

Author: Prof. Ronan Lyons, School of Medicine, Swansea University.

Author Contact:

Prof. Ronan Lyons
Swansea University
Swansea
SA2 8PP

Email: r.a.lyons@swansea.ac.uk

Tel: 01792 513485

WISERD Hub Contact:

Cardiff University
46 Park Place
Cardiff
CF10 3BB

Email: wiserd@cardiff.ac.uk

Tel: 02920879338

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Evidence review:

UK Health Performance: findings of the global burden of diseases study 2010 and the potential for data linkage to inform and support the evaluation of interventions and policy initiatives to improve performance.

Prof Ronan Lyons, Director Farr Institute of Health Informatics Research (Centre for Improvement of Population Health through E-records Research - CIPHER), and Co-Director of DECIPHer Public Health Research Centre, Swansea University

Measuring Health Performance

There is wide variation in health outcomes even between countries at similar levels of economic development. Murray and Frenk wrote an evidence briefing on this topic for the World Health Organization in 2000 (1,2). That briefing discussed the several frameworks that existed then for measurement of health system performance and proposed a number of improvements to get over difficulties from multiple and overlapping attributes of health systems and a common tendency to focus on available but inadequate indicators. They expressed a belief that a consistent coherent framework should start by addressing the very simple question "what are health systems for?" and set out their views on the conceptual basis for measuring health system performance and the operationalisation of those concepts. The discussion covered a large number of issues, including setting boundaries for a health system, the concepts of intrinsic and instrumental goals, social systems and social goals, health system goals, health, system responsiveness, fair financing, financial risk protection, instrumental goals, goal attainment, the performance of sub-systems and factors that explain health system performance. They also proposed that annual assessments of health system performance be undertaken and that global institutional assessment of performance would be a helpful development.

Global Burden of Diseases Study

Subsequently, Murray and others were able to contribute to this agenda through the development of the Global Burden of Diseases (GBD) (3) study. GBD adopted the approach of using Disability Adjusted Life Years (DALYs), a concept developed by the World Bank in the early 1990s to measure health system performance. DALYs are a composite measure of health derived by combining a measure of premature mortality (Years of Life Lost, YLLs) with a measure of disability (Years Lived with Disability, YLDs). GBD computes DALYs for diseases, risk factors and injuries. The results of the 2010 update of the GBD study were published in 2012 and work is ongoing to produce updates and profiles for individual countries and regions. Increasingly, DALY rankings are used to compare health performance between and within countries and to guide policy development, including in England where local updates of the GBD methodology are now being used to inform health policy (4).

Whilst GBD 2010 is undoubtedly a major development in this field and the update is a very substantial improvement on previous study there are inevitably a large number of assumptions inherent in the complex methodologies involved, some of which are based on fairly scanty empirical data. One particularly contentious issue is around the operationalisation of the methodology used in the valuation exercise to create disability weights. These used very short descriptors of the experience of living with conditions in order to reduce cognitive load on responders and hence may not reflect the average experience of people with such conditions (5). There are also some concerns around the accuracy of the estimates for durations of disability for acute conditions as these were largely based on expert opinions of clinicians. Most clinicians now work in health care systems that are designed around efficiency do not routinely follow up patients. Researchers working on the burden of injuries have been to the forefront in highlighted these issues.

Empirical evidence from the UK Burden of Injuries longitudinal study, which used standardised instruments to measure disability at fixed points during recovery, produced YLDs some 2-3 fold larger than those from the GBD (6). Data from the six largest injury outcome cohorts (n=40,000) are now being brought together in a meta-analysis to refine the calculation of disability weights, durations and YLD metrics for injuries (7). From the research undertaken so far it is clear that the societal impact of injury in the cohort studies is considerably higher than the 11% of global and 8% of the UK DALY total estimated in the GBD2010 publications. It is possible, and perhaps even likely, that there could be similar issues with other health conditions. GBD is an ongoing global activity with a series of planned improvements in methodology and incorporation of additional data as they become available. The accuracy of GBD estimates will inevitably improve over quite short timeframes as more scientists contribute their expertise and data. In the meantime policy makers would be wise to use multiple sources of evidence on the burden of conditions when deciding on health priority spending.

However, whilst there may be some caveats over the GBD2010 rankings of the burden of specific diseases, between-country comparisons will be much more robust, particularly for countries with relatively good data on mortality and morbidity.

The Lancet paper on UK health performance involved a comparison with 18 other countries (original EU 15 members plus Australia, Canada, Norway and the USA) using DALYs, YLLs, YLDs and healthy life expectancy (HALE) as indicators and reported results for 259 diseases and injuries and 67 risk factors (4). For both mortality and disability overall health has improved considerably between 1990 and 2010 with UK life expectancy increasing by 4.2 yrs. However, the UK had not improved to the same extent as other countries and was generally towards the bottom of the comparator league tables on many topics. Whilst mortality rates and hence YLLs fell disability (YLDs) increased. The major contributors to YLDs were mental and behavioural disorders, including substance abuse, and musculoskeletal conditions.

Apart from the all-age results it is also worth studying the data in some detail as ranking vary considerably by gender and age group. For example, self-harm is the second largest contributor to premature mortality in the economically active 20-54 year age group.

The GBD methodology is very helpful in creating a single metric by which policy makers can judge the impact of individual diseases and conditions on important aspects of the population health, and in gauging how these change over time. Whilst there is considerable on-going debate about the underlying disability weights and durations of disability used in GBD derived DALYs the overall construct is very helpful as it highlights the societal impact of many chronic disorders with low levels of fatality.

