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

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

***The Learned Society of Wales / Cymdeithas Ddysgedig Cymru (LSW)*** *celebrates and encourages excellence in all of the scholarly disciplines. A Royal Charter charity established in 2010, the LSW is an independent source of expert scholarly advice and commentary on matters affecting the wellbeing of Wales and its people. The Society draws upon the expertise of over 460 distinguished Fellows based in Wales, the UK and beyond. For more information, please visit: www.learnedsociety.wales*

The Learned Society of Wales in its first submission welcomed the establishment of the Parliamentary Review into the long-term future of health and social care in Wales, and the opportunity for the Welsh Government to set out a distinctive Welsh vision with 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 have considered the Review Panel's Interim Report and **we strongly support both the assessment of the health and social care challenges and the principles proposed as the foundation for making step improvements in the quality of health and social care in Wales.**

The Review Panel has rightly identified the need for rapid evidence based implementation of reconfigured health and social care pathways, but we noted in our first submission that though Wales has had a long and distinguished track record in developing innovative thinking in health and social care, it was weak on implementation. The timely **implementation** of innovative and responsive patient-centred care models is what will demonstrably improve health and wellbeing outcomes and will be the true test of the Welsh Government's legacy for health and social care.

In our first submission, we limited our focus on three imperatives; the first was the vital necessity to recapture the impetus for **prevention** using sustainable development principles applied across all policy domains. The second recognised and used contemporary understanding of **complexity** and the huge advances in informatics in Wales to redesign care pathways. The third recognised and fostered the role of caring communities and **cultural competence** in the health and social care system. We were pleased to see that the Review Panel's Interim Report had embraced each of these issues. In particular, we welcome the Review Team's identification of the importance of primary prevention as well as the need for principles of prevention to be integrated into all stages of health and social care. However, we hope that the final report will set out new approaches to address the recruitment problems in clinical staffing and how to make Wales a more attractive location for training and career development.

**We strongly support the Review Panel's conclusion that** *"**A wider set of 'social determinants' – in particular poverty, poor education, and worklessness – have a bigger influence on the well-being of a population than direct provision of health or social care … it is evident that health and care***

***organisations must work effectively with their partners to address the root causes of ill health; taking action expected under the requirements of the Well-being of Future Generations (Wales) Act, 2015***".

We pointed out previously that the root cause of much of the burden of ill health and poor wellbeing of older people is set at the prenatal and early year's life stages. So whilst we appreciate the reasons why the Review Panel identified as a priority the urgent need for new integrated models of care for the frail elderly in Wales, we would at the same time reiterate that **Wales cannot afford to lose sight of the longer term generational impact of the health and wellbeing needs of mothers-to-be, infants and pre-school children.** Wales has relatively high levels of pregnancy risk factors for poor birth and early years' outcomes, including low school readiness, which set a life course of disadvantage for these children. Consequently, we strongly support the "Future Generations" paradigm as the right paradigm to tackle the wider determinants of health, and we reiterate that the place based approach -"Cynefin" - offers an appropriate distinctive Welsh way "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".

**Model Development and Evaluation**

The Review Panel have rightly identified the urgent need to develop and evaluate new models of integrated health and social care. The current model of health and social care is reactive in nature and dominated by crisis management. Numerous other models of radical integration of health and personal social care exist in the UK (for example, in Scotland where new Integrated Care Organisations have been set up) as well as in other countries. The new Welsh Government approach should therefore begin by identifying reasons for the persistent failure in Wales to learn from others.

One barrier to progress we believe to be of great significance, is reflected in the limitation placed on the Review Panel in not being able to consider the financing of services; it is impossible to separate assessment of models of service from their finance, especially when much of the current care crisis has to do with the division between financing health and personal care. A second major barrier is the long standing reluctance within Wales to invest in the measurement of health and social care outcomes. We note that the NHS is assessed only through "failure metrics" such as the failure to meet waiting time, treatment time or financial targets. None of these sorts of measure recognise the huge increases in the productivity of the NHS as it has had to face the challenge of a population living significantly longer but with multiple complex morbidities. **NHS performance assessments should contain success as well as failure metrics.** The Welsh Government's Prudent Healthcare policy made the case for valuing patient outcomes as much as crude performance and throughput metrics, and recognised that care pathways must be underpinned by data tools that support local teams in improving the service they provide[1];

- "*Data that measures outcomes, experience and flow needs to be collected for providers of care to make appropriate decisions with citizens about service configuration and provision. This will ensure that organisations are focused on delivering what really matters to the people they serve*",

[1] http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/Achieving%20prudent%20healthcare%20in%20NHS%20Wales%20paper%20Revised%20version%20%28FINAL%29.pdf

- "*Clinicians are operating in the absence of data which describe what happens to people. Clinical data tend to focus on clinical episodes and sectors do not join up*",

However, we are not aware of significant progress in translating this thinking into action within NHS organisations.

