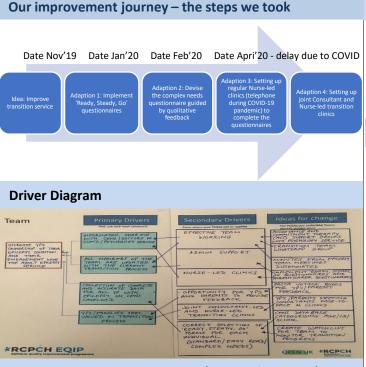
# Aneurin Bevan University Health Board Establishing a Transition Service

Team members: Dr M. Barber, Dr J. Anderson, Dr C. Lawthom, L. Capeling, J. Barber, K. Spender, J. Edwards, A. Johnson, Dr D.Demetriou

# **Aim/purpose:** 90% of all 14-16 year old young with epilepsy will have been sent 'Ready, Steady, Go' forms by May 2020.

**Background:** Paediatric patients with Epilepsy reaching transition stage to adult neurology, were only been offered one joint "handover clinic". The patients and their families had little or no preparation at all for this transition. Likewise, there was little preparation by clinicians for what issues where to be discussed. An urgent need for improving the transition of our patients to adult neurology services, was identified by both teams. The transition programme 'Ready Steady Go' developed by the Southampton Children's Hospital, was chosen.



## How did you diagnose the issue (Pareto, flowchart)



#### Your tests of change

1. Difficult obtaining feedback about 'Ready, Steady, Go' questionnaire content and best method to complete the questionnaire i.e. over the phone or in clinic. For that reason, we created a simple smiley faces feedback form.

2. Developing electronic delivery method of questionnaires and collecting phone numbers/email addresses to facilitate this process.

3. Finding an optimal way to maintain the Watch list so all forms get sent and completed by the time patients reach transition age. CENS currently confirm and check the Watch list.

4. Ascertaining return rate for the 'Ready, Steady, Go' questionnaires.

#### **Outcome Data**

98% of all 14-16-year olds with epilepsy were sent the 'Ready, Steady, Go' questionnaires by May 2020. Transition clinics have been set up, nurse-led clinics and consultant-led clinics on Friday every 2 months. So far, 19 nurse-led clinics and 3 consultant-led clinics have taken place.

#### **Qualitative Feedback from Families/Colleagues**

The Complex Needs questionnaire has been redrafted 4 times, in response to feedback received. Questionnaires are lengthy. Not uniformly positively received but only by some small number of YP and families. Almost all patients and careers needed to complete the questionnaire with a CENS. It significantly increased workload. Patients & careers needed prompting completing the questionnaires.

Most of the responses have been positive. Families have commented that they have a better understanding of transition process and what to expect in adult services.

## **Bright Spots and Challenges**

Using the 'Attend Anywhere' video consultation software was technically difficult with 4 different devices signing in. It was difficult appreciating who was needing to speak next and developing rapport. Successful with teenagers although and visual element suits YP with epilepsy and ASD.

#### Team personal learning/next steps

1. Embedding the routine collection of transition information into regular clinical practice.

2. Resurrect the face to face transition clinics.

3. Delivery of questionnaires to patients via Doctor /Doctor emails and texts alongside paper versions to be completed in clinic. Hard copies will be posted for those with a preference for post.

4. The project has proven that the CENS are essential and valuable members of the team. Therefore we need to retain CENS resources and improve numbers.

5. Now realising multiple aspects of care involved and complexity of some areas of transition, e.g. needing to include transition social worker and learning disability nurses. Aim to improving MDT working for all YP in transition.

