

Autism Spectrum Conditions

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Autism Spectrum Conditions (ASC)

It remains unclear whether ASCs comprise one condition or a range of similar inter-related neuro-developmental conditions, with separate subtypes. Experts have achieved a broad consensus on what constitutes the category of ASC, and the diagnostic criteria set out in the fifth Diagnostic and Statistical Manual (DSM-5) (APA 2013) and the International Classification of Disease (ICD-10) (WHO 1993) are very similar.

ASC encompasses disorders previously referred to as early infantile autism, Kanner's autism, high-functioning autism, atypical autism, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder and Asperger's disorder.

There is a plethora of national legislation relating to ASC notable The Autism Act (2009), The Equalities Act (2010) and the Care Act (2014) along with a significant guidance and advice. Quality standards have been set by National Institute for Health and Care Excellence (NICE) along with the autism pathway, and statutory guidance has been given to local authorities and the NHS on how to support the implementation of the Autism Strategy. In terms of Kent the County Council have prescribed key recommendations to meet the needs of the ASC community and are in the process of finalising a strategy to address the issues.

In terms of best practice and research-led practice there are many examples of practitioners to follow covering all the main areas of ASC including workforce related matters, pharmacotherapy, design living environments, music therapy and early interventions.

National prevalence rates indicate that in Kent (2015) over 17,000 patients would have autism with 3,700 being under 18 years of age and some 7,500 between the ages of 25 to 60. This latter age group are expected to rise to 8,000 by the year 2030. There is a gender divide with a ratio of 4:1 male: female as females it is argued are more likely to be mis-diagnosed.

ADHD rates for Kent show much higher numbers (five percent children and two and a half percent adults) with approximately 45,000 all age patients having the condition. Kent wide for five to 17 year olds is 12,000 with 3,343 young adults (18-24). No data are offered for the under-fives as symptoms are difficult to distinguish from highly variable behaviours. Data is also displayed at CCG level.

Prevalence rates/levels are displayed using the Kent Integrated Data set (KID). The KID is person level data linking routinely collected administrative activity and cost data from almost all NHS providers across Kent, and other non NHS organisations. Each linked person has the same NHS number throughout the dataset.

The table below expresses the number of patients diagnosed as a rate per 10,000 patients. Across Kent, autism is the most prevalent of these conditions, with a rate of 16.58 per 10,000 population. This ranges from 3.66 in Dartford, Gravesham and Swanley Clinical Commissioning Group (CCG) to 46.19 in Thanet CCG.

West Kent CCG has the highest rate of people with ADHD with 15.87 patients diagnosed per 10,000 population, while Thanet CCG has the lowest rate (4.16). Kent has a prevalence of 11.59 per 10,000 population.

The prevalence of Tourette's was 2.39 per 10,000 population across Kent, and ranged from 1.66 in Ashford CCG to 3.01 in Dartford, Gravesham and Swanley CCG.

Table 1

Patient Count	ADHD	Autism	Tourette's
Ashford CCG	10.07	13.08	1.66
Canterbury and Coastal CCG	11.38	16.98	2.04
Dartford, Gravesham and Swanley CCG	12.76	3.66	3.01
South Kent Coast CCG	8.58	20.26	1.68
Swale CCG	11.35	27.96	2.29
Thanet CCG	4.16	46.19	2.85
West Kent CCG	15.87	11.48	2.52
Kent	11.59	16.58	2.39

Source: Kent Integrated Dataset

Autism prevalence based on the Special Educational Needs (SEN) register have been calculated based on a primary or secondary SEN need of ASC, as at January 2016, and apply to people aged 19 and under. Data have been extracted from the KID for the same age band, and adjusted to reflect the proportion of practices participating within each CCG.

Across Kent, the ASC prevalence according to the SEN register is 124.9 ASD pupils per 10,000 population aged 19 and under, significantly different to the KID based prevalence of 45.1 per 10,000 population. All CCGs also have significantly different SEN and KID prevalence rates, with the exception of Thanet CCG.

Estimated Attention Deficit Hyperactivity Disorder (ADHD) prevalence is based on those who scored six or above on the Adult ADHD Self-Report Scale (ASRS), indicating more severe levels of ADHD. Applying the estimated national prevalence across Kent, we would expect 8,926 people to be diagnosed with ADHD; based on adjusted KID data, there are 1,183 people aged 16 and above diagnosed with ADHD.

These numbers vary according to CCG, as shown on the charts within the assessment.

