

Bevan Commission Meeting 9

Date of meeting: 6 June 2013

Version: Final approved

Members attending:

Prof Sir Mansel Aylward
Dr Tony Calland
Dr Jo Farrar
Lt-Gen Louis Lillywhite
Prof Donna Mead
Prof Ceri Phillips (left at 14:15)
Prof Allyson Pollock
Prof Sir Anthony Newman Taylor
Prof Ewan McDonald
Prof Marcus Longley

In attendance:

Jon Matthias, Public Health Wales
Scott Thomas, Public Health Wales

Apologies

Sir Ian Carruthers
Prof Bim Bhowmick
Prof Jennie Popay

Presenters:

Professor Andrew Morris
Glyn Jones
Gwyn Thomas
Bev Thomas
Andrew Sallows
Emrys Elias
Dr Judith Greenacre
Professor Andrew Morris
Professor Ronan Lyons
Dr Carwyn Jones
Dr Alan Williams

Welcome and apologies

The Chair welcomed all to the ninth meeting of the Commission.

Guests

Professor Andrew Morris, Dean and Professor of Medicine, School of Medicine, University of Dundee and Chief Scientific Adviser, Scotland was present during the presentations and invited to contribute his thoughts during proceedings.

Opening Business

The Chair reminded members of declarations of interest. No declarations were made

The notes from the previous meeting were read and approved. The Chair noted as a matter arising that the new NHS Wales Improving Quality Together framework has attracted considerable interest in New Zealand and British Columbia. The Commission will receive invitations to do the online course.

Following the presentation of the Bhowmick Innovation Model on elderly care, the Health Minister has asked the Chair to work with Baroness Ilora Finlay in a “new conversation” about care services in Wales.

The Commission discussed the forthcoming paper on primary care and agreed it needed to be more radical in its approach. It was agreed to keep Jan Williams, Chair of the Health and Wellbeing Best Practice and Innovation Board apprised of the contents of the paper. The paper on primary care is an opportunity to address the unthinkable, but there are certain things that will not likely change, e.g. the GP contract. However, the forthcoming paper could be used to drive desired activity in primary care.

The Commission also discussed holding a public meeting in September. This will be a new addition to diaries. It was agreed to cancel the scheduled Commission meeting on 8 August, with a public meeting and a regular Commission meeting in September. The Commission agreed to consider dates and also moving the October meeting to November and cancelling the December meeting.

The Chair also informed the Commission that the Health Minister has suggested the Commission may wish to comment on the reconfiguration of services in NHS Wales. The Chair also confirmed that a King’s Fund report into reconfiguration of services has been commissioned by NHS Wales Chief Executives, not by the Welsh Government.

The Chair then introduced the main topic of the meeting – whether NHS Wales is using data / information / intelligence to its maximum potential – and handed over to Prof Ceri Phillips for the introductory presentation.

Data and information

Professor Ceri Phillips presented a paper to inform the discussion around the day's topic of data and information management.

Prof Phillips' paper raised several questions arising from a previous paper produced by the Commission in 2009. At that point an Information Requirements Board had been established in NHS Wales. The Commission were unsure what had happened to this board or what its findings were.

The discussion around the paper concluded that data doesn't glue the system together the way it should. This is due in large part to power-bases, arbitrary boundaries between organisations and a perceived lack of willingness to share information.

Data in Wales – the high level view

The Commission welcomed Glyn Jones, Acting Chief Statistician, Welsh Government and Gwyn Thomas, Chief Information Officer, Welsh Government and Director of Informatics for Health and Social Services, to present a high level view of the use of data in NHS Wales.

Presentations explained how statistics are collected for accountability purposes and used for resource allocation. The Commission was assured that statistics were collected and collated in Wales with maximum transparency and independence. The role of Chief Statistician is independent of government and can challenge the way the Government is using statistics if need be.

Producing genuine figures relating to outcomes is a major challenge because many statistical releases revolve around process measures. Data quality can, therefore, sometimes be questionable. Technology can be a constraint, but new technology presents greater opportunities for data collection and processing.

In discussion with the Commission, the following issues were noted:

- Data collection methods do not currently link together;
- Ownership of data can sometimes hinder sharing of data despite a commitment to sharing data being in place;
- There is no central analysis or evaluation of data;
- Targets can sometimes mean the use of data by NHS Wales organisations is distorted;
- Current information systems probably do not support the aims of NHS Wales; and
- There are capacity issues with only 12 statisticians involved. Capacity would increase if there were better links across the system.

In response to the Commission's opening observation that one of the main barriers to sharing information was that IT systems in Wales 'could not talk to each other', It

was impressed on the Commission that IT systems do not self organise and the way in which they have been designed and deployed merely reflects human behaviour. Things are the way they are because of decisions and actions taken by people. They will change only when those people take different decisions and actions that allow this to happen. There are significant cultural barriers to sharing data that need to be overcome.

