

## Development of first seizure pathway

### Royal United Hospitals Bath NHS Foundation Trust

#### **RCPCH Epilepsy Quality Improvement Programme project team:**

Dr Eve Bassett, Consultant Paediatrician, Epilepsy and Neurology Lead

Dr Toby Hunt, Consultant Paediatrician with Epilepsy Interest

Dr Carrie Furnell, Consultant Community Paediatrician

Dr Sam Amin, Consultant Paediatric Neurologist with responsibilities for Bath outreach service

Jenny Ferguson, Specialist Clinical Physiologist

National audit results included within this case study acts as a guide only to performance standards. The service improvements made during the EQIP cannot be entirely attributed to the reported results in the Epilepsy12.

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## **Project aim**

To develop and implement a pathway for first paroxysmal events allowing review by paediatricians with special interest in epilepsy. We aim that 90% of new epilepsy referrals will be seen within epilepsy clinic within 6 weeks (and 50% within 2 weeks) by May 2020.

## **Background:**

- All patients with epilepsy are not necessarily seen by epilepsy specialists who hold clinics jointly with an epilepsy nurse, resulting in a disparity in the quality of care provided to children and young people with epilepsy. In addition, new referrals for possible epilepsy could be triaged by any one of the consultant teams and subsequently allocated an appointment in any clinic with a space, again contributing to inconsistency in the service received. As the Epilepsy12 audit was completed for cohort 1, it became clear that this lack of consistency was impacting the quality of patient care.

## **Area of focus**

- Begin the process of mapping the patient pathway as a starting point to identify the barriers and begin the process of improvement. The team estimated demand for new epilepsy clinic slots and anticipated the need for 7-9 new epilepsy slots per month. This was obtained from the local referral database (spreadsheet) and Epilepsy12 combined: the DM spreadsheet estimated 9.4 referrals per month and 7.6 referrals per month from Epilepsy12.

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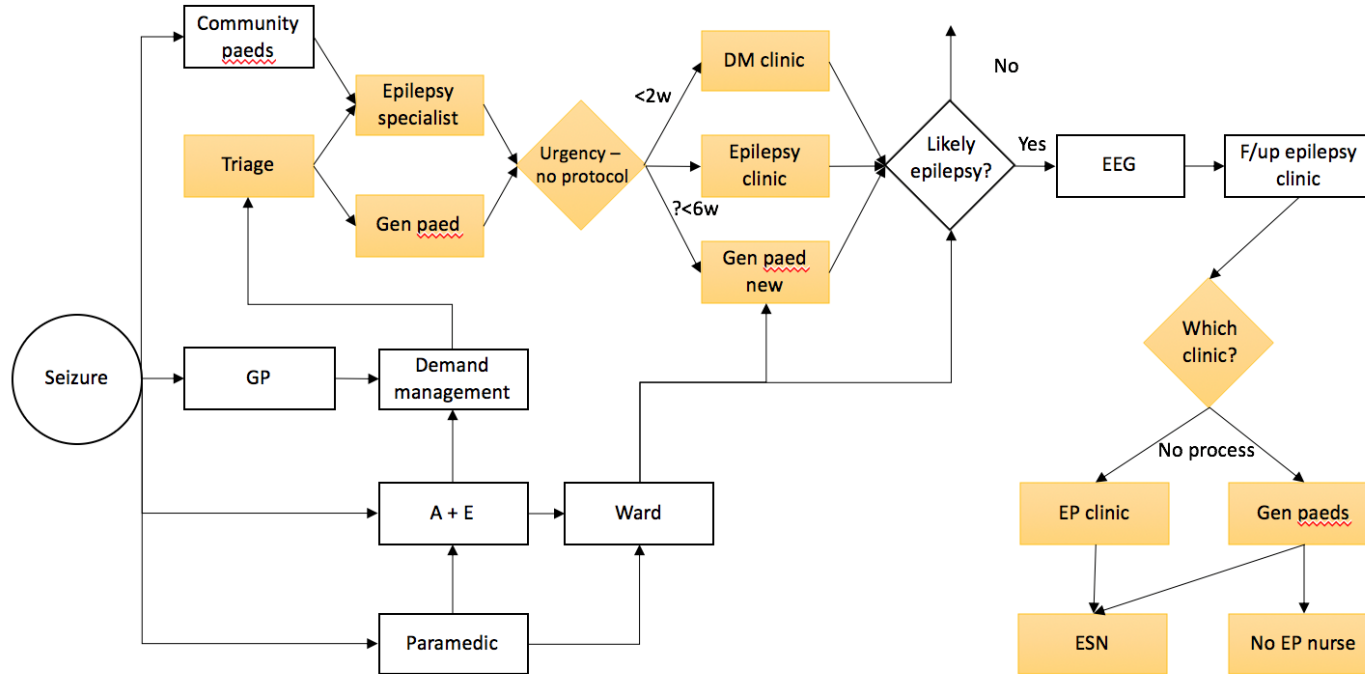
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## Changes:

