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Time trends in autism diagnosis over 20 years: a UK population-based cohort study

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Background: Autism spectrum disorder is a diagnosis that is increasingly applied; however, previous studies have conflicting findings whether rates of diagnosis rates continue to grow in the UK. This study tested whether the proportion of people receiving a new autism diagnosis has been increasing over a twenty-year period, both overall and by subgroups. **Method:** Population-based study utilizing the Clinical Practice Research Datalink (CPRD) primary care database, which contains patients registered with practices contributing data to the CPRD between 1998 and 2018 (N = 6,786,212 in 1998 to N = 9,594,598 in 2018). 65,665 patients had a diagnosis of autism recorded in 2018.Time trend of new (incident) cases of autism diagnosis was plotted for all, and stratified by gender, diagnostic subtypes, and developmental stage: infancy and preschool, 0–5 years old; childhood, 6–11 years old; adolescence, 12–19 years old; adults, over 19 years old. **Results:** There was a 787%, exponential increase in recorded incidence of autism diagnoses between 1998 and 2018; R^2 = 0.98, exponentiated coefficient = 1.07, 95% CI [1.06, 1.08], p < .001. The increase in diagnoses was greater for females than males (exponentiated interaction coefficient = 1.02, 95% CI [1.01, 1.03], p < .001) and moderated by age band, with the greatest rises in diagnostic incidence among adults (exponentiated interaction coefficient = 1.06, 95% CI [1.04, 1.07], p < .001). **Conclusions:** Increases could be due to growth in prevalence or, more likely, increased reporting and application of diagnosis. Rising diagnosis among adults, females and higher functioning individuals suggest augmented recognition underpins these changes.
Keywords: Autism; autism spectrum disorder; diagnosis; primary care; clinical practice research datalink; time trends.

Introduction

Much interest surrounds the rising use of the autism spectrum disorder diagnosis, the various forms of which we refer to as 'autism'. Several studies in both the United States and Europe report increasing application of this diagnosis over the last twenty years, but have measured autism in different ways, limiting comparability (Boyle et al., 2011; Keyes et al., 2012; Maenner & Durkin, 2010; Parner, Schendel, & Thorsen, 2008; Smeeth et al., 2004). In contrast, Taylor et al. found the incidence of recorded autism at age eight remained stable across a six-year period in the UK, in data from the General Practice Research Database (GPRD; Taylor, Jick, & MacLaughlin, 2013). Previous US studies have shown how diagnostic substitution (Shattuck, 2006), increased awareness, and expansion of the spectrum to include high functioning and cognitively able individuals (Keyes et al., 2012) have led to increased diagnosis of autism. A Swedish study found that levels of autism symptoms were constant in the population over a ten-year period, in contrast to large increases in recorded diagnoses in the Swedish patient register (Lundström, Reichenberg, Anckarsäter, Lichtenstein, & Gillberg, 2015). As time passed, noticeably fewer autism symptoms seemed to be required for a clinical diagnosis of autism (Arvidsson, Gillberg, Lichtenstein, & Lundström, 2018). More diagnoses were made with time, despite no parallel increase in autistic symptoms in the population, because autism symptom thresholds for diagnosis had dropped (Arvidsson et al., 2018; Lundström et al., 2015).

The current study aims to establish the time trend in new (incident) autism diagnosis in the UK over a period of twenty years (1998–2018). The UK National Health Service (NHS) is a publicly funded health service, free at the point of use. General practitioners (GPs) are the 'gatekeepers' of the NHS, referring patients to secondary care. Over 98% of the population is registered at one of the 7,300 GP practices, all of which routinely code diagnostic data into the Clinical Practice Research Datalink (CPRD, formerly GPRD). We expand the previous GPRD study (Taylor et al., 2013) by calculating incidence applying a much longer timeframe, with an examination of new autism diagnoses by multiple developmental stages, gender, and diagnostic subtypes.

This study is, to our knowledge, the first to establish trends of diagnosis across developmental stages, which are of particular interest for policy and commissioning reasons. During the last twenty years, there has been a strong policy directive to provide earlier recognition and diagnosis of autism,

*Deceased.

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in other words to diagnose children at younger ages (Fernell, Eriksson, & Gillberg, 2013; Landa, 2008; Teitelbaum, Teitelbaum, Nye, Fryman, & Maurer, 1998). Additionally, the Autism Act of 2009 in the UK made provision of adult autism diagnostic services a statutory duty of local authorities (*Autism Act*, 2009), a response to the campaign championed by the National Autistic Society. The resulting UK network of adult autism diagnostic services should have had a dramatic impact on rates of diagnosis in this age-group. In 2009, less than 50% of local authorities in England had adult diagnosis services, compared with almost all (93%) by 2019 (NAS, 2019). Time trends within developmental life stages can prove any impact of such policy directives. There has also been mounting research and policy interest in possible under-recognition and under-diagnosis of girls and women with autism (Loomes, Hull, & Mandy, 2017). Ten years ago, a UK study found that, even with severity of autistic traits held constant, boys were more likely to receive a diagnosis than girls (Russell, Steer, & Golding, 2011), while work from the United States has highlighted possible gender bias in the identification of children with special educational needs more broadly (Arms, Bickett, & Graf, 2008). Such research attention has contributed with stories in UK media about females missing out on diagnosis (Russell, 2020), broadcasting a message that diagnosing females with autism is a priority. Comparing rising rates of diagnosis in males versus females over time is therefore of interest.