The Potential for Data Linkage to support Health Policy

Whilst studies like GBD can help policy makers understand the relative impact of a variety of disparate conditions that methodology alone is not particularly useful in evaluating population-wide interventions and policies, especially where such interventions are designed to apply preferentially to subgroups as in the case of proportional universalism. Outcomes occur to individuals. Interventions need to be assessed by comparing the outcomes of individuals in groups receiving interventions with either a control group or in a well designed self controlled series. This is where recent developments in data linkage are now coming to the fore. There has been considerable investment by UK governments and research councils in data linkage centres and facilities, including the four Health Informatics Research Centres that have now come together as the Farr Institute of Health Informatics Research, and the ESRC funded Administrative Data Research Network (ADRN) (8,9).

These investments are now starting to pay dividends as more data are now being linked across the UK and are increasingly being used to answer policy relevant questions.

In Wales, there has been a focus on methodologies that underpin the creation of population-wide anonymised e-cohorts designed not only to answer complex aetiologic questions but also to act as a platform for the evaluation of embedded interventions and measurement of their population impact. Wales is well positioned in this field following earlier investment by Welsh Government through the National Institute for Social Care and Health Research (NISCHR) into the Secure Anonymised Information Linkage (SAIL) data bank (10). The co-location of SAIL, the Centre for Improvement of Population Health through E-records Research (CIPHER) component of the Farr Institute of Health Informatics Research and the Administrative Data Research Centre Wales at Swansea University will increase efficiency and provide a vibrant multi-disciplinary research environment. The SAIL system already provides direct research to Welsh Government policy researchers, for example, through the ESRC/Welsh Government co-funded data maximisation programme (11). Also, there are strong links between CIPHER and the DECIPHER Public Health Research Centre of Excellence, which focuses on health improvement in children and young people, purposely designed to strengthen multi-disciplinary research capability and capacity in the evaluation of complex interventions (12).

The Wales Electronic Cohort for Children (WECC) is a good example of this collaborative approach. It was designed to inform and support the development of policy interventions to improve the health and well-being of children and young people. Anonymised linked records from more 800,000 children born between 1990 to 2008 were included in the first phase of WECC. A second phase incorporating data from 2009 to 2012 is now underway, including the creation of a hybrid cohort involving 1800 Welsh participants from the Millennium Cohort Study. WECC research themes include: vulnerable births, obesity, injury, the health of looked after children and frequent movers, and increasing understanding of the complex inter-relationship between health and educational. Several papers have been published, or are in press, including a paper on effect of frequent home moves on educational outcomes for children at age seven (13). That paper was based on a sub-cohort of 121,422 children with linked health and educational records and reported a dose-response relationship between the frequency of address changes and sub-optimal educational achievement at age seven.

Another WECC paper focussed on the impact of pre-term birth on the risk of being admitted to hospital with an acute respiratory condition up to five years of age in a sub-cohort of 318,613, with adjustment for a wide range of confounders, including socio-economic conditions, maternal and peri-natal health, and subsequent health service interventions (14). Emergency admission rates increased monotonically with each week of prematurity up to and including 39 weeks of gestation, contributing to a growing evidence base on refining normal gestation. The results suggest that the impact of deprivation on health in the under fives could be partially mitigated by interventions that change the prevalence of two influential factors, teenage pregnancy and breast feeding.

A third WECC paper studied the relationship between significant head injuries in young children and educational assessment at age seven in 90,661 children (15). Children with prior intracranial injuries, but not concussion or skull fractures, were only half as likely to be recorded as reaching expected levels of educational attainment at age seven.

One of the most useful developments in the Welsh SAIL system is the ability to anonymise and link data at both individual and household level. The household level linking development underpins a range of evaluations, primarily using natural experiment methodologies, of the impact of non-healthcare interventions on health. The system was designed to overcome the difficulties in data sharing between health, local government and

third sector organisations, whilst protecting privacy, and has been a very effective catalyst for multi-agency and multi-disciplinary research (16). Such systems could easily be adopted across the rest of the UK.

Conclusion and Further Steps

Integrating the work of policy makers, practitioners and academics in an information driven, outcome focused system is the surest way to make progress in translating research findings into population impact. The creation of the Farr Institute of Health Informatics Research and the Administrative Data Research Network has now placed the UK in an excellent position to exploit the research opportunities through privacy-protecting data linkage across vast array of administrative and service data collected across the public sector.

There are still a number of challenges to be overcome, including providing safe and secure access to the large amounts of detailed data on health conditions and their treatments held by the NHS in databases not yet available to researchers. Most NHS organisations have hundreds of unlinked databases. Bringing such data together would not only help the NHS to implement services designed to maximise patient outcomes but would also be tremendously valuable to research underpinning service improvement. Bringing such data together is a considerable task but will be helped considerably by MRC investment in the development of NHS Research Data Appliances (RDAs) through the Farr Institute. The recently created Administrative Data Research Centres and Network will perform a similar function in providing access to non-health data and will benefit from utilising the RDA technology in non-health settings. Several of the Farr Institute coordinating centres and ADRCs are co-located, increasing opportunities for multi-disciplinary research. Greater linkage of health and non-health data is essential in enabling broader and deeper evaluations of the human and social impact of a wide range of policies and interventions (16).

To gain maximum benefit from data and linkage facilities it will also be necessary to have a greatly expanded cadre of skilled personnel, not only in academia but also throughout policy, practice and industry. The McKinsey Global Institute identified a short fall of between 140,000 to 190,000 data scientists in the US in 2011 to meet business needs (17). Hence, the UK is likely to be short by at least 30,000. The capacity building activities of the Farr Institute and ADRN are a welcome impetus but it is important that employers and research funders also play their part in providing support and finance to train a new generation of analysts and researchers.

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