'Together for Health' contains a commitment to absolute transparency. In fulfilling this commitment it will be important to strike the balance between the unrestricted publication of poor quality data that undermines confidence in the quality of healthcare services that the open data policy is actually attempting to improve and, at the other extreme, creating a centralised risk averse bureaucracy of data definition, assessment and review that is completely risk averse and stifles pace and progress.

Official Statistics in Welsh Government should have responsibility for collating and analysing the management information being published and provide periodic reports to users covering issues such as:

- The quality of the data being routinely placed in the public domain and the extent to which it is fit for purpose
- A narrative on the key messages arising from the data and what can reasonably be concluded from the data
- A comparison of the narrative emerging from the performance data with other sources including UK and international comparisons

Department of Health and Social Services should be responsible for:

- mandating and specifying the information and data that public services are required to produce and publish (taking into account responsibilities such as meeting user needs, managing burden, international obligations etc)
- Setting the publication timetable and defining the level of quality required for the data published by service providers
- Providing clear guidelines on anonymisation and disclosure control in order to protect the confidentiality of individuals
- Setting the technical standards for the published data to ensure that it can be linked appropriately

Public Services (e.g. Health Boards) will be accountable for the handling of their data within the defined framework. In particular they will:

- Publish their performance information and underlying datasets to the agreed definitions and timetable
- Publish associated metadata describing the quality of the data released and the extent to which it conforms with the defined quality levels

Seek to publish their data in machine readable formats to facilitate reuse

- Publish their data primarily via the internet, but summary paper performance reports will be available to the citizen on request

The view was expressed that there was a shortage of informatics capability but not necessarily a shortfall in capacity. Existing information services were not optimally organised to take advantage of modern network based information reporting and analytical applications, roles and responsibilities of the various organisations and units involved were often not clear and there was overlap and duplication of activities. It was suggested that the Commission should recommend a functional review of all information services so that options for more efficient and effective delivery could be identified and a configuration for Information Service provision determined that enabled the delivery of the 'Together for Health' Strategy.

It was emphasised that developing expertise in data analysis, presentation and interpretation was becoming increasingly important. This point was illustrated by displaying a figure of the performance data routinely collected against the A&E 4 hour waiting target. Whilst there would always be 'one version of the Facts' (i.e. the data collected), there were in fact 'many versions of the truth' because the same data could be interpreted in various different ways, all of which were equally valid, depending on any particular perspective.

The Commission discussed obvious gaps. In response to a request, Dr Thomas suggested that digital internet technology now made it very easy to collect and publish real time information and gave as an example that GPS data from individual ambulances could be displayed on a geographic platform such as Google Maps so that any member of the public could find out where any particular ambulance was located at any time. This was already available for planes and trains across the UK.

The Commission acknowledged that NHS Wales had an IT Strategy (Informing Healthcare) but this was now 10 years old and needed to be updated to reflect developments in digital technology. However, It was also recognised that NHS Wales has no equivalent Data and Information Strategies that support Standards, Publication, Transparency, Information Sharing and Transparency. The Commission concluded that this omission needs to be rectified.

Issues for consideration:

- The Commission concluded there had been no progress since it had published its

paper 'A Visible Hand' on data collection in 2009.

- The Commission could publish a further paper emphasising that in their opinion there is no obvious plan for data in Wales, but that a robust plan is needed.
- Issues around ownership of data should reflect that data belongs to the citizens, not the government and that citizens should have a say in how it is used. Most citizens would want to know data is being used to improve services.
- There are opportunity costs to collecting data. Some data may not be needed any more and collection can cease.
- A more proactive approach of publishing data without waiting to be asked for it may be helpful.

Data in Wales – Data in practice

Bev Thomas, Director of Nursing and Social Care Information, NWIS, presented the Commission with an SBAR form outlining the situation and offering detailed assessments of the key issues. (This was circulated to all members and is included in the meeting papers.)

Mr Sallows and Mr Elias NHS Delivery Unit previously Delivery and Support Unit (DSU) outlined the function of the Unit and explained how they used data to monitor and evaluate Tier 1, Tier 2 performance, as per the escalation requirements of the Welsh Government Delivery Framework. When an organisation is not delivering an intervention will be triggered by the Welsh Government Internal Delivery Board...

A DSU intervention can take a phased approach depending upon the escalation level.

Level 1 – Assurance review

Level 2 – Formal intervention, Diagnostic report with recommendations

Health Boards are required to develop appropriate action plans against the recommendations. These plans are monitored and evaluated via the monthly Welsh Government Quality and Delivery Meetings.

