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.nhswalesawards.org.uk by **Friday 25 January 2013**.

**Storyboard submission**

1. **Storyboard Title**

Deactivating ICDs in end of life care and emergency situations

2. **Brief Outline of Context** *(Where this improvement work was done; what sort of unit/department; what staff/client groups were involved)*

Arrhythmia Team, Cardiac Centre, Morriston Hospital, Swansea.
Staff group – Multi-disciplinary team for patients with Implantable Cardioverter Defibrillators (ICDs)
And any health care professional throughout South West Wales that may encounter a patient with an implantable cardioverter defibrillator
Patient group – patients (& their relatives) who have an ICD implant

3. **Brief Outline of Problem** *(Statement of problem; how they set out to tackle it; how it affected patient/client care)*
An Implantable Cardioverter Defibrillator (ICD) is a small cardiac implant that monitors, detects and treats life threatening arrhythmias by delivering an electric shock to the heart (known as defibrillation). If a patient has a terminal illness requiring end of life care (EoLC) it is questionable whether life sustaining treatment such as defibrillation is appropriate. Unfortunately, both locally and nationally, many palliative care patients had died with an active defibrillator; often receiving shock therapy (defibrillation) during the last hours/minutes of life.

It was felt there was lack of understanding by patients, relatives and health care professionals (HCPs) of the importance of deactivating (switching off) an ICD to avoid unnecessary suffering. Whilst deactivation is a simple technical procedure; from a psychological perspective it is sometimes thwarted with challenges for the patient, their relatives and professionals. Therefore improvements were necessary in line with DOH End of life care strategy (2009), All-Wales ICD Deactivation operational document (2011) and End of Life Care in heart failure (2010).

**Objective:** Improve end of life care for patients with ICDs

**Aims:**
- Explore patients, relatives and professionals views on ICD deactivation
- Raise awareness of the All-Wales ICD deactivation operational document & referral form
- Introduce & reinforce the concept of deactivation (turning off) of ICDs in end of life care to patients, relatives and professionals
- Address health professionals educational and clinical needs by producing an education DVD training package

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

(Quantified problem; staff involvement; assessment of the cause of problem; solutions/changes needed to make improvements)

To identify patients understanding, views and needs in regards deactivation a questionnaire was developed with patient representatives. The anonymous, postal questionnaire was sent to 394 patients registered with an ICD implant at the cardiac centre.

A postal survey was also distributed to key areas in Hywel Dda and ABMU health boards to ascertain staffs education and training needs in regards arrhythmias and ICD care. 61% of professionals surveyed identified deactivation as an area of learning need.

The patient survey identified themes which were explored in a series of patient/relative focus groups. Several key action points, two of which were;
1. Patients wanted an opportunity to discuss deactivation of their ICD (75%)
2. Patients had concerns about non-specialist staff knowledge and competency in dealing with deactivation.

The results of the staff questionnaire also highlighted the need for practical guidance on deactivation.

To address these; 4 key actions were agreed:-
- Deactivation of ICDs in end of life and emergency situations are systematically discussed with patients/relatives in their 1st ICD clinical appointment in addition to a brief discussion in their pre-implantation ICD counselling
- As part of a regional cascade awareness campaign, develop an education DVD for health professionals on deactivating ICDs.
- Via conferences and publications, raise greater awareness of the All-Wales ICD deactivation operational document and the simplified process (4 step plan) of deactivation and the DVD

Evaluate the effectiveness of the above and disseminate findings/share good practice
5. **Strategy for Change** (How the proposed change was implemented; clear client or staff group described; explain how they disseminated the results of the analysis and plans for change to the groups involved with/affected by the planned change; include a timetable for change)

**DVD and awareness campaign**: The process of ICD deactivation needed to be simplified so the “4 Step” instruction plan was conceptionalised. Patients, relatives and staff from the ICD team and Medical Illustration department collaborated in the production of the DVD. The DVD provides a simple 4 step plan to deactivation, and was filmed in the clinical area so it replicates “real life” practice. The first draft was piloted and modified in response to feedback of patients and staff. The final version was agreed by the patient support group committee and the ICD team.

An official launch was held in July 2012 and the DVD distributed locally/regionally via a cascade roll-out programme which included primary, secondary, tertiary and palliative care, NHS Direct and the ambulance service.

**Timeline**
- Sept – December 2011 – Postal questionnaire and patient focus groups
- January – May 2012 – Production of DVD
- May-June 2012 – Pilot DVD and modifications
- July 2012 – Launch of DVD & article published in professional journal
- July-August 2012 – Funding for copying of DVDs agreed by Trust and the Patients ICD support group (RE-START).
- August 2012 onwards – Roll out of awareness campaign and promoting DVD
- February 2013 – Guest speaker at national conference, London - sharing experience & good practice
- DVD and awareness campaign: The process of ICD deactivation needed to be simplified so the “4 Step” instruction plan was conceptionalised.

6. **Measurement of Improvement** (Details of how the effects of the planned changes were measured)

Measurements of change/effectiveness
1. Change in health care professionals knowledge and confidence scores (Linkert scale) in ICD deactivation prior to and after viewing the DVD
2. Evaluation of DVD – see below
3. Number of HCPs who have viewed DVD = May - December 2012 = 874 (many more as part of roll out programme)
4. Number of planned ICD deactivations in end of life since introduction of DVD & awareness campaign = 11

7. Effects of Changes (Statement of the effects of the change; how far these changes resolve the problem that triggered the work; how this improved patient/client care; the problems encountered with the process of changes or with the changes)

Improved patient dignity and choice in end of life care
Improved awareness of deactivation in end of life & emergency situations
Streamlining and simplifying the deactivation process
Increased numbers of planned deactivation in end of life
More efficient use of the specialist staff time and expertise by using IT/DVD technology to share accurate, clinical information across large organisational boundaries.
Improvements in health professionals knowledge and confidence scores in regards to deactivation
Potential cost efficiency from an increase in “planned” deactivations undertaken in the clinic setting as opposed to clinical time and travelling costs to visit other hospitals to deactivate in the last days/hours of life DVD now used as part of paramedic annual update training throughout Wales and resuscitation training throughout Hywel dda Trust.

8. Lessons Learnt (Statement of lessons learnt from the work; what would be done differently next time)

Patient engagement and involvement is the key to effective change
Establishing patients/relatives views is essential as their perspective of the service is very different from health professionals.
Involving patients/relatives in all stages ie development of questionnaire, focus group discussions, encourage them to come up with solutions to their concerns/problems, involve them in the production of DVD
Simplify processes/information
Health professionals are very busy, therefore simplifying what you want them to learn is more effective ie 3-4 steps.
Multi-disciplinary Team approach (MDT)
Team involvement especially the patient focus groups as some staff don’t have opportunities to listen to patients views and learn from this seeing the patients perspective
Team support
Change can be challenging for some; so be mindful of this. This is important and key to the success of the project
Timelines
Leading and implementing the project on top of ones everyday workload is challenging.
Sharing good practice – ICD deactivation seems to be a national problem as copies of the DVD have been requested from throughout the UK and even Australia !!

9. Message for Others (Statement of the main message they would like to convey to others, based on the experience described)

ALWAYS over estimate the project timelines, then double them !!!
Remember “Less is more”