

Health and Social Services Committee

HSS-22-02(min)

MINUTES

Date: Wednesday, 4 December 2002

Time: 9.00am to 12.05pm

Venue: Committee Room 2, National Assembly for Wales

Attendance: **Members of Health & Social Services Committee**

Kirsty Williams (**Chair**) Brecon and Radnorshire

Geraint Davies Rhondda

Jocelyn Davies South Wales East

Brian Gibbons Aberavon

Jane Hutt (Minister) Vale of Glamorgan

Ann Jones Vale of Clwyd

Huw Lewis Merthyr Tydfil and Rhymney

Dai Lloyd South Wales West

David Melding South Wales Central

In Attendance

Peter Finch NHS Partnership Forum (*Chartered Society of Physiotherapists*)

Jane Hanna Epilepsy Bereaved

Jane Jeffs Association of Welsh Community Health Councils

Richard Jones NHS Partnership Forum (*Royal College of Nursing*)

Dr Hywel Lloyd	General Practitioner
Mandy Price Jenkins	NHS Partnership Forum (<i>Gwent Healthcare NHS Trust</i>)
Janet Wilkinson	NHS Partnership Forum (<i>Pembrokeshire & Derwen NHS Trust</i>)
Prof. John Williams	Information Task and Finish Group (<i>Clinician</i>)

Officials In Attendance

Dr Ruth Hall	Chief Medical Officer
Peter Lawler	Primary and Community Health Division
Ann Lloyd	Director, NHS in Wales
John Morgan	Health Information Management Technology & Estates Division
Hilary Neagle	NHS Human Resources Division
Dr Sarah Watkins	Senior Medical Officer

Secretariat:

Jane Westlake	Committee Clerk
Claire Morris	Deputy Committee Clerk

Item 1: Apologies and Substitutions and Declarations of Interest

1.1 An apology was received from Lynne Neagle. Huw Lewis substituted.

1.2 There were no declarations of interest

Item 2: Informing Healthcare (9.05 - 10.10am)

Paper: HSS-22-02(p.1)

2.1 The Chair welcomed Professor John Williams, Director of the Wales Office of Research and Development, practising clinician and member of the Information Task & Finish Group; Dr Hywel Lloyd, a GP from Llanidloes and member of the Sharing Clinical Information in the Primary Care Team (SCIPiCT); and Jane Jeffs, Chief Officer of the Association of Welsh Community Health Councils.

2.2 The Minister introduced the paper, saying that *Informing Healthcare* developed the themes in *Improving Health in Wales*. It made proposals for development in five areas to ensure the timely and free flow of information to support health and healthcare, as well as developing the role of the patient as a member of the team. The five development areas were:

- Care Process Improvement
- Workforce development;
- Patient and Public empowerment;
- Electronic Health Records;
- Better use of information

The development areas were complementary and had to be progressed at an even pace through a corporately managed Strategy Implementation Programme. The vision set out in *Improving Health in Wales* and *Informing Healthcare* had been embraced by staff in the consultation to date. Four roadshows had been held around Wales during November attended by a cross-section of interests and a report on the consultation responses was expected later in the month.

2.3 Professor Williams said that a recent article in the Journal of the Royal Society of Medicine claimed that 41% of a clinician's time was not spent with the patient. He then showed the Committee an example of the volume of paperwork that made up the case file of a single patient. He said that the current method of recording information on a paper file put patients at risk and increased pressure on clinicians, as it was extremely difficult, particularly patients with complex conditions, to put together a coherent picture. Also, there would not be a single record but a set held by every healthcare organisation the patient had been in contact with. A single electronic patient record (EPR) across Wales could be

accessed at any location or time and could enable the patient to contribute their wishes, concerns and preferences to the record. It would also enable the primary care team to have immediate access to details of any treatment their patient had received in hospital rather than having to wait for a discharge letter. The EPR would also provide a useful tool for clinical governance, planning, appraisal and performance monitoring. He welcomed the recommendations in the strategy and said they would require a significant change in the way in which clinicians worked.

