Review of re-referrals for autistic spectrum disorder (ASD) assessments:

Alexandra Ducroizet[1] , Dr Su Sukumaran[2]

1 St George's university of London, medical school; 2 Springfield hospital London, Child and Adolescent Neurodevelopmental service

Aim: This audit will explore each stage of diagnosing ASD to determine the main reasons for re-referrals.

Method:

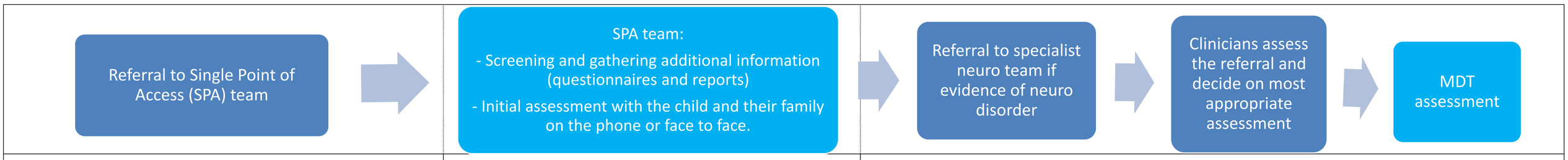
4% of referrals made every year to a neurodevelopmental assessment unit are re-referrals for ASD assessments. A retrospective review of clinical notes and local database was done to explore referral and re-referrals. 51 patients between 6-17 years old (mean 10.3yo; SD 3.1), from October 2017 to October 2018 that were re-referred to a specialised neurodevelopmental assessment unit covering 5 boroughs of London were identified. 75% of them were male.

Introduction:

Despite the growing awareness of ASD in children in the last few years, for every 3 patient diagnosed with ASD there are 2 undiagnosed patients, thus the process of re-referrals is essential (2). Clinical experience and research suggests that many children with ASD are initially diagnosed with ADHD or other conditions and are thus re-referred for an ASD assessment later down the line (3,4). Re-referrals are made as the situation becomes less manageable for families and at school. Not having a diagnosis initially may delay support for the child and the family. CAMHS rejects on average 21.1% of its referrals while in the unit we are conducting this audit in, the rate of rejections is only 9% (1). However, we will look at the reasons for our re-referrals to determine whether the delay some children may experience could be reduced.

Results:

Figure 1: Process for referral and assessment of a patient with ASD.



Various background factors could be at play in re-referrals:

Figure 2 shows that the major source of re-referrals is community CAMHS, suggesting that these children and families are often being seen for behavioural and emotional problems. The 'other' category includes social services, transfers from other units and CAMHS tier 2 workers.

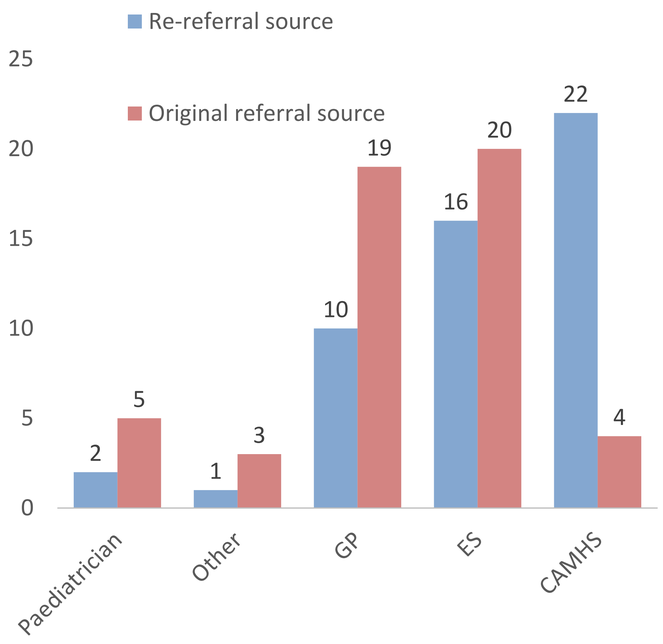


Figure 2: Percentage of children referred by different workers

In this second stage of the referral process, which is a screening stage, 12% of patients referred for the first time were discharged, often as another assessment and/or therapy was being put in place. Some of them also did not return forms within the required timeframe or, after further discussion, decided to not go through with the assessment.

The borough with the lowest referrals has had strategy in place for autism since 2013, potentially picking people who might have otherwise come to neurodevelopmental services. The borough with the highest rate of re-referrals (43%) only implanted a similar strategy in 2018. Perhaps we will see a decrease in the number of re-referrals for this borough in the coming years.

Lastly no socio-economical or demographic correlation was found with the re-referrals rate.

For 24% of children, their first referral did not contain information which suggested that an assessment was necessary and therefore their referral was rejected.

