healthcare Intelligence Hub, illustrate some of the stark challenges facing Wales.

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<sup>9</sup> <http://www.wales.nhs.uk/documents/wanless-review-e.pdf>

<sup>10</sup> Global Burden of Disease, Mortality and Causes of Death Collaborators. Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980–2015: a systematic analysis for the Global Burden of Disease Study 2015. *The Lancet* 2015; 388:1459-1544. [http://dx.doi.org/10.1016/S0140-6736\(16\)31012-1](http://dx.doi.org/10.1016/S0140-6736(16)31012-1) (published 08/10/16). [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(16\)31012-1/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(16)31012-1/fulltext)

**Figure 1: Percent of people in Wales receiving GP prescription for 0-8 or more disease categories by age group, 2015 data from the Secure Anonymised Information Linkage Databank**

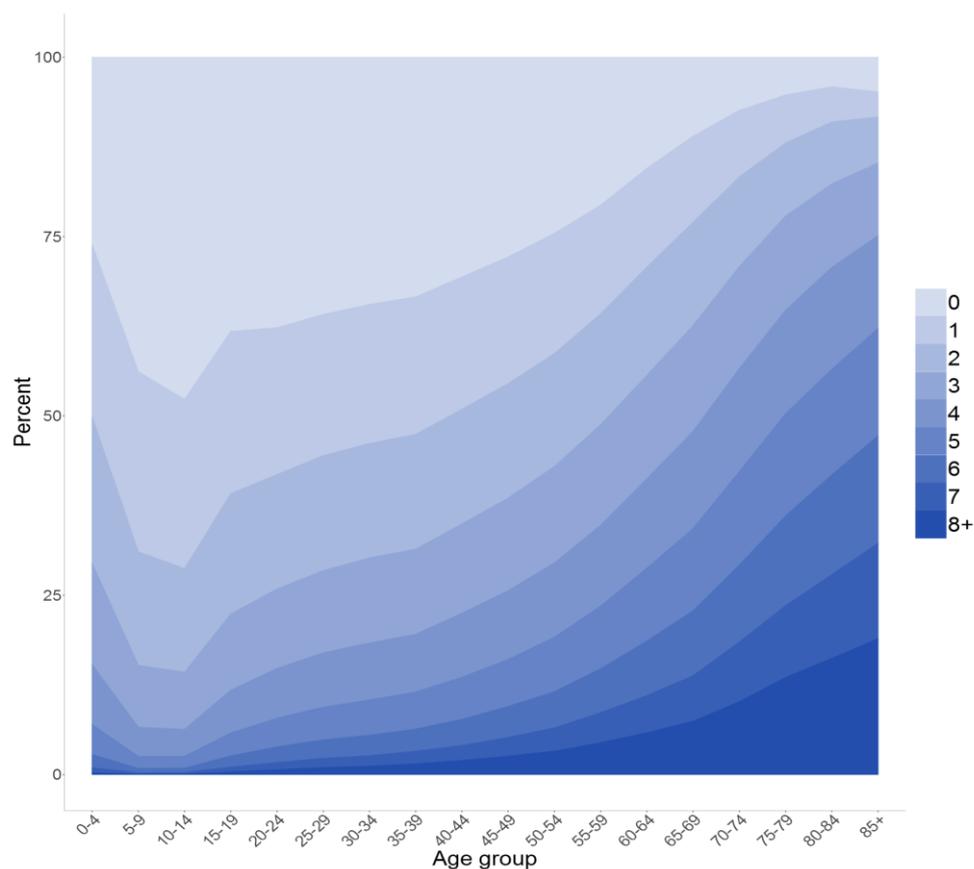


Figure 1

At no age is less than half the population prescription free. By middle age, more than half the population are prescribed treatments for two or more conditions that affect different organs or parts of the body, with a quarter of those aged 60 and over having at least five different conditions.