- Trialled the development of an ESN call service for families prior to attending the clinic for specific pre-identified patients. This was added to the process after a participant EQIP team shared their experience offering a more specialised service for families at an earlier point in their journey, which allowed for further stratification of appointment urgency. This meant the team could start some of the processes often initiated in first clinic a lot earlier, e.g., requesting videos of an event, requests for EEG ahead of the clinic (this was rarely done before the pandemic, but the pathway has evolved under new circumstances). A new (specialist) triage process was put in place for new possible epilepsy patients.
- All new possible epilepsy patients were now being seen in epilepsy clinics.
- New in-house referral form has been developed for first-afebrile seizures.
- New Standard Operating Procedures (SOP) are in place for the first-fit pathway.
- New patient/family guides created for common comorbidities (mental health, behaviour, education, sleep).
- New RUH paediatric epilepsy web page was developed to allow all resources to be easily located in one place.
- NPF staff joined the team to support Epilepsy12.

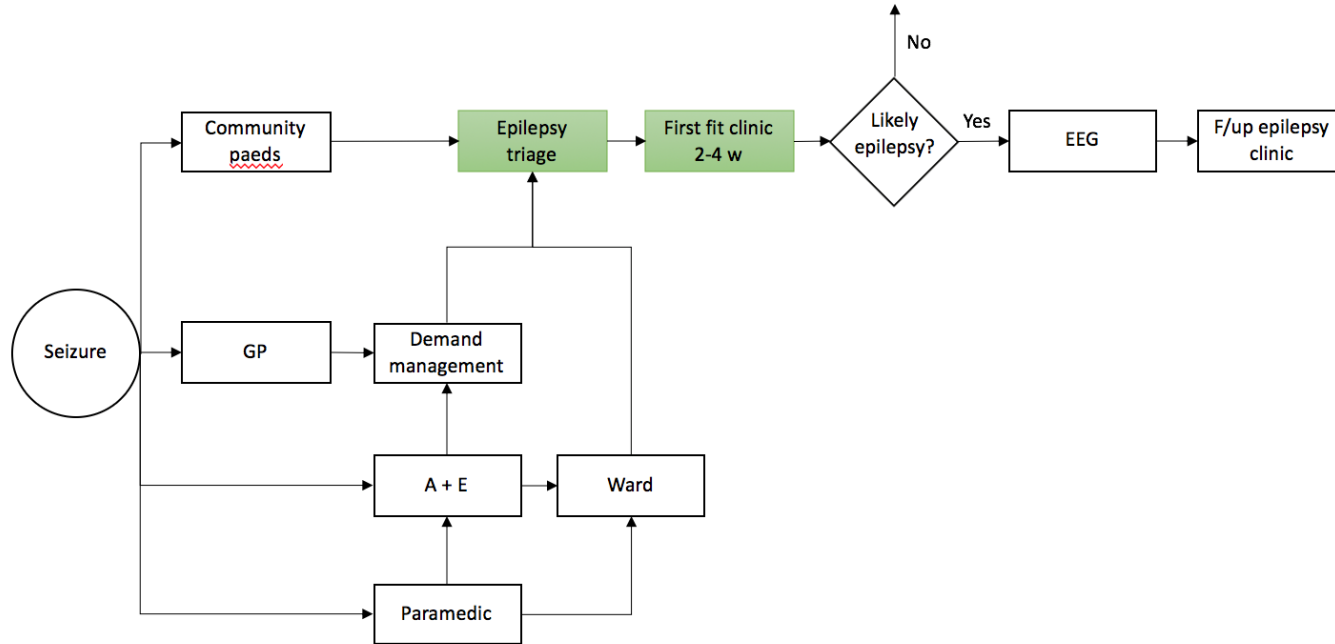
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## Process map of patient journey prior to EQIP