2.4 Dr Hywel Lloyd said that GPs spent a lot of time chasing up information from secondary care providers. There were often problems with the legibility of emergency discharge letters, and more formal letters from consultants to GPs could take up to six weeks to come through. He said that in his practice the impending visit of Breast Test Wales had necessitated his staff trawling through A3 printouts of patient information provided by the health authority to determine eligibility. This would take nearly three weeks to complete. A recent survey of health visitors showed that 30-40% of their time involved form filling. There was also poor co-ordination across the professions, which resulted in duplication of effort and information. As part of the SCIPiCT project, a group had been set up to look at what patients thought and what they expected. The results of this work showed that patients expected healthcare professionals to have immediate access to all their information and expected them to share it with other healthcare professionals.

They wanted to be able to access their records on-line and amend any errors; book appointments on-line and access websites with approved links to other healthcare websites. He concluded that lack of information was a fundamental problem. It put patients at risk, made services inefficient and left professionals unable to monitor their performance.

2.5 Jane Jeffs said this was an extremely welcome development, which would secure patient safety and enable patient empowerment, as more effective use of technology would result in more effective working practices. Much of the complaints work of Community Health Councils was about problems caused by poor communication. Patients should have more say in their healthcare and should be encouraged to take responsibility for their own health. The public needed to be aware of the risk of breaches confidentiality and there should be wide public debate of the issue. She believed there would be people who would not wish their records to be available electronically and their needs would also have to be taken into account.

2.6 In response to comments and questions from Members the presenters made the following points:

- Standardisation of equipment and input by clinicians would be necessary to ensure compatibility.
- Training in both technical use of new equipment and different ways of working would be critical, and that should be starting now at undergraduate level.
- It was not envisaged that the electronic record would be entirely structured with everything coded. Free text could be added in much the same way as it could currently be added to a paper record. It was not believed that the electronic record would entirely replace the paper record for many years.

- There was no statutory requirement for the content of medical records only nursing records, but the General Medical Council required doctors to keep accurate records.
- Medical records had to be kept for only seven years after the last consultation.
- Most patients thought healthcare professionals had access to all their information and were surprised to discover how little communication there was between different sectors in the NHS.

2.7 John Morgan made the following points:

- The Task and Finish Group had looked at the issue of confidentiality in detail and had concluded that the new technology represented greater confidentiality and security than the current paper record, which was vulnerable to being lost or stolen.
- Standards of security should not be imposed on technical solutions that were higher than or different from those currently in place.
- Sharing information in the clinical team should be selective and in accordance with the patient's wishes. Staff would be given a pin number, which would enable them to access certain parts of the record.
- It was vital that an all-Wales approach was adopted. It should then be possible to build into the contract that any upgrade offered by manufacturers should include the easy transfer of existing data. Computer equipment becoming obsolete quickly was a problem, but a way of refreshing the system without a major upheaval would have to be found.
- The Task and Finish Group had considered proposing a single integrated health and social care record, but had felt it was too ambitious as there were issues in both sectors that needed to be resolved. The move to a single record for both sectors would need to be planned over time.
- The system would look the same at all locations. A healthcare professional moving around the Service should not have to learn a new system every time.
- Problems had been experienced in the past in the take up of technology by clinicians and this was a result of the lengthy training required. If a user could not navigate their way around the system on their first attempt it would not succeed. Nevertheless, a readiness programme was being developed for all organisations. This would require each organisation to demonstrate how they were engaging clinicians.
- The experiences of other countries were being taken into account.

2.8 The Minister said that the Task and Finish Group had already done a lot of foundation work. The Welsh Assembly Government now had to decide whether to approve the strategy and recommendations. If it was approved an announcement would be made in March. The Implementation Board would be critical to implementing the strategy and officials had begun work on a number of implementation plans. A budget uplift of two per cent was included in future spending plans to cover the costs of implementation. It was noted that in his report on the NHS in England, Derek Wanless had referred to four per cent being the figure needed and he would be asked to look at this in the work he would be doing in Wales. Informing Healthcare was a three to five year strategy and the major expenditure would occur at least three years into the programme.