We reiterate that to achieve the ambition of flexible, patient-centred, outcomes-oriented, prevention-focused adaptive health and social care pathways in Wales, we need to accept that we are operating in a "complex system"; this means that changes to one part, however well-meaning and "common sense" they may appear, can have unexpected and disproportionate and often negative consequences overall. This is illustrated by the increasing trend to provide social care in people's own homes rather than in care or nursing homes but without adequately addressing their frequent nursing and medical needs, leading to carers calling emergency services and creating patient jams at Accident and Emergency centres for problems better dealt with in the community.

The Review Panel comment that many initiatives in Wales, though promising in themselves, have not been tested against the wider implications for the health and care system as a whole. They say "*We have not seen enough emphasis on the consistent and comprehensive evaluation or assessment of the value and benefits across the whole system of different models. If there is no mechanism to assess these and scale up the most effective then variation becomes a permanent state, effort is dissipated, and there can be little learning. This provides little basis for systematic quality improvement and the transformation necessary to meet future need*." **We fully agree with this important critique.**

Designing service changes within the conceptual framework of complex models offers huge potential for clear thinking as well as full engagement of service providers with patients, and could be the way to make the step change that is required.

- "*Building a model of a system is a collaborative process that can generate unexpected insights that help to scope the problem that needs to be addressed, setting the agenda of what actually needs to change and why".*
- *"The process of building and analysing a system model is itself an ideal forum for shared dialogue, enabling ideas and knowledge to be pooled from a variety of stakeholders in order to build a true picture of how a service works in reality.*" [2]

As a pre-requisite for the sort of "real world learning" implicit in timely model building and testing, we re-emphasise three fundamental requirements,

(i) the necessity to harness Wales' health and social care "big data" in a timely way to track patients through care pathways and monitor outcomes whilst protecting privacy[3]

(ii) the development of health and social care leaders in Wales who understand systems thinking and embrace "smart governance" and

[2] http://mashnet.info/wp-content/files/2016/09/Change-By-Design-Booklet.pdf
[3] https://saildatabank.com/

(iii) the introduction of a transparent accountability framework that focuses on outcomes of health and wellbeing pathways from primary to tertiary care, and has a "relentless focus on quality, prevention, and efficiency".

Consequently, we strongly support the application of powerful predictive modelling techniques (from qualitative modelling to mathematical and simulation modelling and economic modelling). Operational Research (OR) has for many years held considerable promise for the radical redesign of care pathways, but as has been pointed out "the adoption of OR solutions in healthcare is, in general, disappointingly low"[4]. However, technology for securely holding large health and social care data sets and analysing evaluating health care models has developed massively in Wales in recent years, and whilst we agree that the reasons for the reluctance of health care managers to take up OR approaches needs to be understood, we believe that Wales has a special opportunity to benefit from big data and could even become internationally leading. There are recognised pockets of excellence in the application of OR techniques within the NHS in Wales[5] and experience here offers realistic promise of what might become a generalised uptake of evidence base planning.

**The experience from pockets of excellence in Wales suggests that special attention must be paid to the resource management and organisational framework within which models are built and assessed, as well as the criteria that will be used and the decision making process that will be followed to implement change.**

Bringing data and modelling expertise together will be a pre-requisite, but just as critical will be the way in which genuine public engagement can be brought in to co-produce effective, efficient and acceptable solutions. Therefore, we suggest that the proposals in the Interim Report for the role of scientific model develop and evaluation require a new approach. Set solely within the academic environment, such research and development programmes will have to compete for funding with other subject areas so that winning large grants that address Wales' urgent priorities cannot be guaranteed. Furthermore, the timescales for protocol development and grant capture, delivery and reporting are often on a timescale that renders the results irrelevant to policy and service decisions. However, short term and process-based evaluations set within the health and social care services may be deficient in scientific rigour, and the lack of openness to public scrutiny means that proposed changes may not carry public trust. In neither the academic nor the service setting is public engagement currently at levels that could be said meet the requirements of "co-production".