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## Process map of patient journey after EQIP intervention



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## Results

Pathway from initial referral to epilepsy clinic up and running:

- 53 referrals in 6 months (in keeping with estimated 8 per month as per previous)
- 15 from GP
- 7 from community
- 15 at least from ward / ED

## Acute referrals:

- Vast majority within 6 weeks, and 11 (57%) within 2 weeks.
- Of the 8 patients who waited > 2 weeks, 5/8 had ENS contact within 2 weeks. Of the three that did not, one was not a new epilepsy patient, and they were given contact details for the ENS
- Shortest wait – 1 day
- Longest wait – 3 months
- Qualitatively – duration of wait matched severity of concerns well (i.e. those who waited longer were less likely to be seizures, longest wait for new GTCS 3 weeks and contacted within 2 weeks by ENS).
- Telephone Consultations – 1 test done so far for a follow up patient

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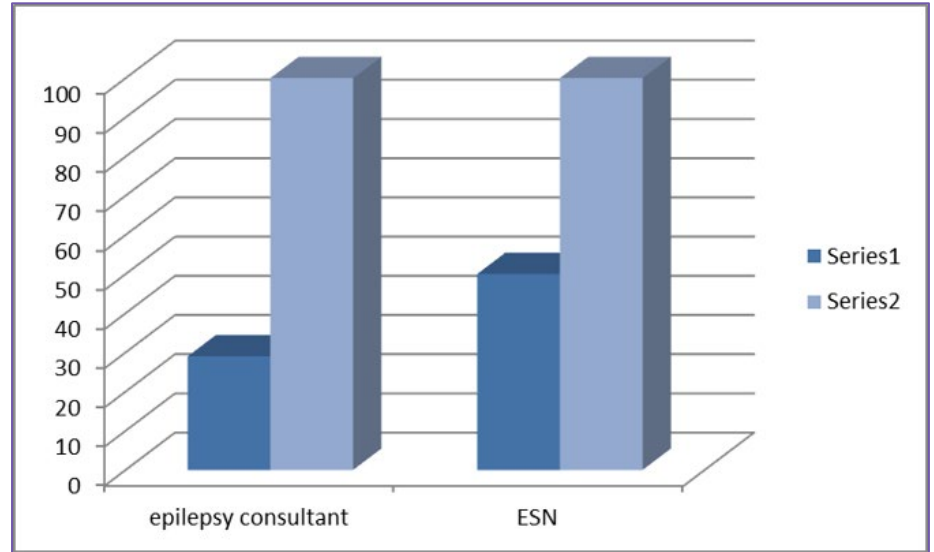
## Results

### Before EQIP – E12 Cohort 1

- 24 patients
- 4 seen from the start by epilepsy specialist,
- 7 seen subsequently
- 12 has been referred to ENS
- Longest wait for clinic following GTC 4 months

### After EQIP

- 53 patients
- All seen by epilepsy specialist, all had ESN input
- Majority seen within 6 weeks of referral
- Longest wait for clinic following GTC 3 weeks with ESN contact within 2 weeks



# Feedback & Other Projects

## Our new webpage

The screenshot displays the NHS website's 'Our new webpage' for children with epilepsy. The main navigation includes 'Parents & Visitors', 'Paediatric Epilepsy', 'Living with Epilepsy', and 'Our Team'. The 'Paediatric Epilepsy' section features a table with links to 'About us & Contact information', 'What's new & Events', 'Diagnosis & Investigation', 'Treatment & Medication', 'Support & Services', and 'Research & Clinical Trials'. Below this, there are sections for 'Mission Statement', 'Epilepsy Matters', 'Working Together', 'Making a Difference', and 'Our Team'.