In addition to these universal consequences of ageing societies, the relatively high prevalence of underlying poor risk factors in Wales means that NHS Wales has a bigger hill to climb in producing good outcomes of treatment and care. The most recent data for avoidable deaths shows that for males the rate was 300.4 per 100,000 population compared with 273.3 per 100,000 in England<sup>11</sup>. Similarly, rates for females were 183.6 per 100,000 in Wales compared with 167.6 per 100,000 in England. The greatest burden is borne by the lowest income communities. The reasons are due mainly to the greater prevalence of the determinants of poor health, which are related to low income, high unemployment, unhealthy lifestyles (e.g. alcohol, smoking, lack of exercise, poor diet) and poor nurturing (e.g. severe adverse childhood experiences). These factors begin to have an effect even before a child is born and often determines the course for a lifetime of disadvantage. The consequences can be seen early in life - from low birth weight and prematurity to lower

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<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/causesofdeath/bulletins/avoidablemortalityinenglandandwales/2014>

learning attainment in school, from adverse events in childhood to antisocial behaviour and common mental disorders in young adults. Furthermore, patterns of behaviour learned in childhood such as smoking, alcohol consumption poor diet and lack of exercise lead in later life to increased risk of cancer and higher prevalence of diabetes, heart disease, stroke and dementia.

**Consequently, we strongly support the Governments focus on Early Years and Childhood within a life course approach to prevention.**

However, if prevention is to be a meaningful and sustainable strategy it must be much more than raising awareness and the proffering of health advice. “Attempts to change behaviour are often based upon ‘common sense’, flawed assumptions about how people behave and unrealistically optimistic interpretations of limited evidence. For example, strategies relying on provision of information or guidelines alone seldom result in significant change but are often used despite repeated failures of this approach”<sup>12</sup>. On the other hand, there is considerable evidence that policies implemented by Government at the population level such as controlling the price and availability and advertising of tobacco and alcohol can have major health benefits.

We also draw the panel’s attention to the value of a broad view of prevention. The 2017 Campaign for Social Sciences Report also went on to address secondary and tertiary prevention, saying, “More importantly for healthcare systems across the world is the improvement of population health, primarily through the prevention of ill-health, but also through shifting presentation, diagnosis and treatment further upstream, so that healthy lives are prolonged and healthcare becomes more than simply a patch and repair service for acute and chronic conditions”.

The [UK Academy of Medical Sciences](#) has also recently reported on “Improving the Health of the Public by 2040”.<sup>13</sup> The Report concluded “there remains much we do not know about the complex array of interlinking factors that influence the health of the public, and about how to prevent and solve the many health challenges we face as a population, including obesity, diabetes, dementia, depression, cancer and persisting and emerging infections. We do not yet have a robust understanding of the long-term impacts of many of the wider drivers of health that cut across local, national and global environments, from political and economic change to technological development and demographic shifts.”

The Academy recommended six key developments to address these issues:

- Rebalancing and enhancing the coordination of research
- Harnessing new technologies and the digital revolution
- Developing trans-disciplinary research capacity
- Aligning perspectives and approaches between public health and clinical practices

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<sup>12</sup> The Health of People, How social sciences can improve health, Campaign for Social Sciences, 2017, Sage, London.

<sup>13</sup> <https://acmedsci.ac.uk/file-download/41399-5807581429f81.pdf>

- Working with all sectors of society
- Engaging globally.

We endorse these conclusions and encourage the Welsh Government to move away from overly simplistic approaches to prevention, building on the principle that health is a product potentially of collective government policies including policies on the economy, housing, the environment, sports, education and training and employment, as already recognised in the Welsh Government’s Sustainable Development vision. Indeed, social care and housing policies should be the bedrock of a preventative approach. Insufficient attention is currently given to these aspects in the prevention agenda. The Social Services (Wales) Act 2015 provides the legitimacy of a user focused, person centred model of care with its stress on personalisation, citizenship, engagement and a community based approach.

As a recent commissioned report on housing<sup>14</sup> states, “It makes good policy sense to get housing right for our ageing society”. Better quality and suitably located housing can make it possible for people to live at home for longer; it has the potential to create more resilient and connected communities and should be seen as a key component in delivering the vision set out in the Well-being of Future Generations (Wales) Act 2015. There is also great potential for some of the structures being established by the Act, particularly the Public Services Boards, to ensure that housing is integrated more fully into action being taken at the local level to achieve the well-being goals.

The LSW welcomes the growing appreciation of the relationship between ‘place’ and the health of populations, as highlighted in the House of Lords 2017 report on the Built Environment<sup>15</sup>. For example, in 2015, the Lancet published a report of its Commission jointly with the Rockefeller Commission on safeguarding human health in the anthropocene epoch<sup>16</sup>. The InterAction Council proposed that governments should consider engaging with their communities to adopt approaches of the sort exemplified in the Wellbeing of Future Generations Act (Wales) 2015. Policy propositions would include addressing the environmental roots of ill health, and integrating the prudent approach to health care with environmental care at local level.