KID also confirmed the higher prevalence in males to females of almost 4:1. Prevalence was also higher for autism in the most deprived decile and there was a clear decrease across the deprivation deciles.

KID also showed the majority of people diagnosed with ADHD to be under 35 (90%) and those with autism also under 30 years of age (93%). Age by gender showed that across the condition spectrum that the proportion of female patients diagnosed increased with age.

In terms of comorbidity data of those diagnosed with autism, 57.1% have just autism, just over a quarter (26.3%) have one other long-term condition (LTC), and a tenth (9.9%) have two other LTCs. Over half (55.2%) of patients with ADHD are diagnosed with no other LTCs, 26.8% with one other, and 10.4% with two others. Patients with Tourette's are most likely to have another LTC, with 31.2% having one other LTC, and nearly a fifth (19.6%) diagnosed with two other LTCs.

The most common comorbidities were asthma, depression, anxiety and bronchitis. Learning difficulty was also present with autism and Tourette's patients and the KID maps out comorbidity in great detail.

Utilisation of health and social care was extracted from the KID and for those diagnosed with any LTC; any provider activity preceding the diagnosis date of the LTC was excluded. In some cases, the numbers of people diagnosed with ADHD, autism and Tourette's accessing varying provider types were relatively small.

In terms of social care since 2014, £1.27 million has been spent on social care for patients diagnosed with ADHD. Acute provider care has cost £0.77 million in this same time period, and just under half a million pounds was spent on both community and GP care provision. Social care has also been the biggest provider expenditure for patients with ASD, with just under £6 million spent since April 2014. £1.45 million has been spent by community providers, and a further £0.86 million spent on acute provider care. It has also been the biggest provider expenditure for patients with Tourette's; however, the cost was substantially less than for autism or ADHD patients, at just over half a million pounds.

Of all the provider types, social care accounts for the highest cost per activity across the whole population (£899.50), those with any LTC (£1,037.64), and those with autism (£2,074.97), ADHD (£1,703.64) or Tourette's (£2,092.78).

Patients with autism or Tourette's have higher costs per activity for mental health than those with one or more LTC or the whole population, and all three LTCs have a higher cost per activity for community care.

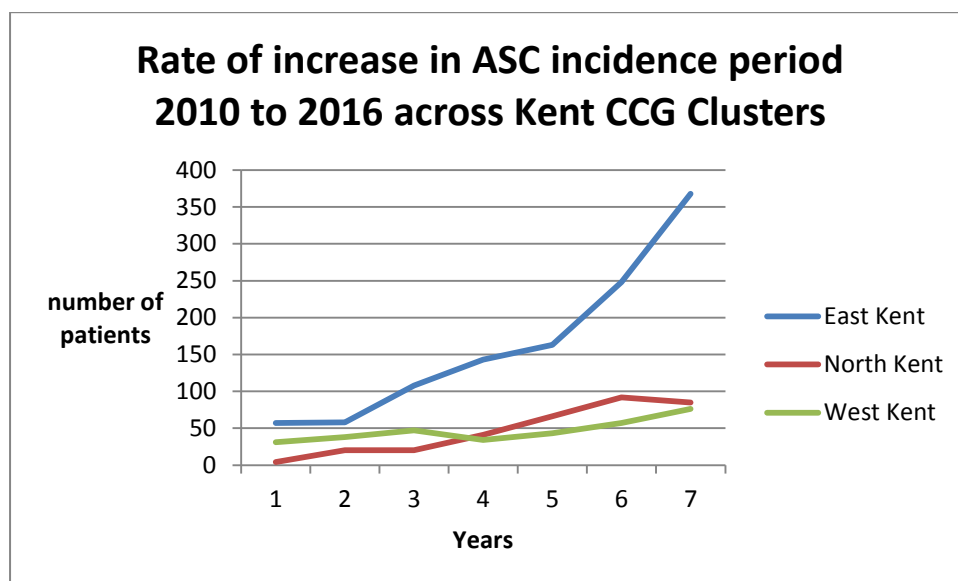
Adult social care records are accessible within the KID; however, children's social care data is not currently available. Consequently, the analysis applied to patients aged 18 and above. Approximately, 87% of adult social care records in the KID do not have an NHS number, which may result in an underestimate of the proportion of adults with autism, ADHD or Tourette's known to adult social services. However this proportion of unknown NHS numbers is reducing and will be more robust in future iterations from KID.

