

Data and Information in NHS Wales: the good, the bad and the ugly!

Background

The Bevan Commission (BC) has previously offered a definition of world-class health care as “health care that is best suited to the needs of Wales and comparable with the best anywhere” and which:

- must perform well against the Bevan Commission principles;
- must be balanced, integrated across all levels and effectively link health and social services;
- must achieve an excellent level of quality;
- must be matched by efforts to create world class health – with government having a crucial leadership role;
- **must be supported by excellent information to analyse, compare and develop services.**

Further, one of the BC papers submitted to the Minister and led by Anthony Newman-Taylor concluded that “the visible hand of transparent information, freely and openly provided to funders, patients and public, can enable and encourage excellence in healthcare in Wales.”

Subsequent to the BC meeting in September 2009, a paper was provided to discussions which had taken place at the meeting relating to:

- the number of bodies and organisations involved in the collection and analysis of data
- the extent of duplication and lack of coherence in information requirements
- the rationale for data required to be collected
- the nature of analysis undertaken
- the means by which information would inform decision-making and policy direction

This paper indicated that:

- there is no easily available simple description of the information bodies in Wales and the data they collect
- an Information Requirements Board has been established which could inform the Bevan Commission’s requirements for descriptions of data flows.
- there are three questions surrounding the collection of data:
 - What data should be collected (a clinical and policy perspective);
 - How should that data be collected and;

- How should that data be used?

The establishment of the Information Requirements Board was seen as key in addressing the deficits that had been identified in the BC. It was to be:

- the definitive, authoritative and strategic body for approving all information developments at an all-Wales level; that is information for purposes such as planning and evaluation, and will consider situations where a clinical or operational system may need investment in order to facilitate information provision.

and its role specification was viewed as addressing the lack of coherence within NHS information.

The Welsh Information Systems Strategy was produced in 2012 with an aim “to deliver information systems that improve quality and efficiency so that citizens and staff working together can deliver more efficient and better quality services.” While, it may be premature to assess the extent to which the strategy has had any effect, the perception twelve months on from the publication of the strategy is that the configuration of organisations, bodies and groups involved in the collection, processing and dissemination of information relating to the health and social care systems in Wales have failed to act as the ‘glue to the system.’ The existence of inappropriate power-bases and high boundaries surrounding information systems have served to act as major obstacles to the effective use of data and information produced by the information industry within NHS Wales. In summary, the position presented to BC on 6 June highlighted some good features:

- World-class facilities and technologies available within Wales
 - SAIL
 - Commissioning Activity Tool being developed at ABMU Health Board
- Highly impressive websites and documents
 - NWIS, Public Health Wales
- Vast quantities of data and information collected and managed with good governance systems

some bad points:

- Emphasis on acute sector with little information on primary/community services and patient experience
- Limited dissemination and usage relative to data collected
- Insufficient analysis for decision-making
- Very limited linkages with social care services

and some very ugly issues:

- Plethora of organisations and bodies collecting data for different purposes resulting in:
 - Duplication
 - Variation
 - Waste and efficiency loss
 - Resources
 - Health gain
- Integrated health boards but fragmented information support systems

Presentations to Bevan Commission (June 2013)

As a result of these concerns, a series of presentations from representatives of a number of the organisations involved with data and information relating to NHS Wales were requested. These were:

- Glyn Jones – Acting Chief Statistician, Welsh Government
- Gwyn Thomas – Chief Information Officer, Welsh Government
- Bev Thomas – Director of Nursing and Social Care Information, NWIS
- Andrew Sallows, Emrys Elias – Welsh Government, Delivery and Support Unit
- Dr. Judith Greenacre – Director of Health Intelligence, Public Health Wales
- Professor Ronan Lyons – Director of Centre for the Improvement of Population Health through e-health Research (CIPHER), Swansea University
- Dr Carwyn Jones, Dr Alan Williams – GPs from Carmarthen

In addition, Professor Andrew Morris - Dean and Professor of Medicine, School of Medicine, University of Dundee and Chief Scientific Advisor to the Scottish Government had been invited to describe the informatics system in NHS Scotland that has contributed to very favourable outcomes in the treatment of diabetes. He demonstrated that through shared protocols and information about diabetic patients between primary and secondary care, initially in Tayside and subsequently in Scotland, readmission rates, foot amputation rates and rates of laser treatment for eye complications of diabetes were all reduced by one third, i.e. greatly improved health and healthcare at lower cost.

Emerging themes

The notes from the presentations are contained within the notes of the meeting held on 6 June. In many senses the presentations served to confirm the perceptions and suspicions that had existed. The following serve to highlight some of the issues that emerged:

- Data collection
 - Lack of rationale relating to data parameters
 - Limited co-ordination
 - Lack of common approaches/definitions
 - Duplication of effort and collection systems
 - Excess data being collected
 - No priorities
 - Limited attention to community services and patient experience
- Data systems
 - Do not support aims of NHS Wales
 - Lack of integration
 - Do not relate to patient management and quality assurance
 - Social services has to be involved
 - “information is a catalyst for change but healthcare is the last industry to embrace the information age”
 - Are a barrier not a help and not easy to use
 - Lack transparency
- Data quality
 - Significant room for improvement
 - Emphasis on quantity of data rather than quality or usage
 - Inappropriate and conflicting (national) targets
- Data linkages

- Technology available but organisational will not evident
- Risk-aversion
- Security comfort-blankets
- Capacity / cost issues
- Need to be improved to inform patient care /management and outcomes
- Data analysis
 - No central analysis or evaluation
 - Limited input in decision-making; prioritisation
 - Patient-level data essential
 - Population health and inequality data separate
- Data usage
 - Overload
 - Accessibility/ transparency
 - No feedback on how data is used

Questions remain

- What data do we need?
- Why do we need such data?
- Who can provide it?
- Can we accurately plot the persons / patients' journey (from wellness to illness) from entry to exit in health and social care systems and the appropriate patient outcomes?
- Is this available to all relevant professionals and organisations eg. police education etc?

Recommendations

The current situation relating to data and information is unacceptable and represents a major obstacle in driving the health system in Wales forward in line with strategic intent. The Bevan Commission advises the Minister to take immediate action to address the points raised with a clear plan of action by early 2014, addressing the following:

1. Review the information needs and requirements to ensure effective population health (health promotion, protection, treatment and care) across the whole system, including primary/ community and social care
2. Review current functional contributions of all information providers and identify opportunities for improvement, addressing duplication, gaps, efficiencies and effective use of resources at local and national levels
3. Learn from other agency developments (Information Centre, NHS England, NHS Scotland and other relevant private organisations) to identify best practice and some clear early wins.
4. Identify opportunities to ensure information is embedded within performance accountability and governance systems and underpins service and workforce planning and improvement
5. Set out options and actions for improvement in the immediate, medium and longer term working within existing resources