We also draw the attention of the Review Panel to the work of the British Academy during 2016, which brought together academics and practitioners in the humanities and social sciences to review the contemporary notion of ‘place’ in policymaking. The key project findings were that the history, character and physical form of places make significant contributions to personal and societal wellbeing yet “we are largely place blind when we come to making policy often designing policies for health, education, social care,

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<sup>14</sup> <http://gov.wales/docs/desh/publications/170213-expert-group-final-report-en.pdf>

<sup>15</sup> <https://www.publications.parliament.uk/pa/ld201516/ldselect/ldbuilt/100/100.pdf>

<sup>16</sup> The InterAction Council held high level Expert group meetings in Wales. <http://interactioncouncil.org/new-realities-global-health-security>

employment, the economy and new infrastructures separately as if places were all the same<sup>17</sup>. These observations resonate in Wales where strong local identities seem to have a major influence on the public's perception of health and health services.

The conclusions of the British Academy project were that every community should begin its planning processes by identifying what in the locality matters to people and what constitutes its character and identity, its sense of place (in Welsh *Cynefin*). They say "place-based policy-making offers new possibilities to reconnect public policy with our lived experience and the places and relationships we care about; and as a result to deliver more meaningful and effective solutions". This perspective is supported by recent research in Wales where long term follow up of population cohorts has demonstrated that features of the economic, social and physical environments impact on population health. For example, alcohol harm is linked to pricing and density of outlets<sup>18</sup>, exercise and obesity is related to safe walking opportunities<sup>19</sup>, and mental health is related to green space<sup>20</sup>. Welsh data emphasize that social cohesion of communities are major factors in protecting mental health and providing resilience in times of community stress<sup>21</sup>. There is also increasing recognition internationally that environmental exposures to air pollution and particulates continue to have a major impact on morbidity and mortality<sup>22</sup>.

From these examples, it is evident that decision making across the full spectrum of government and local authority functions will have a major influence on the ability of the people of Wales to choose and sustain healthy living.

**Recommendation 1: Rediscover the emphasis on primary and secondary prevention of disease and co-production of health in a place-based policy setting that recognises that the wider social, cultural and environmental determinants of health and wellbeing.**

<sup>17</sup> <http://www.britac.ac.uk/where-we-live-now>

<sup>18</sup> Fone D, Morgan J, Fry R, Rodgers S, Orford S, Farewell D, Dunstan F, White J, Sivarajasingam V, Trefan L, Brennan I, Lees S, Shiode N, Weightman A, Wenster C, Lyons R. Change in alcohol outlet density and alcohol-related harm to population health (CHALICE): a comprehensive record-linked database study in Wales. *Public Health Res* 2016;4(3). <http://dx.doi.org/10.3310/phr04030>. (01/03/16).

<http://www.journalslibrary.nihr.ac.uk/phr/volume-4/issue-3#abstract>

<sup>19</sup> Sarkar C, Gallacher J, Webster C. Built environment configuration and change in body mass index: the Caerphilly Prospective Study (CaPS). *Health Place*. 2013 Jan;19:33-44. doi: 10.1016/j.healthplace.2012.10.001. Epub 2012 Oct 17.

<sup>20</sup> Gong Y, Gallacher J, Palmer S, Fone D. , Neighbourhood green space, physical function and participation in physical activities among elderly men: the Caerphilly Prospective study. *Int J Behav Nutr Phys Act*. 2014 Mar 19;11(1):40. doi: 10.1186/1479-5868-11-40.

<sup>21</sup> Fone D, White J, Farewell D, Kelly M, John G, Lloyd K, Williams G, Dunstan F. Effect of neighbourhood deprivation and social cohesion on mental health inequality: a multilevel population-based longitudinal study. *Psychol Med*. 2014 Aug;44(11):2449-60. doi: 10.1017/S0033291713003255. Epub 2014 Jan 22.