Item 3: National Sentinel Clinical Audit on Epilepsy Related Deaths (10.10-11.00am)

Paper: HSS-22-02(p.2)

3.1 The Chair welcomed Jane Hanna, Director of Epilepsy Bereaved.

3.2 Jane Hanna tabled a briefing paper, a copy of which is attached at Annex A. Her presentation covered three main issues:

Potential for Improvement

Every year in the UK 400 potentially avoidable deaths occurred as a result of epilepsy. Welsh statistics were not recorded separately but it was estimated that at least 40 of these occurred in Wales. There was a 20% misdiagnosis rate for epilepsy and a high rate of unnecessary emergency admissions, but potentially seven out of ten people with the condition could be seizure free with the right treatment and medication. People receiving treatment in the NHS could not take it for granted that they would see an epilepsy specialist and Jane Hanna believed epilepsy was deeply unfashionable with clinicians and health service managers. In the past, patient expectations had been very low and many had disengaged from the service, but she believed that was changing. An increasing number of families felt that their only resort was through complaints and litigation. Change was needed urgently, and if cost effectiveness and equity were key objectives for the NHS then the situation needed to be addressed as a priority.

What Should Happen

There were things that could be done immediately that would cost very little but have immediate health gain. If healthcare professionals gave information on voluntary sector support it would encourage self-management. There was a shortage of neurologists, particularly paediatric neurologists, but by encouraging networks of clinical expertise knowledge could be cascaded. Epilepsy clinics in general practice were virtually non-existent, but most surgeries provided clinics for insulin dependent diabetes, which had approximately the same incidence rate. The Joint Epilepsy Council had drawn up a basic strategy and this should be used as a starting point for debate.

Implementation

Implementation of an Epilepsy Strategy would only work if it was supported from the centre, and included ring fenced funding to ensure changes actually happened. In Northern Ireland, the Government had brought the key stakeholders together to consider the issue and this approach was recommended for Wales.

3.3 In response to comments and questions from Members, Jane Hanna made the following additional points:

- There was still a stigma attached to epilepsy. This related to both clinician attitudes and the public perception.
- Epilepsy was a very complex condition and there were many types. Every case was individual and therefore needed somebody with expertise and understanding of the condition to decide on appropriate treatment.
- Due to the shortage of paediatric neurologists, a child would normally be referred to a paediatrician.
- The audit showed a lot of potential for improved self-management. A significant number of patients were not complying with their medication. Patients needed to know the risks associated with their condition, but as late as the early 1980's trainee doctors were told that epilepsy was a wholly benign condition.
- In Cardiff, protocols relating to the interface between specialist epilepsy services and the accident and emergency department had been developed, and this good practice needed to be rolled-out to.
- Outreach services were very important, not just through the voluntary sector but for statutory services as well.
- One of the key findings of the audit had been that most children with epilepsy had other difficulties, and often the treatment and care of other conditions took precedence over the epilepsy.
- The audit in primary care showed a significant percentage of late prescriptions, which indicated that patients were not taking their medication as they should. In secondary care, 15% of patients were not attending appointments. Handling of missed appointments varied. Some clinics recalled patients, others did not.

3.4 The Chief Medical Officer said that she suspected clinicians' attitudes to epilepsy varied across Wales and there could be a case for ensuring there was improved and informed understanding.

3.5 The Minister said that she had met with Jane Hanna to discuss how to move forward in Wales. She said that the National Institute for Clinical Excellence (NICE) was developing guidelines on the diagnosis and treatment of epilepsy in children and adults, but their work would not be completed for a year or longer. In the meantime she wanted to move ahead with stakeholder workshops, such as those

that had taken place in Northern Ireland. The voluntary sector would be key to the way forward, as part of a multi-disciplinary approach. She also said that proposals had been received from Epilepsy Wales.