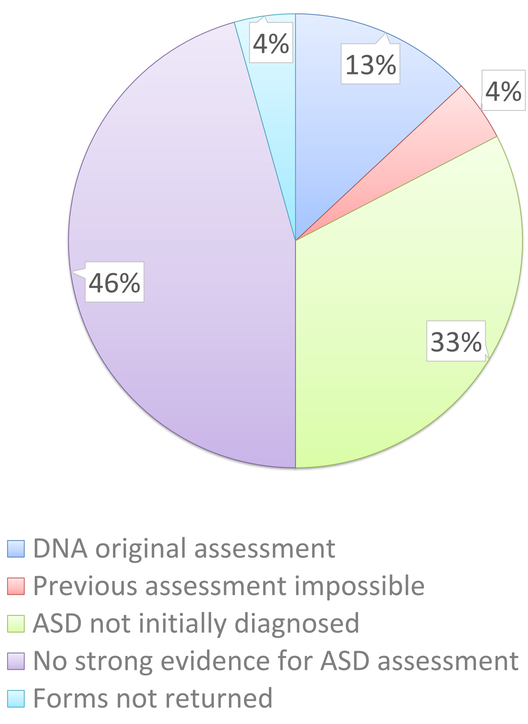
None of these referrals were for patients under 9 years old. The reasons for rejections varied from low ASD screening questionnaire scores, to differences between the school's and the parents' description of the child's behaviour, or often lack of detail in the reports. Each patient received a detailed letter containing the reasons why their referral was rejected and in 79% of cases their subsequent re-referral was accepted.

For people referred for the first time and accepted, 18% had an assessment for ADHD and ASD was therefore not diagnosed initially, though any traits present were highlighted in the final report produced and re-referring was encouraged if these traits were to become more prominent. Together, this makes up 46% of re-referrals as shown in figure 3.

Lastly, 30% of patients were not diagnosed with ASD at the time of the initial assessment. The vast majority had other co-morbidities, such as psychiatric and neurological diagnosis. 72% of them went on to be diagnosed with ASD.

In this last stage 12% of children were re-referred after being discharged as they did not attend (DNA) their initial appointment. 4% were re-referred as it was not possible to do their assessment for example as the parents or carers withdrew consent for the assessment.

Figure 3: reasons for re-referrals



Discussion:

73% of patients reassessed are diagnosed with ASD, thanks to the re-referral process. Looking at figure 3, 79% of re-referrals are due to undiagnosed ASD during the initial assessment and lack of strong evidence for ASD assessment. This represents 5% of all assessments done in a year by the unit. Due to the small sample size and the complex and different patients that are presented, it is quite hard to determine whether this small percentage can be reduced. This audit also only looks at one unit, different units may have different findings.

50% of patients who were not diagnosed in their first assessment had comorbid ADHD, often diagnosed at the first assessment. When a child has ADHD, it is particularly hard to assess them for other disorders as severe disruptive behaviour in ADHD can cloud other symptoms. Furthermore, ADHD itself is linked to difficulties with social interactions, further clouding the diagnosis. One paper suggests using the CASD symptoms checklist as key tool to diagnose ADHD and ASD, with a 99.5% accuracy (3). Many children with ASD suffer also from depression and anxiety, whose symptoms can mimic ASD. This can be misleading for clinicians, hence diagnostic criteria may need to be modified for this group (4).

Lastly, an ASD diagnosis could have a heavy bearing throughout someone's life. Thus, it is key to keep the accuracy of diagnoses high, which makes re-referrals more likely to occur and necessary. However the ethical dilemma brought by the fact that sometimes a diagnosis may not be useful, means that in some cases, holding off on assessment may be appropriate.

Conclusion:

Over half of re-referrals are due to insufficient evidence in first assessments or in referrals. Potential solutions include using extra diagnostic tools, and educating referrers, including encouraging the use of screening tools.

References:

(1) Access to children and young people's mental health services. [Internet] 2018. [cited 2019 June 12]; [33 screens]. Available from: https://epi.org.uk/wp-content/uploads/2018/10/EPI_Access-to-CAMHS-2018.pdf

(2) Baren-Cohen et al. Prevalence of autism-spectrum conditions: UK school-based population study. British Journal of Psychiatry. 2009 Jun. 194(6):500-9.

(2)Mayes et al. Autism and ADHD: Overlapping and discriminating symptoms. Research in Autism Spectrum Disorders. 2011 May. 6:277-285.

(4) Stevens et al. The comorbidity of ADHD in children diagnosed with autism spectrum disorder. Research in Autism spectrum disorder. 2016 Nov. 31:11-18.

Acknowledgments: Thank you to Jannatul Uddin for her input on data collection.