There are 25 members of staff in the DSU including five performance analysts that regularly review and interpret data.

The majority of information gathered is from secondary care. DSU has the capability to produce timely information to inform on NHS delivery requirements. This allows for analysis of trends and to highlight and assure current and future performance. A scenario based example of where increased weekend discharges would have a significant effect on health board bed occupancy levels.

The lack of link between data sources was again listed as a frustration. Issues surrounding data reliability and verifying the accuracy of data were also mentioned. It was noted that there are no standard definitions used across all organisations. For

example, health boards' class patients attending A&E as major or minor, but these categories vary across organisations.

DSU supports health boards in analysing their data, but often organisations simply do not know what data they have, or what they could learn from their data.

Data in Wales – produced for service users, part one

Dr Judith Greenacre, Director of Health Intelligence, Public Health Wales outlined how Public Health Wales produces and processes data, with a view to creating intelligence to inform strategic leadership. She echoed previous presentations by identifying information problems are often caused by stakeholders not working together. There are also problems regarding data definitions of common terms, for example, what constitutes 'unscheduled care'.

It was noted that there is some degree of dependency on the Office of National Statistics and the Department of Health in England. It was recognised that some data products developed by those organisations is now under threat and Wales needs to negotiate on threatened data streams, which may just be cut off. In England more data may be collected by commercial organisations, who may charge for the information. Additionally, English and Welsh data may be collected differently, making comparison or aggregation difficult.

Internal problems can be experienced with delays from data gatherers within NHS Wales. There are no contracts within NHS Wales so data providers and processors have been known to choose not to deliver data.

The Commission was asked to consider the need for data to be collected at a national level, with common approaches/definitions and to avoid duplication of effort and ensure nothing is omitted. Data gathering needs coherence in collection and adherence to strategies and plans. Clarity is also needed on data priorities.

The Commission discussed how European laws on informed consent may affect certain data sets. Should this happen, an alternative to fully informed consent must be developed to enable public health data to still be collected.

It seems that NHS Wales is a long way from being transparent in informing and engaging people in debates about the collection and use of personal data.

Diabetes and data in Scotland

Sir Anthony Newman Taylor formally introduced Professor Andrew Morris, (Dean and Professor of Medicine, School of Medicine, University of Dundee and Chief Scientist Health to the Scottish Government) to the Commission. Prof Morris had been invited to explain the informatics capability enjoyed by the NHS in Scotland that has contributed to very favourable outcomes in the treatment of diabetes.

Prof Morris explained the system in use in Scotland, including the nation-wide adoption of a Community Health Index that runs in parallel to the NHS number and allows for data to be collected on all patients. This system has allowed NHS Scotland to lead the field in attracting research projects to the country worth several million pounds, and providing positive benefits to the health of the population.

With regard to diabetes the Scottish dataset is embedded in primary care and can tell clinicians exactly how many people have diabetes almost in real-time. This has enabled systematic approach to diagnosis monitoring and treatment. There has been a 40 per cent decrease in amputations (despite an increase in diagnoses) and a 45 per cent decrease in sight threatening retinopathy.

The following observations and recommendations emerged, based on the presentations already made to the Commission.

- Wales needs to 'do data as a nation', not as individual organisations.
- Information is a catalyst for change but healthcare is the last industry to embrace the information age.
- Health systems will fail unless they tackle chronic disease, and a cornerstone of good management is using information to proactively treat and prevent disease
- Data should be collected once and used often.
- Durable policy is very important. The diabetes strategy in Scotland is 11 years old and has not been tampered with significantly. Strategies need to be led by clinicians, patients and managers acting as a team.
- Using information tracks journeys in care and can reveal where problems are.
- Citizens are keen to take part in research. Scotland has a consent system which means NHS Scotland can contact anyone on the database who fits the parameters and ask them to take part.
- A national approach can also help evaluate policy. Scotland has evidence of the positive impact of smoking bans.
- There is challenge of "big data". Whole genome tests can be done, but storing that data is a challenge. Large amounts of data need considerable amounts of storage and this is not available on local computers. Cloud computing is a solution which would allow Wales to introduce a big data infrastructure
- Governance issues are very important but sometimes used as a smokescreen to avoid change. Proportionate governance is an approach, whereby only high-risk sensitive data should be reviewed in committee. All data can be anonymised and processed in 'safe havens' to support governance issues.
- Informatics is often under-financed, but it should come under clinical safety and be resourced through that.

Data in Wales – produced for service users, part two

The second part of this section was presented by Professor Ronan Lyons, Professor

of Public Health at Swansea University and Director of the Centre for the Improvement of Population Health through E-health Research (CIPHER), one of four new UK centres of excellence, funded by an MRC-led consortium.