Item 4: Statement by the Minister for Health & Social Services (11.15-11.20am)

4.1 The Minister made a statement on the decision of the National Institute for Clinical Excellence to locate the National Collaborating Centre for Cancer in Cardiff. A copy is attached at Annex B.

Action

- In response to questions from Members, a further note on the details of the bid would be provided.

Item 5: Recruitment and Retention, A Strategy for NHS Wales (11.20-12.00pm)

Paper: HSS-22-02(p.3)

5.1 The Chair welcomed Peter Finch, Richard Jones, Mandy Price Jenkins and Janet Wilkinson from the NHS Partnership Forum.

5.2 The Minister introduced the strategy and emphasised that the Assembly Government, NHS Employers and Trade Unions were working together towards meeting the recruitment and retention needs of the NHS in Wales, taking a co-ordinated approach that could be monitored and reviewed as necessary. The strategy worked in tandem with other strategies within the NHS and was a "live" document that could be added to and built on at any time to enhance recruitment and retention and covered **all** staff in the NHS.

5.4 The workforce planning process had developed over the last two years to include a more sophisticated process of collecting data for all staff in NHS Wales. This would enable the identification of trends of movement of staff in and out of the NHS, as well as looking at future staffing needs. Trusts were already being encouraged to use appropriate workload measurement systems for nursing and nine trusts had systems in place.

5.5 To raise awareness of the variety of NHS careers available a report on the provision of careers information in NHS Wales was due to be completed shortly. They were looking at the feasibility of all initial careers enquiries about the NHS in Wales being handled through one bilingual source.

5.6 Discussions were taking place between UWCM, University of Wales Bangor and North East Wales about the development of occupational therapy education programme in North Wales. It was intended that a four year part time programme would commence in September 2003 in Wrexham and two year accelerated programme would start in Bangor in January 2004. It was anticipated this model could then be used to develop programmes for other professional groups in North Wales e.g. physiotherapy, speech & language therapy.

5.7 All vacancies were currently advertised to existing staff on the HOWIS website through the Intranet. On 26 October 2002 vacancies that were advertised externally to the public went "live" on the all Wales recruitment website. Six trusts were currently advertising their vacancies as a pilot to "iron out" any technical difficulties, before an official launch in the new year. After that anyone in the world would be able to access all vacancies in NHS Wales on one website and work was underway to develop an online application facility.

5.8 A return to practice campaign for Allied Health Professions was being planned using radio, newspapers and leaflet distribution. It would be the first of its kind in Wales and the campaign was due to start in January 2003. The professions being targeted were Speech and Language Therapists, Physiotherapists, Occupational Therapists, Audiologists, Radiologists and Dieticians. Funding was in place to provide bursaries for Allied Health Professionals attending Return to Practice Programmes and this funding also included funding for childcare support.

5.9 The representatives of the Partnership Forum all welcomed the strategy. Peter Finch stressed the importance of affordable childcare and flexible working and Richard Jones highlighted the crèche at Conwy & Denbighshire NHS Trust as an example of good practice. In response to comments and questions from Members, they also made the following points:

- Every trust had had to develop their own recruitment and retention action plan.
- Research had been carried out into why people left the NHS. The most common reason was pay, followed by continuing professional development, flexible working, the amount of time available to treat patients and the way staff were treated.
- Exit interviews had been included in the work of the Good Practice Teams, and trusts were spending a lot of time carrying out exit interviews and questionnaires.
- In Gwent, a competence based training scheme was being developed for health support workers to have the opportunity to access nurse training.
- The majority of nursing students who dropped out did so because they could not afford to continue their training, as bursaries were too low.
- Reducing stress would make nursing a more attractive career.
- Newly trained staff more readily accepted the need for record keeping for audit purposes and were more skilled in the technology, than longer serving colleagues.