Overlaid on the screenshot are several resource cards:

- First afebrile seizure in children - referral proforma**: A form for recording a seizure, including fields for patient details, medical history, and a section for 'Clinical details'.
- Resources to support Challenging Behaviour**: A card titled 'If you're worried about your child's behaviour, there are lots of resources to support you'. It mentions 'Behaviour support may be available through your health visitor in the practical age group or the school's parent support advice for older children' and 'Ask if there is a course or resource available locally that you can access'.
- Resources for Mental Health and Wellbeing**: A card titled 'If you're worried about your child's mental health, there are lots of resources to support you'. It states 'Children and young people can have times when they feel worried or anxious' and 'We want children and young people who have epilepsy have an increased chance of difficulties with their mental health'.
- Safety and Lifestyle advice for young people/adults with epilepsy**: A card titled 'You may have had epilepsy for as long as you can remember or it may be a new diagnosis. This booklet is designed to help you understand the main safety issues surrounding your epilepsy and offers tips on how to minimise those risks and live as normal a life as possible'.

There is some excellent work taking place in the epilepsy team at the moment

Its great to have the same team looking after us from the start

Can you keep these new video consultations after Covid – they are so much easier and we don't have to find somewhere to park!

Thank you for phoning ahead of our clinic appointment, it really put my mind at rest

The website looks fab!



# Audit results for cohort 3 – Professional input- Royal United Hospitals Bath NHS Foundation Trust

NICE recommends that children and young people presenting with suspected seizure are seen by a specialist in the diagnosis and management of epilepsies within 2 weeks of presentation (Quality statement 1).

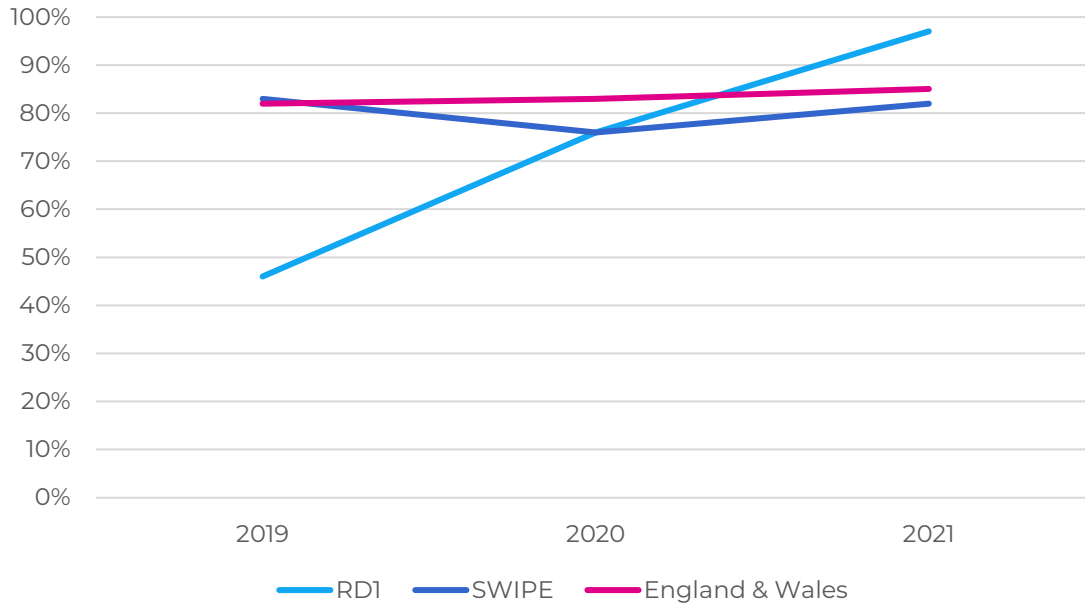
The percentage of children and young people diagnosed with epilepsy that was seen by a paediatrician with expertise in epilepsies in Royal United Hospitals Bath NHS Foundation Trust is 94% compared to 88% for England and Wales.

**The percentage of CYP diagnosed with epilepsy that was seen by a paediatrician with expertise has increased from 72% in 2020 to 94% in 2021 and has risen above national and regional levels.**

	2019	2020	2021	2021 - SWIPE	2021- England & Wales
Percentage of children who had input from a paediatrician with expertise OR a paediatric neurologist within the first year of care	46%	72%	94%	89%	88%
Paediatrician with expertise in epilepsy	46%	76%	97%	82%	85%
Paediatric Neurologist	0%	10%	12%	31%	25%

# Audit results for cohort 3 - Paediatrician with expertise - Royal United Hospitals Bath NHS Foundation Trust

Percentage of CYP with input from a paediatrician with expertise in epilepsies



The percentage of CYP with input from a paediatrician with expertise has continued to increase from 76% in 2020 to 97% in 2021 and has risen above the national and regional average.

