Name of project: Rapid diagnosis of Autistic Spectrum Disorder (ASD)

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NHS
Kent Community Health
NHS Foundation Trust

What was our aim?

Evaluate and review the process of rapid diagnosis of ASD for suitable children, to understand the benefits such as reduced referral to diagnosis times and number of clinic appointments required.

Why is it important to service users and carers?

Autistic Spectrum Disorder (ASD) is one of the most common conditions encountered in community paediatrics. Around 1 to 2 per cent of the population (1 in 100 children) live with this condition; therefore, demand for diagnosis is high. This is seen nationally, resulting in long delays in waiting lists.

Kent Community Health NHS Foundation Trust (KCHFT) has significant delays and waiting lists, meaning children can wait between 12 and 18 months for a diagnosis, sometimes longer. These delays have been further compounded by the COVID-19 pandemic and the subsequent suspension of face-to-face appointments.

Several projects are currently ongoing to improve service provision around the child, not only from community paediatrics, but from schools and other health professionals. This particular project, within community paediatrics, looked at children who met specific criteria within their initial assessment, who could be diagnosed quickly.

Doing this would mean the child and family could access support quicker, waiting lists would be reduced and appointment time would be saved for both families and clinicians.

Ideas and tests of change

Paediatricians can diagnose ASD if a child fulfils certain criteria and shows evidence of these traits or behaviours in several different settings. At present, most children with suspected ASD are referred for a formal assessment using a BOSA (brief observation of symptoms of autism). If this assessment is not performed, children must have reports from either speech and language therapists (SLTs), specialist teachers or another professional, which can be used as supporting evidence for a rapid diagnosis.

As rapid diagnosis is not yet a formalised pathway for children, this project aimed to compare a small dataset of rapid diagnosis patients with a selection of conventional pathway patients, to understand the benefits to determine whether it would be valuable to formalise the pathway.

In order to measure the benefits, quantitative data was collected from information on Rio (the trust's electronic patient record system):
1. Total time from date of initial referral to date of formal diagnosis of ASD.
2. The total amount of time each patient has spent at clinic appointments during the referral pathway (for example, community paediatrics virtual appointment, then face-to-face examination, then a SLT BOSA, then a feedback appointment).

The tools we used

Process mapping
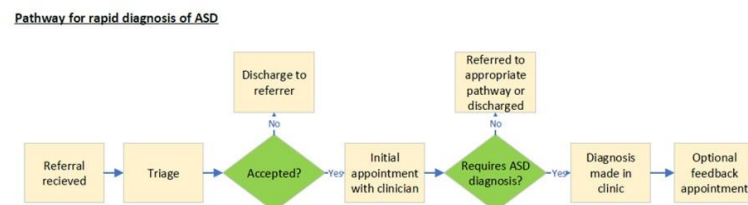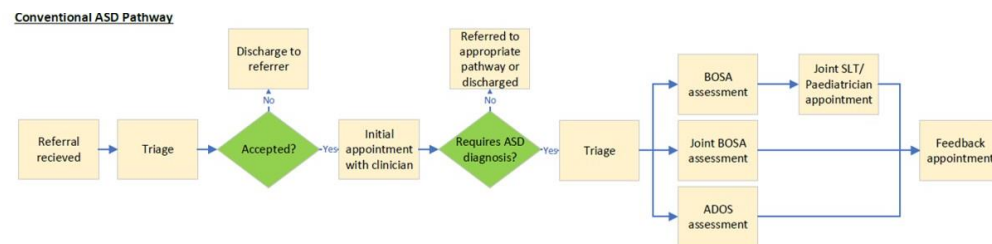
Results/How did we do/Anticipated outcome

Due to limited access to information, only eight children could be quickly identified as being rapidly diagnosed with ASD. In order to fairly compare this to the conventional pathway, seven children were randomly selected who were also diagnosed around the same time. Those referred into the service at the same time were still on the diagnosis waiting list and therefore couldn't be compared.

Figure 1- Conventional pathway

Patient ID	Age at referral	Date of referral	Date of Dx	Time from referral to Dx (months)	Total No. of Clinics	Total Time in clinics (min)
1	1 yr 1 mo	01/10/2019	08/06/2021	20	3	225
2	1 yr 5 mo	12/06/2019	16/06/2021	24	3	255
3	3 yr 6 mo	10/03/2020	17/08/2021	17	3	210
4	9 yr 5 mo	26/03/2019	28/07/2021	16	3	240
5	7 yr 5 mo	20/09/2019	28/07/2021	22	2	180
6	6 yr 9mo	14/01/2018	07/07/2021	42	2	210
7	3 yr 7mo	22/11/2018	20/07/2021	32	2	215
			Average	24.7		219.3

Figure 2- Rapid Diagnosis Pathway

Patient ID	Age at referral	Date of referral	Date of Dx	Time from referral to Dx (months)	Total No. of Clinics	Total Time in clinics (min)
1	3 yr 4 mo	20/01/2020	17/02/2021	12	2	90
2	3 yr 1 mo	21/10/2020	26/03/2021	17	2	90
3	2 yr 4 mo	27/08/2020	25/11/2021	15	2	145
4	2 yr	29/04/2020	07/05/2021	12	3	150
5	1 yr 9 mo	25/08/2020	11/10/2021	14	3	165
6	2 yr 3 mo	12/04/2021	29/10/2021	6	2	165
7	4 yr 4 mo	22/07/2021	11/02/2022	5	1	90
8	2 yr 5 mo	24/03/2021	07/01/2022	22	1	90
			Average	12.9		123.6

Average amount of time spent in clinic appointments (with a community paediatrician or in a BOSA):
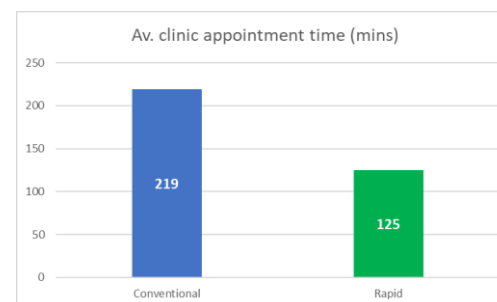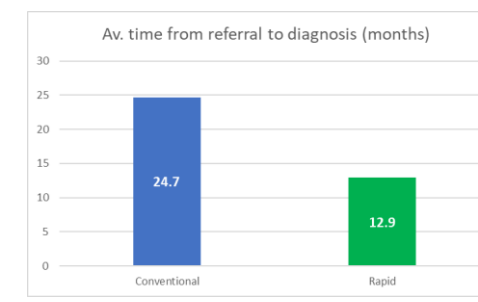- Conventional = 219 minutes
- Rapid = 125 minutes

Average time from initial referral to formal diagnosis given:
- Conventional = 24.7 months
- Rapid = 12.9 months

What we learned and what's next

What we learned:
The data indicated that the rapid diagnosis pathway can significantly reduce time from referral to diagnosis and the amount of time spent in clinic appointments.

This can therefore improve:
- Patient experience – enabling families to access appropriate support quicker, and reduction emotion distress and uncertainty
- Use of clinical resources
- Length of waiting lists.

Next steps:
- Parent feedback will be gathered as the current missing qualitative data around the experience of the rapid diagnosis pathway.
- Stakeholder analysis will be completed to understand who should be involved in the design and formalisation or a rapid diagnosis pathway.
- Data collection will be considered for the new formal pathway to ensure data can continue to be monitored.
- NICE guidance and best practise will be adhered to and consideration of equity across service provision.

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