5.10 David Melding expressed concern that the strategy contained no financial information.

5.11 The Minister said that £1m was being invested in childcare over the next three years and a task and finish group had been set up to look at the issue. Elder care was also very much on the agenda. A study had been commissioned on reducing bureaucracy and this would report in the summer, and a review of occupational health in both primary and setting care would also be undertaken. One and a half per cent of the annual uplift in NHS funding had been earmarked for meeting the targets of the strategy. £22 million was earmarked for next year and the growth targets were manageable.

<div>Action<ul style="list-style-type: none">● Details would be provided on which trusts had taken up the bursary scheme for nurse training.</div>

Item 6: Minutes of 20 November 2002

Paper: HSS-20-02(min)

6.1 The minutes of 20 November were agreed. There were no matters arising.

Item 7: Paper to Note – Committee’s Forward Work Programme Jan to March 2003

Paper: HSS-22-02(p.7)

7.1 The Committee’s forward work programme for January to March 2003 was agreed.

Item 8: Any Other Business

8.1 The launch of the Committee’s report on the review of services for children with special health needs would take place on Thursday 12 December at 2.15pm in the Special Needs Advisory Centre, Margam.

8.2 A demonstration of automated dispensing was taking place in the Assembly Hall.

Committee Secretariat

Briefing Paper to the Health and Social Services Committee

4 December 2002 – Jane Hanna, Epilepsy Bereaved

Summary of Key findings of the National Sentinel Audit into Epilepsy Related Death (Detailed findings at www.sudep.org)

- Only 13% of 2,412 deaths of people with epilepsy were adequately investigated.
- Every year in the UK about 1,000 people die because of epilepsy.
- At least one third never saw the appropriate specialist.
- The audit found a lack of review or care plans in 89% of deaths in primary care with 41% having no record of monitoring in two years before death.
- There was poor medical recording of type of epilepsy, seizure activity and response to treatment and only 8% of patients who should have been re-referred to specialists were referred.
- There was poor drug management in 18% of cases and 14% had recorded problems taking their medications.
- Information was poor to families. In only 1% of cases was the fatality risk from seizures recorded as being discussed.
- Overall, 42% of deaths were potentially avoidable.

Background on the Case for Epilepsy

1. Although epilepsy can affect anyone and indeed affects more than 300,000 people and their families, it is more than 2 times more likely in the poorest groups in society (BMJ October 2002). There are over 20,000 people in Wales who have epilepsy. About 30% of cases of epilepsy are unreported, and there is about 20% misdiagnosis.
2. 7/10 people with epilepsy and their families should be seizure free with modern drug treatments of epilepsy. There is plenty of evidence and guidance already on good practice – on early and better diagnosis, quick access to a specialist but as importantly better co-ordination between GPs and hospitals and good information and support to patients and families.
3. In spite of its prevalence and potential for treatment, it remains a hidden and neglected condition. Research shows that 20 to 25 percent of cases are wrongly diagnosed. We know that 30 percent of patients with active epilepsy are not receiving treatment from a specialist and that one in 12 people are not referred to a specialist at all. On average, it takes six months to one year from the onset of a first seizure to receive definitive diagnosis and treatment. Epilepsy clinics at general practice level are almost non-existent compared with clinics for other chronic conditions.