# Audit results for cohort 3 - Performance indicators- Royal United Hospitals Bath NHS Foundation Trust

NICE recommends that children and young people with epilepsy are seen by an epilepsy specialist nurse (ESN) who they can contact between scheduled reviews (Quality statement 5).

100% of children and young people diagnosed with epilepsy had input from an epilepsy specialist nurse (ESN) by one year in Royal United Hospitals Bath NHS Foundation Trust as shown in Performance indicator 2.

**The percentage of CYP diagnosed with epilepsy that had input from a paediatrician with expertise increased from 72% in 2020 to 94% in 2021. Additionally, the percentage of CYP diagnosed with epilepsy that had input from an ESN has increased from 80% in 2020 to 100% in 2021 and remained above regional and national averages.**

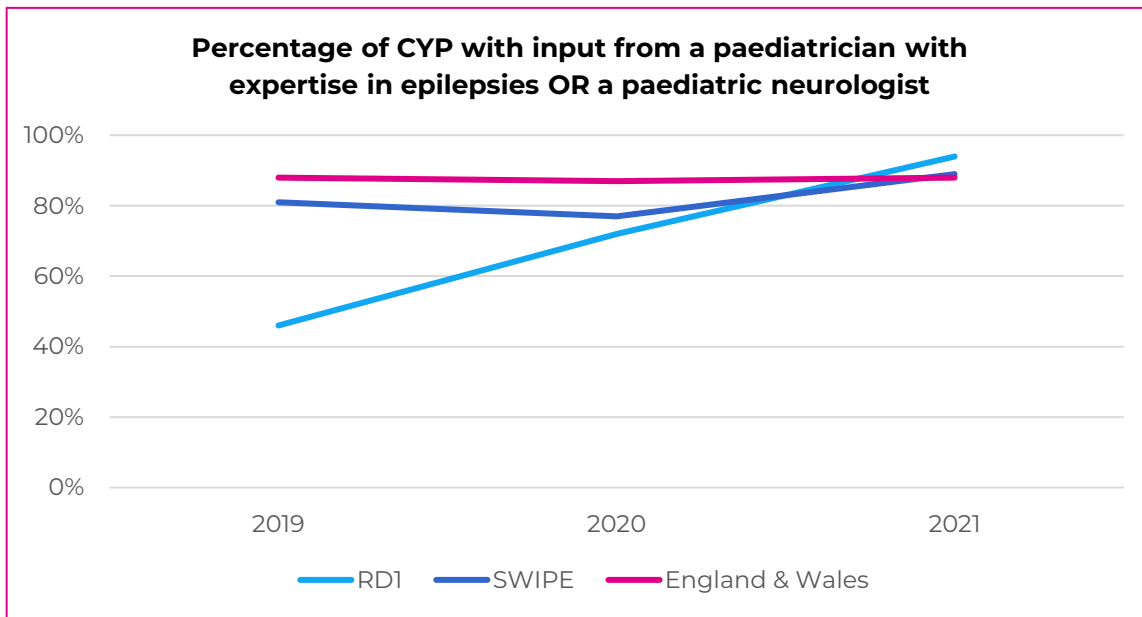
Performance indicators	2019	2020	2021	Regional network SWIPE	Overall Eng & Wal
1. Paediatrician with expertise:	46%	72%	94%	89%	88%
2. Epilepsy nurse specialist	69%	80%	100%	83%	76%

# Audit results for cohort 3 - Time since referral- Royal United Hospitals Bath NHS Foundation Trust

NICE recommends that children and young people presenting with suspected seizure are seen by a specialist in the diagnosis and management of epilepsies within 2 weeks of presentation (Quality statement 1).

91% children and young people diagnosed with epilepsy in Royal United Hospitals Bath NHS Foundation Trust had valid dates for calculation of time since first referral to paediatrics assessment.

47% were seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral.



