Storyboard submission

Follow the detailed instructions in this template for writing a description of your storyboard. Type your information in each section below and save this completed storyboard document as a Microsoft Word file.

Please spell check your storyboard before submission as it will be published on the NHS Wales Awards website.

**Please note: The storyboard should be between 500 – 1000 words maximum (including references but excluding headings, images or graphs)**

Submit your storyboard using the online submission system at www.eventsforce.net/nhsawards2013 by Friday 25 January 2013.

Category: **WORKING SEAMLESSLY ACROSS ORGANISATIONS**

**Storyboard submission**

1. Storyboard Title

**WORKING TOGETHER TO PREVENT PREMATURE HEART DISEASE: FINDING FAMILIAL HYPERCHOLESTEROLAEMIA**

2. Brief Outline of Context

We have pioneered a multidisciplinary cross organisational approach to diagnose and treat the maximum number of individuals with Familial Hypercholesterolaemia (FH) in Wales.

No such co-ordinated service existed previously in the UK.

In 2010 an All Wales service was launched with support from the British Heart Foundation (BHF) which linked together a wide range of health professionals.

Day to day delivery is carried out by FH specialist nurses and genetic counsellors working across Wales with primary care, hospital physicians and laboratory staff. This is linked by a dedicated IT system and coordinated by a service management
team, which reports to a multi-organisational steering group (see diagram).

The service has strong links with a patient and family support group.

The Wales service is now regarded as an exemplar of best practice for other parts of UK.

3. Brief Outline of Problem
FH is an inherited single gene disorder that approximately doubles blood cholesterol levels. FH has a prevalence of ~1 in 500. People
with FH have a very high risk of early onset heart disease. Life expectancy is restored to normal if identified and treated in time.

The problem was that FH was being missed and not diagnosed or treated because it fell between professional stools. Individuals were suffering early onset coronary disease and nothing was being done to prevent this in other family members.

It was everybody’s problem but nobody’s problem. Cardiology teams would treat the premature coronary disease if the patients reached them, but not recognise the cause; physicians and medical biochemists would treat the cholesterol, but not make a genetic diagnosis or be able to follow up families; GPs and paediatricians would not be aware of the condition and would not think of it in younger people, and geneticists did not provide a DNA diagnosis because it was not a condition that they traditionally got involved with. Wales had no system for family “cascade” testing.

If one person is identified as having FH, immediate relatives can be contacted and offered testing and so forth through the family in a “cascade” fashion.

Prior to the introduction of this service, very few patients had been formally identified in Wales.

**Assessment of Problem and Analysis of its Causes**

**Problem**

There was no DNA testing service available.

There was no family cascade testing service.

Lipid (cholesterol) clinic provision was patchy and uncoordinated particularly in North and West Wales

There was lack of awareness in primary care about FH and how to refer.

**Solutions**

The NICE guideline on FH published in 2008 gave a blueprint that we could follow for the service that was needed for Wales.

We learnt lessons from a successful service in the Netherlands.
We worked hard to engage all the clinical stakeholders to agree the patient pathway from case identification to referral, diagnosis and treatment.

We identified the need for a multidisciplinary service that had local and regional components.

The local components were in primary care (case recognition) and secondary care (specialist diagnosis).

The regional components were DNA diagnosis and the family cascade testing.

We recognised the need to coordinate this in a secure and structured way using a dedicated IT system – to be hosted centrally but delivered locally.

5. Strategy for Change

The service change took 6 years to develop and 2 to implement

2005 – 2010 Pilot projects
• Pilot FH specialist nurse, DNA diagnosis and cascade testing
• Success of pilot led to development of business case to Welsh Government and BHF.
• Evaluate and adapt Dutch software systems to meet local needs supported by Cardiff University - Wales Gene Park.
• Encourage patient support group (FH family forum)
• Developed a web site
• 2008- Health Minister commits to implementing FH NICE guidance
• Partnership and funding from British Heart Foundation (BHF) for specialist nurses
• Patient stories – collaboration with University of Glamorgan

2010-2012 Implementation
• Project management
• Multidisciplinary All Wales FH steering group
• Awareness raising across NHS Wales
• Identification of cases in primary and secondary care
• Genetic testing
• PASS Clinical IT system adapted for NHS Wales.
• Genetic testing criteria based on “Dutch” scoring system
• BHF Nurse led FH assessment clinics
• Paediatric services included

6. Measurement of Improvement
The FH database now includes 1147 individuals with possible FH. Of these 471 have a DNA diagnosis. Cascade testing from index patients using DNA testing has led to 222 relatives being diagnosed with FH and 181 being reassured that they do not have the condition.

A BHF evaluation of cardiac genetic nurses (CGN) demonstrated clinical and financial value from these individuals who can lead and cross link the various aspects of the service with the patient being at the centre.

7. Effects of Changes

This multidisciplinary approach working across primary and secondary care has delivered a service for hundreds of patients and families that did not exist previously.

Accolades include
Peer recognition at genetic, nursing, primary care and cardiac conferences. The service had prizes at Heart UK annual conference for leading presentation for 3 consecutive years 2010, 2011 and 2012

An audit by Royal College of Physicians in 2010: This concluded that Wales service was leading the UK-

Publication of patient stories describe experience of a family from Dyfed where 5 family members being started on life saving treatment.
http://medicine.cf.ac.uk/news/could-letter-save-your-life

Recognised as exemplar of good practice in the UK Guardian newspaper (Jan 2013)
http://www.guardian.co.uk/society/2013/jan/22/blood-screening-heart-attacks

8. Lessons Learnt

Working across professional boundaries can be challenging.
Early communications, groundwork and repeatedly making the case across Wales in a range of professional settings was essential to bringing clinicians and others on board.

We found that focus on the patient pathway is key to bridging different professional barriers and enables development of systems and processes to deliver the required clinical outcome.

We have found that working in partnership with British Heart Foundation as “third sector” organisation has been very positive not just for funding but also for expertise, training and patient focus.

A strong clinical and economic evidence base is key (NICE clinical guideline 2008).

Good IT systems and expertise are vital.

9. **Message for Others**

We feel that Wales can lead the way in cross disciplinary working if health professionals focus on processes needed to deliver the patient pathway – communicating, putting building blocks in place, showing benefits and ensuring that primary care can link up with secondary and specialist services.