# APPENDIX J. (See Chapter 3 Essay 10)



GIG CYMRU NHS WALES

Chronic Conditions Management Demonstrators
Arddangoswyr Rheoli Cyflyrau Cronig
CARDIFF | CAERDYDD

## THE CARDIFF AND VALE EXPERIENCE

**The Cardiff Chronic Conditions Management Demonstrator**
The delivery of co-ordinated, comprehensive and consistent Chronic Conditions Management (CCM) services in the community is an integral part of effective mainstream service delivery in the community. This is a key Ministerial priority, the basis of which was drawn from international evidence and published in *Improving Health and the Management of Chronic Conditions in Wales: an Integrated Model and Framework for Action* (WAG).

Improving CCM across Wales depends on good integrated planning and management in partnership with all stakeholders. The aim of the strategy was to improve health and well-being and reduce the incidence and impact of chronic conditions and the inherent inequalities that exist across Wales.

To help deliver and drive improvements in CCM across Wales in an action centred way, three large scale Service Improvement Demonstrator Projects were established, one in Cardiff, one in north Wales and one in Carmarthenshire. This provided an opportunity to focus effort, support and resources in localities to test and learn from concerted effort across organisational and professional boundaries. Lessons and practical solutions were worked through and used to develop the business case for change which supported further mainstreaming across Wales. The aim of this was to;

> *"Provide and test a sustainable, affordable generic CCM service model that supported patients' needs locally and promoted independent living within the community in order to communicate and inform service change across Wales"*

The Cardiff CCM demonstrator was tasked with establishing how Results Based Accountability (RBA) could be used to drive and support implementation of the CCM strategy to ensure services deliver on meaningful outcomes for the population.

## CASE STUDY 1.
## RESULTS BASED ACCOUNTABILITY AND THE WELSH EPILEPSY UNIT

The Welsh Epilepsy Unit is a tertiary referral centre for specialist epilepsy services in south Wales. The immediate catchment population covered is 700,000 but many referrals are also taken from elsewhere in Wales. The unit offers a multi-disciplinary approach to epilepsy care and offers a very broad range of services to people with epilepsy, their family and carers.

**Getting Started with RBA**
In the summer of 2009 a multi-agency steering group was formed to develop and test service improvement opportunities in line with the Epilepsy Service Development Directive (3). One of the core objectives of the group was to establish an RBA framework for monitoring performance and evaluation of epilepsy service improvement. Prior to undertaking any RBA training or workshops a comprehensive service mapping exercise was carried out to ensure the steering group had a common understanding of the gaps in current service provision.

Support was provided by Richard Morton from the Partnership Support Unit (PSU) in the Welsh Local Government Association (WLGA) to deliver an introduction to RBA session to steering group members. Following this session, trainers were trained within the Health Board and all further training and facilitation was carried out internally by the author (CCM Demonstrator Project Lead for Cardiff).

Following discussion it was clear that performance accountability was appropriate. Discussions then focussed on whether the epilepsy "customer group" should be divided to ensure that the needs of patients at different points along the care pathway were met. Using information from the service mapping and gap analysis exercise members of the steering group determined that the group should be split and that "patients with a first suspected seizure or unexplained blackout" would be the customer group for the first RBA exercise.

**The Process**
A facilitated session was held with the steering group to work through the 7 performance accountability questions for this customer group. Participants completed up to question 6 of the exercise during the 2 hour workshop. A number of tasks were identified regarding the collection and baselining of information and an action plan (question 7) was developed at a further meeting.

The 7 question process for performance accountability was repeated at 2 hour facilitated sessions for other customer groups within the epilepsy service:
• Women taking medication for epilepsy between the ages of 14 – 45 who may become or who are pregnant
• People who are admitted to hospital as a result of a presumed seizure

A further introduction to RBA session was held when new partners joined the group after 6 months. The introduction session followed the same format as the original session.

A report card (Appendix 2) was developed for each of the epilepsy customer groups. Data for these report cards are monitored by the steering group on a monthly basis. All of the Epilepsy report cards and details of the epilepsy developments are available at www.ccmdemonstrators.com.

