







Dr Afaf Tebbal

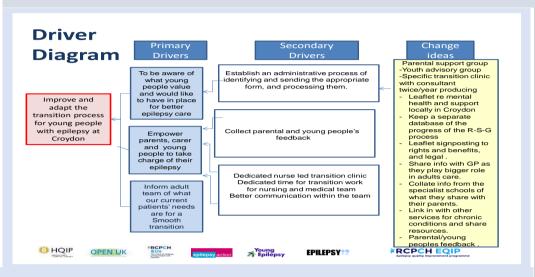
Anne Makunde

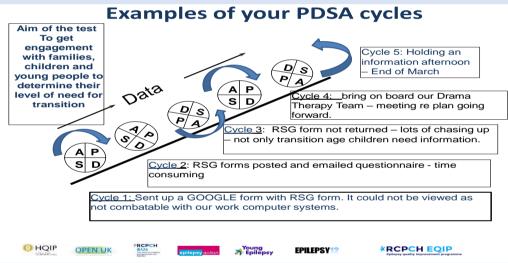
Dr Sherry Fang

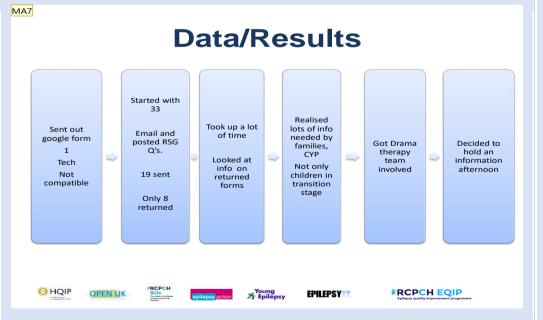
Our Aim: To improve and adapt the transition and information sharing process for the children and young people with epilepsy in Croydon by March 2022.

What is the problem: Families and CYP with epilepsies understanding of transition is poor.

They reported that they did not know enough about it.







## Challenges/Limitations Successes Opening discussions with families Technology Children, young people and Families Questionnaire's – not reliable engagement – they want Numbers – not many returns information. Lack of engagement from some Families acknowledgement that things are improving in Croydon -Time: holding a caseload and fitting (but we still have more to do). in meetings etc. Families feel they are being listened Admin time – don't have any to. Sickness - unfortunately Working with other teams in the

epsy action Young

\*RCPCH EQIP

trust. – Drama therapy team, adult

Epilepsy team.

## **Patient and Family Engagement**

Who is involved? Parents and young teenagers age 14 and above both – mainstream and children with Learning needs in special schools

How did we involve them? By introducing the RSG questionnaire What did you change as a result of engagement? We needed to change the way we shared information

What feedback did you receive? Very little - Questionnaire's ....... As has been discussed all the way through this programme.

They take up a lot of time and are unreliable.



- We thought this was going to be an easy and straight forward project to do with a questionnaire.
- Very easy to make up a Google questionnaire form.
- Technology. Google form set up from home but our work computers were not compatible.
- Posting and emailing this is extremely time consuming.
- Questionnaires take up lots of time for little reward/answers.



## **Team learning highlights**

Technology is not always compatible.

Questionnaire – not the quickest or best way to get feedback. Communication Communication

The need to keep everyone updated.

With families CYP

Drama therapy team are a Brilliant support – we are lucky to have them in Croydon. – We know –



## **Next Steps**

We are holding an information sharing afternoon for all school age children.

We have put together lots of information packs/leaflets for different age groups

We will start holding transition clinics to answer all families and young peoples questions – to get them ready for moving on.

We will constantly look to improve our systems of working together with our families and CYP.