Of those with ADHD, autism and Tourette’s, 1.88%, 14.65% and 3.74% of patients are known to social care respectively. The proportion of patients with ASC known to social care is significantly higher than the proportion of either ADHD or Tourette’s patients known to social care.

Residential care has accounted for the biggest proportion of social care package cost for patients with ADHD, at £0.6 million. It has accounted for the biggest proportion of social care package cost for patients with Autism, at £3.5 million, and has accounted for the biggest proportion of social care package cost for patients with Tourette’s, at £0.28 million.

An exercise was carried out looking at incidence data in KID on the basis that in disease and conditions such as autism with long durations and relatively very low levels of incidence, there may be little difference between prevalence and incidence. The levels of incidence for ADHD and Tourette’s remain fairly level with a significant increase in the incidence of autism. Whilst the graph below shows the level and degree of increase in autism it is not evenly reflected across Kent.

Figure 1



Clearly there has been a significant rise in incidence of autism in East Kent CCGs over the past few years when compared with North Kent CCGs and to some extent in West Kent CCG. The East Kent CCGs are currently investigating this aspect to try to understand the driving force behind the level of demand.

Pharmacy data was examined and showed that there are significant differences between CCGs in terms of prescribing practice for under 18s in North and West Kent CCGs particularly in DGS CCG. In terms of the over 18s there seems to be better comparability. It is suggested that there is therefore a need for the relevant organisation possibly KCC public health to undertake a prescribing review with the support from the CCGs to ensure that prescribing inequalities are recognised and addressed.

Stakeholder views are highlighted in this assessment with links to national sources. There is substantial evidence of robust qualitative data from Kent locality communities of interest but there is need for additional work to be commissioned particularly around clinical and educational groups. However, twelve key themes have emerged from the existing base of knowledge:

1. System challenges accessing formal Support from services.
2. No clear functioning pathway from diagnosis, assessment, planning to services.
3. Complex and conflicting eligibility criteria – it's a daily battle.
4. Quality of support not always good or what is needed or when you need it.
5. Getting lost in the system.
6. Parents and carers not being listened to.
7. Additional challenges of seeking informal support.
8. Families and marriages under tremendous strain.
9. Parents and carers have clear and basic emotional needs that need support.
10. Parents and carers have clear and basic needs to help them in their caring role.
11. Life as a carer – what is it like?
12. Some key gaps in services identified by parents and young people living with autism.

Applying national rates of prevalence has produced significant numbers of potential health and social care patients/clients yet in practice, depending upon which service speciality you choose, these numbers are not being seen. There is however the exception of SEN children who appear to match predicted rates more closely. So in essence different services and different commissioners see different numbers presenting which can be confusing as to understand the correct picture.

In reality this makes sense as, by way of example, taking the primary education sector children, and young people, they will present their ASC symptoms clearly for the educational staff to see and who are therefore more likely to initiate a referral for a diagnosis and hence the reason for higher numbers. However more work needs to be done to ensure that there is a consistency in referral policy and its application in primary school settings across Kent to ensure equality of access to services. The current absence of KCC children and young people's data from KID frustrates this process and is an essential component that needs to be included.

Clearly some patients/clients are better than others in managing their condition (perhaps with their carer) and therefore do not appear on the radar but if this applies to the autism spectrum then it will apply to other LTCs and requires further development.

Education is seeing something like the national rate of prevalence but the health economy a fraction of it. Social care (adult) sees little numbers when compared with education and

health and the Children's and Young Adult data in KID when accessed should help to see the prevalence within that cohort. Lack of this data is a significant omission.

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Recommendations

- Commission further work to develop better collaborative opportunities between the information teams from social care, health care (CCG and providers) and Public Health and optimise interrogation of the KID by jointly designing robust approaches/methodologies to answer complex/'wicked' questions.
- Seek to ensure that pharmaceutical practice in ASC is consistent throughout Kent to ensure that inequalities are addressed.
- Formulate an agreed set of appropriate read codes for ASC clinical practice that ensures quality clinical practice and data interrogation.
- Health, Social Care Commissioners and education services across Kent ensure that common ASC referral guidelines are in place and applied in a consistent manner to ensure equality of access to services and that these guidelines are audited at agreed intervals.
- Health and Social Care Commissioners across Kent ensure that appropriate performance/clinical data is recorded by service providers and that providers are mandated to share this data with approved data analysts.
- Qualitative data from clinicians, social care and the education sector professionals needs to be commissioned to better understand their views regarding the spectrum conditions in terms of pathways, service access and service standards.