<sup>22</sup> <http://www.who.int/mediacentre/news/releases/2014/air-pollution/en/>

## C. Complexity

The multiplicity of interacting environmental, economic, social and cultural factors that conspire to influence health risk, health service utilisation and outcomes is enormously complex. In particular, there are important interfaces which are critical to acceptable, efficient and effective care. These include interfaces between:

- i. primary, secondary and tertiary health and social care. In many respects the legacy of the hospitals and services in Wales such as the quality of the infrastructure and the location of services is often no longer appropriate for 21<sup>st</sup> century care. For example, referral of elderly patients to distant centres for minor investigations and follow up procedures should be replaced by modern primary care centres that are linked to social services and voluntary agencies within local communities. For decades, governments across the UK have repeatedly acknowledged the importance of high quality modern general practice, but investment has actually moved in the opposite direction.
- ii. domains of health and wellbeing conditions that include frailty, serious mental ill-health and acute and chronic illnesses. The ever increasing subdividing of specialties within medical professions means that often a patient with multiple needs will be referred to multiple specialists in an uncoordinated and highly inefficient way that places enormous emotional and logistic burdens on patients and their families. The requirement to staff an increasing number of specialisms poses particular challenges for the sustainability of rural hospitals. Whilst some outcomes for relatively uncommon conditions are undoubtedly improved by care in specialist centres there is little evidence that this is the case for common chronic disorders. New pathways for investigation, treatment and care need to be designed that recognise the needs of patients with complex multiple morbidities. New digital solutions to streamline patient experience and assist patient navigation will be necessary.
- iii. Public expectations for ever improving access to local services and better outcomes and the reality of limited resources and sustainability. There is a need for brave and honest conversations between political and professional leaders and the public so that we all have a better understand of the constraints of sustainable services and the need for strategic changes if Wales is to catch up in health outcomes.

We recognise the immense difficulty leaders and managers of the NHS face in dealing with such challenges but we believe that NHS Wales and local authorities providing social care must embrace this complexity using new approaches. For example, in the USA the national Academy of Medicine has published “Vital Directions for Health and Health Care”<sup>23</sup>. This outlined some compelling opportunities and novel tools emerging to solve some of the systems challenges of ageing populations. A central message of the report is the importance of social, behavioural and environmental factors for people’s health through the life-course. New advances

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<sup>23</sup> Vital Directions of Health and Care –A National Academy of Medicine Initiative 2016-17.

offer breakthrough potential for greater precision in prevention, detection, and treatment of illness and disease. In particular the recognition of the value of continuous learning using real-world evidence has particular resonance for Wales. Health care must not only be safe and effective but must also take into account patient and family perspectives and circumstances, using modern technologies to support patient decision making within their own family and community contexts.

Another concept that may be of importance is “smart governance”, a term coined by Willke<sup>24</sup> and adopted by the WHO as a way of describing the major institutional adaptation observed in public and international organizations in the face of increasing inter-dependence and the need for collaboration across portfolio boundaries. Smart governance requires high level systems thinking and recognition that theories of complexity science are increasingly relevant to public policy. However, “there is little research on managing systems and relatively little is taught about it in our universities and institutions. It is a matter of growing importance that we begin to understand that systems thinking and leadership holds the key to many improvements we can make in health and health care”<sup>25</sup>.

In this regard it is noteworthy that one approach to complexity that has had international traction has Welsh roots. The Cynefin Framework<sup>26</sup> developed by David Snowden, Director of the IBM Cynefin Institute explores the relationship between people, experiences and context and draws on research into complex adaptive systems theory, cognitive science and other disciplines. The Cynefin Framework is also compatible with the aims of the British Academy’s project “Where We Live Now”. We suggest that serious consideration be given to urgently exploring the contribution of such approaches to meeting the challenge of 21st century health and social care.

Significant progress using systems approaches has been made in Wales drawing on the disciplines of Mathematics and Operational Research and Analytics helping healthcare decision-makers to better plan and redesign services for the future, ensuring they have the capacity to meet patient needs from strategic and operational perspectives.

Such approaches can for example help predict the effect that a demographic change or new clinical practice could have on a service in order to inform the redesign of primary, hospital and community services. They can assist with decisions of where to locate ambulances to maximise survival. They can improve personalised health care by using data on the outcomes of similar patients’ experiences; and they can support real-time scheduling of staff and operating room schedules in order to avoid unnecessary patient

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<sup>24</sup> Helmut Willke, *Smart Governance, Governing the global knowledge society*, University of Chicago Press, 2008.