# Audit results for cohort 3 - Time since referral- Royal United Hospitals Bath NHS Foundation Trust

The percentage of CYP that were seen by a paediatrician with expertise in epilepsy within 2 weeks of first referral has continued to increase from 22% in 2020 to 47% in 2021 and above regional and national averages. Additionally, the percentage of CYP that were seen by a paediatrician with expertise in epilepsy at +16 weeks of first referral decreased from 22% in 2020 to 6% in 2021.

Time since first referral to first paediatric assessment	2019	2020	2021	2021 - SWIPE	2021- England & Wales
0 – 2 weeks	8%	22%	47%	25%	23%
2 – 4 weeks	0%	6%	12%	9%	12%
4 – 6 weeks	0%	6%	16%	12%	9%
6 – 8 weeks	8%	2%	6%	8%	7%
8 – 10 weeks	0%	2%	0%	4%	5%
10 – 12 weeks	8%	2%	0%	2%	3%
12 – 14 weeks	0%	2%	0%	2%	3%
14 – 16 weeks	0%	2%	3%	3%	2%
16 + weeks	8%	22%	6%	12%	13%

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## Challenges

- Lack of accurate coded data regarding potential demand for service emphasised how important data capture is going forward so the team can capture how they are doing and areas requiring improvement in the future.
- Time capacity for an epilepsy nurse
- Geography of the patient cohort.
- Allocating time to participate in the EQIP was a real challenge over the winter, and then by February, everything focused on the related issues concerning the COVID pandemic.
- Extracting data from Epilepsy12 was time consuming (someone specifically was recruited to the team to facilitate this).
- Patients were being referred from multiple different sources; reviewing the process map really helped the team identify all routes into the service with the aim of eventually streamlining this process via the PDSA (Plan, Do, Study, Act) cycle method.

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## Outcomes:

- Implemented pathway from initial referral to epilepsy clinic.
- Introduction of the ESN phone call ahead of clinic review for the majority of patients.
- Development of epilepsy resources for parents and carers on the RUH paediatric epilepsy service webpage.
- Developed a system to allow an epilepsy clinic via virtual interface.
- First afebrile seizure referral proforma went live.
- A feedback tool is embedded.
- Increased the number of patients processed through the new referral pathway.
- All were seen by an epilepsy specialist; all had ESN input.
- Majority seen within 6 weeks of referral

National audit results showed the percentage of children and young people diagnosed with epilepsy that was seen by a paediatrician with expertise had increased to 94% in 2021 and has risen above national and regional levels.

- The percentage of CYP diagnosed with epilepsy that had input from an ESN had increased to 100% in 2021 and remained above regional and national averages.
- 47% were seen by a paediatrician with expertise in epilepsy within 2 weeks of the first referral.

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## Lessons learnt

- “Patient Story” won buy-in from several consultant colleagues. By making this about patients, this brought a different and powerful dimension to the discussion and made it easier for colleagues to reflect on how the service is run pre-EQIP and how it could look different – which became more effective than data in terms of persuading colleagues change was necessary.
- Extracting data from Epilepsy12 to ensure data drives service development – more complicated than first thought!
- The pandemic had enabled a prompt EEG service with a quick report turn around had led to ideas of implementing “protected” slots and practicalities of this with resumption of routine clinics.
- The November launch of the EQIP was a challenging time to begin working on QI interventions due to entering winter pressures – COVID-19 added to limitation in time for EQIP.
- Generally difficult to allocate time to work on project – learning from COVID re: virtual meetings would mean that the team could be more efficient and set aside team meetings even when unable to meet face-to-face. EQIP was a catalyst for change and brought individuals together as a team. Monthly calls brought focus and the deadline made the team progress things – an opportunity to build relationships and improve joint working.



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## Lessons learnt

- An opportunity to critically assess processes and service with access to tools and strategies that were new. EQIP provided a more evidence-based and measurable approach.
- An opportunity to recognise good practice and compare with other teams doing the same kind of work.
- Also to learn from other teams and share best practices.

## Visual presentation of team project intervention

- [Video Presentation](#)
- [Team poster](#)

<https://eqip.rcpch.ac.uk>

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[eqip@rcpch.ac.uk](mailto:eqip@rcpch.ac.uk)

 [@RCPCHSEQIP](https://twitter.com/RCPCHSEQIP)