

## PROGRESS REPORT

EQIP champion name: Joe Anderson/ Michelle Barber – February 2020 report

Trust/Health Board team name: ABUHB (South Wales)

Trust/Health Board team members:

As above + Charlotte Lawthom, Louise Capeling, Anne Johnson, Jenny Edwards, Jenny Barber, Demetria Demetriou

Project aim:

90% of all 14-16yo YP with epilepsy will have been sent 'Ready, Steady, Go' (green) forms by May 2020.

Planned tests:

1. To continue sending out questionnaires to patients of transition age by post, to build our experience of use of the forms whilst we explore other methods of delivery (i.e. email and internet link text). These will be collected from them at subsequent clinic appointments together with mobile numbers and email addresses to enable future alternative methods of sending out questionnaires.
2. To gather feedback about the form content and process from YP with epilepsy and their carers.
3. To setup clinic space and availability for joint consultant led epilepsy transition clinic, and joint nurse-led clinic to occur simultaneously alongside consultant clinic. To gather feedback on how YP and parent's/carers feel about the transition clinic after their first appointment.

Results:

1. 154 patients of transition age have now been sent transition forms, including 77 Green forms (14-16yo). This constitutes all the 14-16 year olds under the care of 2 of the 3 Children's epilepsy nurses. The third nurse has been away but her list is prepared for sending out forms in the next two weeks. Therefore we should meet the 90% target in the next 2-3 weeks.
2. We do not have an accurate return rate as yet (though those that have been returned have been put on the patient's electronic record). Once we have finished the laborious task of adding all these patients to the 'watchlist' we have created we will look at return rates.
3. In any case, we will actually review the forms in clinic, and we have now setup transition clinics as planned, a nurse led clinic and a consultant led clinic running side by side in the same outpatient department. Each clinic has its own waiting list. These will be on a Friday PM every 2 months and commence on 3<sup>rd</sup> April 2020.
4. It hasn't been possible as yet to pin down any relatives or YP to gather feedback on how completion of the form went (as the overwhelming majority were posted out in the last 2 weeks).

## Challenges Successes:

We know from our last report that electronic delivery of questionnaires would be a popular method with patients, but as yet we have not got round to developing this. In preparation we need to start collecting mobile numbers and email addresses in order to text and email these questionnaires.

We have now successfully updated the epilepsy database so that we can filter it by current Age of patients, and therefore generate lists instantly of Red, Amber and Green transition age patients. We are in the process of adding these to a Watchlist (or Worklist) in the hospital patient record system so that everyone can see the transition cohorts within the common hospital system. This is going to take a while as it is quite time consuming.

We have been very fortunate to secure clinic space for adjacent nurse and consultant clinics in a geographically very central and quiet adult clinic space in our Health Board.

The process of sending and collecting these forms and setting up the clinics has been complex and it has been difficult to keep everyone in the team up to speed on this. We have managed to have a catch-up meeting between teams where about 50% of relevant clinicians attended so there is better shared understanding now.

## Next steps:

To set up the delivery of 'Ready, Steady, Go' questionnaires to patients via Doctor/ Doctor emails and texts. This is a platform used by our healthboard to automatically (or manually) push information to patients before appointments, by email or text, and allows them to enter Patient Reported Outcomes/Questions in their own time before clinic. This information is stored on that system & viewed electronically on a dashboard by the clinicians whilst sat in clinic (or before if needed).

We know that some patients are going to want to do this in person in clinic, and so we will need to be prepared with printed versions of the form and pens. These hard copies could be posted to those with a preference for post. Finally, we will also make Word document versions of the questionnaire for patients who want to complete their information on the document electronically and send it back to us (rather than write in pen, or follow the electronic link to the DrDr webpage).

Once we have finished sending out all the transition forms over the next few weeks we will need to transfer these patients to the watchlist and decide how to track their progress (i.e. return of forms, booking to clinic etc).

The IT infrastructure to continue this transition service in the long term is all complete. Staff will need training and to familiarize with this.

We have arranged another team catch up meeting (including to develop our poster for the May EQIP event) on Wed 26<sup>th</sup> Feb all afternoon.