<sup>25</sup> [http://www.euro.who.int/\\_data/assets/pdf\\_file/0005/257513/Smart-governance-for-health-and-well-being-the-evidence.pdf?ua=1](http://www.euro.who.int/_data/assets/pdf_file/0005/257513/Smart-governance-for-health-and-well-being-the-evidence.pdf?ua=1)

<sup>26</sup> Snowden, David J.; Boone, Mary E. (November 2007). "A Leader's Framework for Decision Making". *Harvard Business Review*, 69–76. PMID 18159787

cancellations. Partnerships between NHS Wales and academia have led to innovations including the Health Modelling Centre Cymru (School of Mathematic Cardiff University). The novel research and resulting impact led to a Times Higher Educational Award for “Outstanding Contribution to Innovation and Technology” (“Maths Saves Lives!”)<sup>27</sup>.

However, to truly exploit the potential of these types of new approaches for complexity, Wales needs to develop a more coordinated approach to data analytics and modelling, to prioritise the deployment of existing resources and to provide leadership to ensure that the skills and expertise involved are developed in a strategic and cohesive way. A prerequisite for such “real world learning” is to harness health and social care “big data” in a timely way.

Wales has provided international research leadership in health informatics but this must be embedded as routine practice within the NHS and across wider public services. The Farr Institute’s investment in the Prudent Healthcare Intelligence Hub is a good start. “The Health of People” Report referred to above has recommended that ‘implementation laboratories’ should be set up to drive forward innovation and improvements in health systems, and we agree that such a laboratory in Wales would be a major step forward. Wales is fortunate in having the capability - though not yet the capacity or engagement - to establish such an implementation laboratory through the Secure Anonymised Information Linkage (SAIL) system. SAIL is one of the world’s leading privacy protecting data linkage systems<sup>28</sup>, with modest core funding from Welsh Government, and the only system that supports detailed multi-sectoral evaluation studies through anonymization and linkage of data at individual and household level. It supports major RCUK funded research centres, such as the Farr Institute, DECIPHer centre for public health improvement research and the Administrative Data Research Centre Wales. These centres have enabled some of the world’s most complex and largest scale population health research to be conducted in Wales<sup>29</sup>.

NHS Wales must exploit these advances to streamline patient care pathways and therefore must become an intelligent user of these technologies. Real time analysis and feedback will allow “dashboards” for professionals to track the success of care pathways for specific population groups thereby allowing better evidence based participatory care decisions. Only by tracking activities and openly sharing outcomes will Wales see the benefits of investment in prudent health care. Furthermore, it is imperative to understand that unless multiple outcomes are evaluated the net effect of apparently logical interventions in complex

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<sup>27</sup> <http://www.cardiff.ac.uk/news/view/105269-maths-saves-lives!-healthcare-modellers-win-innovation-award>

<sup>28</sup> Lyons RA, Jones KH, John G, Brooks CJ, Verplancke JP, Ford DV, Brown G, Leake K. The SAIL databank: linking multiple health and social care datasets. BMC Med Inform Decis Mak. 2009 Jan 16;9:3. <http://www.biomedcentral.com/1472-6947/9/3>

<sup>29</sup> Littlecott H, Moore G, Moore L, Lyons RA, Murphy S. Association between breakfast consumption and educational outcomes in 9-11year old children. Public Health Nutrition 2015 doi:10.1017/S1368980015002669. (published online 28/09/15)

settings may be neutral or even negative<sup>30</sup>. We are aware of several evaluations that will shortly be published which also show unintended consequences. Millions of pounds would continue to be wasted on counter-productive interventions if it were not for such evaluations. However, very few interventions and service developments are thoroughly investigated. Evaluation and continuous quality improvement activities are not an academic luxury but need to be embedded in all developments if efficiency and effectiveness are truly of concern to NHS leaders and policy makers.

**Recommendation 2: Develop the capacity to design, implement and evaluate models of care that are systems based, recognising the complexity of care pathways but beginning with highest quality primary care so that patients follow the most effective pathways to improve outcomes.**

Implicit in what we have said is that the performance of an outcomes focused health system must be open and transparent to the public. Without up to date outcome measures that truly reflect the quality of services within specific local settings reported openly and regularly, neither the public nor the clinical professions will be able to trust or make real world evidence-based choices. Better outcomes information is also a prerequisite for better self-management of disorders by “expert patients” and this in turn should reduce pressure on NHS services. The NHS needs to speed up the implementation of cross-sector electronic records that are available to patients as well as NHS staff, if it wishes to see progress in this area.