4. Overall development of essential epilepsy services languish behind other chronic medical conditions.
5. Deaths could be reduced by up to 40% each year, but death rates from epilepsy have remained static at 1,000 deaths a year because of lack of action. The majority of deaths take place in the 20 to 45 year age group and most occur at home. Those tragic deaths in people at the peak of their productive lives are eminently preventable with up to 400 lives that could be saved each year.
6. The cost of not managing epilepsy adequately also includes increased admission rates to Accident and Emergency (CSAG) and failure to free up opportunities for thousands of people with the condition to secure employment and family life. The total financial cost in the UK associated with epilepsy was estimated at £1,930 million in 1994.
7. The Epilepsy Deaths Report 2002 showed that existing good practice guidance for epilepsy was rarely implemented and that any action to reduce deaths must therefore be to support the development of front-line clinicians (see footnote 2 on key findings).
8. Attempts to get local health purchasers to give local priority to epilepsy by recommending good practice guidance to them failed in both 1995 (EL (95) 120) and most recently in 2000 (NHS response to the Clinical Standards Advisory Group 2000).
9. Resources to significantly improve epilepsy services for 7/10 people with epilepsy will be small relative to the resources necessary for patients with conditions that are most likely to require high-tech interventions and long periods in acute care, but national direction and resource are necessary.

Recommendations for strategy from the epilepsy voluntary sector

The Joint Epilepsy Council, representing 21 epilepsy organisations across the UK, has developed recommendations for a strategic vision, which are detailed below. In Northern Ireland a meeting of stakeholders met in September 2002 to make recommendations on the way forward and we would recommend that a meeting of stakeholders in Wales would be an important step in developing any strategy for Wales.

JEC Strategy

We would expect that an effective strategy to reduce deaths and improve quality of care would contain specific targets for cutting the number of deaths within a fixed period, plans to monitor its effectiveness, specific directions to Health Boards and Trusts on what they must do and resources to deliver the plan.

Aim:

To reduce epilepsy-related deaths by 40% within three years by providing access by all patients with epilepsy and families to an adequate epilepsy service.

Strategy:

That government mandate every Hospital Trust and Local Health Board to implement a clinical network of epilepsy expertise delivering

- Specialist consultation within 4 weeks of a possible diagnosis of epilepsy being raised. EEG to be available within 4 weeks and MRI within 3 months of request.
- Annual primary care review of all those with epilepsy with documentation of current situation, treatment plan, information provision, which is subject to audit.
- Implementation of specific care pathways and plans for children, the elderly, those with learning disability, women of reproductive potential and ethnic minorities.
- Tertiary referrals to be available within the Clinical Network for those whose seizures are not controlled.

Government needs to provide leadership, direction and resources

- Setting national target for reduction of epilepsy-related deaths by 40% within 3 years.
- Development and implementation of national guidance on the accurate investigation and recording of epilepsy-related deaths.
- Follow-up audits of epilepsy care at primary, secondary and tertiary levels.

Resources required

- Provision of adequate trained staff to meet the needs of those with epilepsy:
- Specifically: 1 Consultant with a special interest in epilepsy and 1 Epilepsy Specialist Nurse / 100,000 population.
- There should be an identified lead GP responsible for implementing, auditing and monitoring epilepsy provision at primary care level, within each Health Board.
- Sufficient provision of EEG and brain imaging to meet the above waiting time targets.
- Support to the voluntary sector as a vital resource in delivering information and support.

NICE Collaboration Centre for Cancer to be based in Wales

Welsh Minister for Health and Social Services Jane Hutt today said that she was delighted with the announcement made at the National Institute for Clinical Excellence (NICE) Conference in Birmingham, that the National Collaborating Centre for Cancer is to be hosted at Velindre NHS Trust and the University of Wales College of Medicine in Cardiff.

The Minister said "This is wonderful news. It will be a partnership between key Royal Colleges, Specialist Professional Societies and Patient Organisations. It is a very public recognition of the level of experience that exists in Wales and Dr Fergus MacBeth who headed up the bid for the Collaborating Centre is to be congratulated on the achievement. I will be writing to Dr MacBeth shortly to offer him my personal congratulations".

The Collaboration Centre for Cancer will operate from 1st April 2003. NICE National Collaboration Centres are established as a professionally led group, with the expertise, experience and resources to develop clinical guidelines and audit advice. Six National Collaboration Centres already exist for Acute Care, Chronic Conditions, Mental Health, Nursing and Supportive Care, Primary Care and Women & Children's Health.