**Benefits and Outcomes**
Curves have been turned for the first customer group. Preliminary outcomes include:
• The average length of time from seizure to a confirmed diagnosis has decreased by 81 days from 111 days to 30 days
• The number of patients who have been seen by a specialist within the NICE guideline of two weeks has increased from 35% to 61%
• The average waiting time to see a specialist has decreased from 22 days to 11 days
• The number of admissions following a seizure have decreased from 5 a month to 2 a month on average

Other benefits that have been observed include:
• All stakeholders are fully engaged and have ownership of the service
• The team have felt committed and empowered to drive service development
• Performance management is now positively viewed by the team as a tool to enable improvement
• The development of a clear line of sight between Board and LSB priorities and patient outcomes at a departmental level

**Challenges**

Challenges experienced by the team included:

- Knowing how to start the process was difficult and needed support from the PSU e.g. 'how long does it take?', 'who needs to be in the room?' etc.
- The lack of availability of patient outcome data was an issue. During the process the performance measures chosen were changed to enable meaningful data collection.
- Whether partners that joined the group mid-process needed "training" in RBA. One additional training session was undertaken as described above but partners joining later on have not had access to this.

**Next Steps**

The Epilepsy Steering Group continue to collect and monitor data for the performance measures and develop the agreed actions.

# April 2007 - April 2010 (Monthly)

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**THE WELSH EPILEPSY UNIT**
**Service Description:** The Welsh Epilepsy Unit is a tertiary referral centre for specialist epilepsy services in South Wales. The immediate catchment population covered is 700,000 but many referrals are also taken from elsewhere in Wales. The Unit offers a multidisciplinary approach to epilepsy care and offers a very broad range of services to people with epilepsy, their families and carers.

**DEFINED SERVICE USERS:** Patients with a first suspected seizure or unexplained blackout

**HEADLINE PERFORMANCE MEASURES**
1. % seen by a specialist within 2 weeks (NICE guideline)
2. No. admissions to hospital for a seizure
3. Average waiting time to see a specialist
4. % did not attend (DNA) first seizure clinic

**DATA DEVELOPMENT AGENDA**
1. Seizure frequency
2. Death rate
3. % prescribed incorrect medication
4. % who report they feel satisfied or better off

**HOW ARE WE DOING?**

% Seen by a Specialist within 2 Weeks

No. Admissions for a Seizure

Average Waiting Time to See a Specialist

DNA Rate
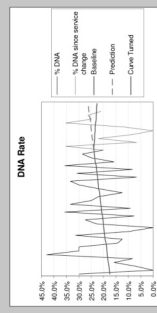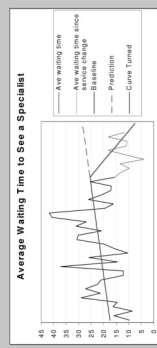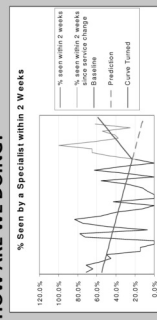
**STORY BEHIND THE BASELINE**
Limited clinic capacity with unpredictable demand
Small team – unable to cover absence to prevent clinic cancellation
Low frequency of clinics causing delay if appointment not suitable for the patient
Clinic booked by Epilepsy Unit admin staff – if admin staff on leave the clinic slots are not filled
Consultant triage's fax referrals – delay if unavailable
Patient anxiety and concern re implications of a diagnosis e.g. driving
Stigma attached to Epilepsy
Patients put off by unit name – diagnosis seems pre-determined
Nurses unable to refer for EEG leading to delay in diagnostics and confirmed diagnosis
New nurse led emergency unit assessment service for first seizure patients has improved performance measures but out of hours service reverts to old pathway
Primary Care does not have fast track access for first seizure clinics
Primary Care are not made aware if a patient DNA's so can't follow up

**PARTNERS WHO CAN HELP US**
Emergency Unit, Radiology, Neurophysiology, Medical Records, A&C staff, Consultants, Specialist Nurses, Ambulance Trust, Cardiology, Psychology, Care of the Elderly, Neurosurgery, Prison, Voluntary Sector, Practice Nurses, GP's, Family members/witnesses, Drug & Alcohol Services, Occupational Health, Referral Management Centre, Obstetrics, Management, Communications Department, Patients

**WHAT ARE WE GOING TO DO TO DO TO IMPROVE PERFORMANCE?**
1. Change the name of the "Epilepsy Unit" to the "Alan Richens Unit"
2. Develop nurse led first seizure clinics to cover when Consultants unavailable
3. Develop dedicated fast track clinic for Primary Care referrals
4. Enable specialist nurse referral for EEG
5. Develop process to inform Primary Care of DNA

http://www.ssiacymru.org.uk/media/doc/2/i/Welsh_Epilepsy_Unit_RBA_Case_Study.doc