**Recommendation 3: Make the most of advances in information systems and data in Wales so that the public and the providers of Health Care can continuously monitor interventions and outcomes in real time and thereby empower patients and professionals to make the best decisions.**

## **D. Capacity and Competence of staff**

We recognise that there is growing concern about morale amongst NHS professionals and managers. NHS Wales faces serious problems in providing the highest levels of skilled staff across the whole of Wales. Especially, we recognise that recruitment and retention in rural areas further away from medical schools is a serious problem. The understandable reliance on agency staff is hugely expensive and leads to criticism from politicians and the media. In particular, there is a major problem in primary care. The gap between service possibilities and public expectations will therefore widen and could become a major crisis. We also note the growing concern from doctors that too much time is taken up by low-value appraisal systems that do not root out underperforming doctors, while taking significant time away from patient contact. Of particular

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<sup>30</sup>For example, the implementation of logical advice from the UK Government Committee on the Medical Aspects of Air Pollution to implement warning systems with the intention of reducing illness and consequent pressures on the NHS, when evaluated through data linkage, was shown to have the opposite effect.

concern in the way in which the loss of clinical “firms” and the introduction of shift working and working time directives has created major handover problems that undermine true continuity of care and undermine the support available to junior staff and the opportunity for their further training.

However, some of the important current challenges are not essentially about resource constraints although affected by increasing demands on the time of staff. Improving health, health care and wellbeing, in addition to systems thinking, all require health leadership, which recognises the contribution of organisational culture. Most leaders do not have measuring or monitoring systems that keep them informed about the quality of their organisation’s culture. Challenges of cultural competence were identified by the Francis Inquiry<sup>31</sup> which called for a “tool or methodology such as a cultural barometer to measure the cultural health of all parts of the system”. Thus far the Francis recommendations have been narrowly interpreted and restricted to internal matters but there a need for a wider view and a comprehensive cultural barometer that measures the whole health and care system. In particular, we see a major challenge for staff within the Health sector to see patients firstly as respected and dignified individuals, and not as anonymous numbers that need to be processed to meet targets. Greater priority should be given to the safety of patients within the health service, the cleanliness of the environment, the safeguarding against harm for all, but especially for vulnerable patients. We also believe that there must be a concordance between the health messages given to patients and the behaviour of staff. Staff need to become good examples of healthy living and therefore, for example, smoking outside hospital premises, obesity and poor lifestyle choices are relevant.

We also recognise that an increasing amount of care that might in the past have been undertaken by family and neighbours has been left to professionals and social care agencies. Within this setting, loneliness is a major problem for older people, particularly after bereavement. Agencies are reactive to a crisis but do not necessarily take a proactive approach to the well-being of individuals in the community. The movement of Byw Nawr (the Welsh part of the Dying Matters initiative) is trying to work with relevant charities, such as Marie Curie, and other providers across Wales to build resilience in compassionate communities and to rekindle concepts of neighbourliness. The concept of compassionate communities is similar to concepts of neighbourhood watch, which detects strange activities that may be indicative of crime. Similarly, the decrease in activity of an individual in the community is often an early warning sign of deterioration in health, often noticed by neighbours but not always acted upon. For individuals who might be friends, neighbours, local shopkeepers etc to take on such roles they need to be freed up as much as possible from bureaucratic processes that can inhibit involvement in care.

**Recommendation 4: Re-emphasise the role of compassionate and caring communities reflected in a patient-centred caring approach, linked to services provided by highly motivated staff, who themselves are role models of healthy behaviours.**

<sup>31</sup> <http://webarchive.nationalarchives.gov.uk/20150407084003/http://www.midstaffspublicinquiry.com/>

## Postscript

In forging a distinctive Welsh vision for future health and wellbeing, we draw the Panel's attention to a resurgence of interest in the contribution of the arts to health in Wales. The Nuffield Trust's Windsor Declaration (1998)<sup>32</sup> laid the foundation and this Declaration has been revisited recently at two major conferences on Arts and Health in Wales. There is now a Cross Party Arts and Health Group at the Senedd. The anticipation of the Windsor Declaration would be: more compassionate and intuitive health practitioners; reduced dependency on psychotropic medication such as tranquillisers and antidepressants; growing confidence and self-reliance of individuals; and less social exclusion.

"The arts and humanities touch people's lives at every level because they encompass those things that make life worth living, contribute to a country's civilisation and enhance the quality of health and wellbeing and help people cope with the challenges of change." Arts and Humanities Research Council.

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<sup>32</sup> <https://www.nuffieldtrust.org.uk/files/2017-01/arts-health-and-well-being-web-final.pdf>