We suggest that there is also a requirement for a new type of national "centre" (probably a hub and spoke network) that draws on the full range of modelling approaches and where experts in modelling from academia, the NHS, and local authorities in Wales, patients and their representatives, health and social care managers and policy makers, test new ideas for system benefits and dis-benefits within meaningful timeframes. The best ideas for improving care pathways are likely to come from the patients themselves and therefore true engagement opportunities must be a fundamental feature of any change process. Furthermore, experience in Wales has shown that the best results come when OR

[4] Implement Sci. 2016 Jun 6;11(1):81. doi: 10.1186/s13012-016-0444-0.
Operational research as implementation science: definitions, challenges and research priorities. Monks T.
[5] https://www.cardiff.ac.uk/news/view/168395-the-awards-2015-winner-outstanding-contribution-to-innovation-and-technology

researchers are resident within Health Boards and work alongside implementation scientists and managers[6].

Such a national "centre" could ultimately function in the sort of way that NICE currently works. That would mean that changes to the health and social care system would have to meet pre-implementation criteria. The opportunity for public and professions to envision (for example, through simulation modelling) proposed changes - the benefits and unintended consequences - and to be involved in the evaluation of service changes to confirm or deny the benefits of the proposed changes - would be a new concept that would help move system changes away from the heated environment of lobbying and narrow interest groups towards an evidence-based whole community setting. The centre would need to be within the service accountability framework, and this would also allow access to the big data sets that will be needed.

A key criterion that should also be built into the modelling accountability framework would be the inclusion of opportunities for primary, secondary and tertiary prevention. The UK Academy of Medical Sciences has pointed out the need "t*o design economically and environmentally sustainable and integrated models of health and social care that place* ***a greater focus on prevention*** *and have the capacity to manage multiple morbidities and end-of-life care in an increasingly aged population. To realise the gains to be made from an integrated approach to treatment and prevention, we need to enhance and bring together our understanding of biological, behavioural and social determinants of health at individual and population levels*." This is particularly needed in Wales where life style risk factors are disproportionately high.

The US National Academy of Medicine Initiative 2016-17 also concluded: "*The rise of digital health technology has opened the door to enhanced health care and provider access,* ***greater patient engagement****, as well as data and tools to support more personalized and tailored health care. Further, increased recognition of the importance of community and population health strategies has helped foster* ***a greater system-wide focus on prevention and overall health promotion opportunities****"*[7].

**Specific proposals for new models**

The LSW has also developed the view that the Interim Report has not given sufficient emphasise **to the scale, gravity and urgency of the mis-match between the capability of health and social care services in Wales** and the demographic challenge of increasing numbers of older people with multiple co-morbidities. Most striking amongst these is the incidence of dementia for which no curable or ameliorable treatment currently exists and which without major system changes is likely to overwhelm hospital services. The first model therefore that has to be tested is the re-drawing of the interface between medical and personal care to focus on the individual's needs for wellbeing within the confines imposed by their conditions.

[6] https://www.youtube.com/watch?time_continue=13&v=Wf0cFD-v81w
and https://www.cardiff.ac.uk/news/view/105269-maths-saves-lives!-healthcare-modellers-win-innovation-award
[7] https://nam.edu/initiatives/vital-directions-for-health-and-health-care/

The Royal Commission on Long Term Care of the Elderly[8] pointed out a long time ago that the term "social care" is misleading because it embraces a cluster of several different things which should be treated differently. In recent years, it has come to mean "personal care". Personal care is required as a core activity to support daily living and wellbeing to meet the individual patient's needs. The integration of the provision and funding of health and personal care under one responsible organisation would seem an obvious solution.

Finally, integration should also apply to regulatory governance. In England, the Care Quality Commission (CQC) has demonstrated an ability to drive up standards of care in many organisations by using some simply tests across all settings, but in Wales, as patients move across organisational boundaries different inspection criteria apply. The English CQC asked five key questions about any particular service - Is it safe? Is it effective? Is it caring? Is it responsive? Is it well-led? The effect has been to generate in many areas a sense amongst all staff at every grade that the health of the local population is their responsibility, and as a result staff have been empowered to find solutions to problems they face**.**

**We propose that the Parliamentary Review consider whether Health Inspectorate Wales (HIW) and Care and Social Services Inspectorate Wales (CSSIW) should be brought together to develop a unified inspection process that reinforces the accountability of services providers to the population served, and streamlines care pathways.**

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[8] http://discovery.nationalarchives.gov.uk/details/r/C14968