Prof Lyons presented a briefing report on the Secure Anonymised Information Linkage (SAIL) system to the Commission. (This was included in the meeting papers.)

In the ensuing discussion the following further points were raised:

- NHS Wales needs to do more around capturing and evaluating patients' experience.
- The concern in NHS Wales about the pressure on NHS Wales is not helped by a lack of data/information regarding what the services are being used for. Understanding a problem is the first stage in developing solutions.
- There is no way to quality assure care if there is no effort to capture data on interventions, co-morbidities and outcomes. The Francis Report requires a change from a health system historically focussed around activity towards one focussed on assuring outcomes.
- There are currently no checks in place to ensure NICE guidance is being followed, so there is no way of knowing whether the guidance is indeed being followed.
- Data and the use of information to assure the quality of care are very low on the list of priorities for health boards. Complete participation in national audits is not incentivised as it is in England (through CQUIN), resulting in some hospitals providing some data to some of the audits some of the time. This does little to assure quality of care.
- Information for care planning and provision is fragmented, particularly when some care is provided outside the NHS (e.g. social care).
- Properly prepared data can be used for shared decision making, hence informing patient choice. Data on outcomes, including the experience of patients who have received treatment, can counter-balance the sometimes over-optimistic view that healthcare staff may give. This could reduce some of the demand on NHS services.

There were some very challenging comments made during the discussion. The question was asked: is NHS Wales about improving people's lives or is it just a social enterprise employing lots of people?

It was also suggested that if NHS Wales was a business it would be bankrupt because it often appears that it doesn't know what it is doing or who is doing what. Wales seems to have capacity but no synergy.

Data in Wales – use in general practice

The final presentation of the day was from Dr Carwyn Jones and Dr Alan Williams, GPs from Carmarthen. They explained how they were presenting from a 'data input' point of view.

Their central points regarding data entry were:

- Accuracy of data reflects the ease of input;
- GP systems are good but hospital systems are poor;
- The patient's needs are GPs' primary priority and data is often considered second. Where there are incentives to gather data this could be done at the opportunity cost of meeting patients needs;
- GPs get very little feedback on how data is used and whether it is needed;
- Not being able to link with social services is probably detrimental to good patient care. It also means patients have to repeat themselves which makes patients feel like they are not being listened to;
- GPs are discouraged from emailing sensitive information to consultants for security reasons but can send sensitive information through the post, which seems just as insecure;
- Generally there is a feeling that data inputted in hospitals is not as accurate as that inputted in primary care;
- Meeting incentives on data collection is time-consuming.

Dr Jones and Dr Williams also presented evidence of how comparing multi-morbidity rates between practices over a ten year period showed considerable differentials based on population affluence. Data also shows that the two best practices for diabetes control are the ones with the lowest per capita spend on diabetes patients.

Co-morbidity data can help show how likely patients are to have more than one problem, enabling practices to focus on disease-specific services and tailor their services to population need, for example, employing a dietician rather than investing in smoking cessation services. Analysing the data shows the clear benefit of continuity of care. Significant negative health events increase when patients see lots of different doctors.

It was suggested that GPs would benefit from warning systems that would flag up individuals at risk of developing chronic conditions. There could also be online systems that would reduce the number of appointments that are needed e.g. people log on and see their blood test results without having to see their doctor.

Publishing data may drive transformation. GPs will want to know where they are and how they compare against their peers.

Conclusion

The Chair concluded the meeting by summing up the main points made in the

presentations. He asked the Commission to consider putting a paper together that would be hard-hitting in its assessment of the situation.

Other business

The Chair asked the Commission to look at value for money in healthcare at the request of the Health Minister. This should be looked at in the context of what has been termed in the USA as 'Parsimonious Medicine.' The Chair preferred the term 'Prudent Medicine' as a working title, since the approach taking in Wales would be markedly different to that followed in the USA.

The Chair also agreed with the request from Members for fact-finding trips, especially to see the SAIL database in action in Swansea. These will be arranged between meetings and need only involve a few members at a time.

Actions

1. Chair to work with Baroness Iora Finlay in a "new conversation" about care services in Wales;
2. Keep Jan Williams, Chair of the Health and Wellbeing Best Practice and Innovation Board apprised of the contents of the paper on primary care;
3. Arrange public meeting and consider moving October meeting to November and cancelling December meeting;
4. Commission to comment on the reconfiguration of services in NHS Wales;
5. Report back to the Commission on findings from the Information Requirements Board;
6. Prepare a hard-hitting paper assessing the data and information situation in Wales;
7. Look at value for money in healthcare using a working title of 'Prudent Medicine';
8. Arrange for members to attend fact-finding trips e.g. SAIL database in Swansea.