Pathways to diagnosis

In the UK, autism diagnoses are made in specialized health services, known as 'secondary care', and not by GPs. GPs will refer a suspected case onto secondary care where autism is normally assessed by a multidisciplinary team. Referrals may also come directly from young people, families, schools, and social workers. The secondary care service for adults is in specialist autism or neurodevelopmental services, or, for those younger than 19 years old, at Child and Adolescent Mental Health Services (CAMHs), or a specialist neurodevelopmental or autism service. Younger, preschool children are most often diagnosed by community pediatric teams. In other words, there are several routes to diagnosis, but all flow through secondary care. There is a risk that information about diagnoses may not be passed from secondary to primary care (pediatricians or CAMHs to GP sources), not be communicated, as parents may not approve sharing with GP, or be incorrectly recorded. The pathways above relate to the National Health Service, which is free at the point of delivery but suffers from long waiting lists, leading some families to seek assessment from private practitioners. Diagnoses made by private services are not routinely fed back to GPs, instead clients (parents or adults) are provided the diagnosis by private companies to use as they will. This means that the CPRD is likely to underreport autism diagnoses. The study objectives were not, therefore, to give point prevalence estimates but to (a) assess the overall time trend in new autism diagnosis rates and (b) examine said trends by developmental stage, gender, and diagnostic subtype to assess the broad impact of policy on diagnostic rates. Our main hypothesis was that the incidence of recorded autism diagnosis would increase over the 20-year period.

Method

Sample

CPRD Aurum is a database containing routinely collected data from 738 GP practices in England (10% of all English practices) and Northern Ireland, capturing diagnoses, symptoms, prescriptions, referrals, and tests for over 19 million patients. Seven million patients were contributing data in 2018, which represents 13% of the population of England (Wolf et al., 2019), with data from Northern Ireland added in 2019. The practices are representative of the broader population in terms of geographical spread and deprivation (median decile on index of multiple deprivation = 5.3), as well as age and gender. CPRD undertakes various levels of validation and quality assurance on the daily GP data collection, comprising over 900 checks covering the integrity, structure, and format of its data. This national patient database contains diagnostic codes for medical conditions, including autism, stretching back over twenty years to 1998.

Ethical considerations

The protocol was approved by the Independent Scientific Advisory Committee (ISAC) of the Medicines and Healthcare products Regulatory Agency (MHRA; ISAC protocol no 20_006R). Ethical approval for observational research using the CPRD with approval from ISAC was granted by a National Research Ethics Service committee (Trent Multi-research Ethics Committee, REC reference No 05/MRE04/87).

Codes for autism

Diagnostic codes are recorded for each patient. Codes and terminology used by GPs to indicate autism have changed since the data in the CPRD were first collected in 1987. We selected all appropriate codes used by GPs over the time period under study, which included: infantile autism, autism, childhood autism, autistic disorder, atypical autism, autistic spectrum disorder, Asperger's syndrome, and pervasive developmental disorders (PDD). A comprehensive list of included codes with number of cases in each code category is provided in Appendix S1. The bulk of diagnoses were attributed to autism spectrum disorder (44%), autistic disorder (10%), or simply autism (20%). 21% of all remaining diagnoses were coded as Asperger's syndrome; however, this code fell out of usage after the DSM-5 was updated in 2013 to integrate it into the autism spectrum diagnosis. All other categories combined constituted only 6% of cases.

Validation

Previous studies have attempted to validate the autism data. Autism data recorded during the period 1990–2014 were validated by comparing CPRD data to the original medical

records of a sub-sample of patients; although the sample size with autism was small, the positive predictive value was 91.9% (Hagberg & Jick, 2017). An earlier validation study on GPRD data was conducted in 2004, which had a larger sample size and more robust methodology (Fombonne et al., 2004); cases numbers were estimated based on a combination of an algorithm developed to classify a range of symptoms, backed by clinical judgment. The limitation of this approach was that the algorithm did not require the full range of autistic behaviors to be present, and the diagnostic criteria themselves have shifted since its publication. Both studies validated against clinical records rather than population-wide assessment specifically for autism, but together suggest that autism diagnosis in this dataset is reasonably valid over time.

Gender was recorded for each patient according to their GP registration form (as self-reported we consider this reflects gender rather than sex). All cases were divided into developmental age bands mirroring stages of development as laid out in UK National Institute for Health and Care Excellence guidance (2017): preschool and infancy (0–5 years), childhood (6–11 years), and adolescence (12–19 years), with an extra group to capture the trend in adult diagnosis (over 19 years). Age of each patient at each year (1998–2018) was calculated from the difference between year of interest and year of birth. The numbers in each age band therefore varied at each time point.

We generated a variable to represent broad autism (BA) versus more severe autism (SA) by using diagnostic subcodes as a proxy, assigning (a) Asperger's syndrome, (b) atypical autism, and (c) PDD-NOS as BA and (a) autistic disorder, (b) infantile autism, (c) childhood autism, (d) Kanner's syndrome, and (e) PDD as SA. All other codes, the bulk of which were simply autism or autism spectrum disorder, were classed as 'Unknown'.

Analysis

All analyses were performed on Stata 16.

Autism incidence was defined as percentage (%) of children, adolescents, and adults with a new record of an autism diagnosis in each year (1998–2018). This was obtained by dividing the number diagnosed with autism by the number of 'acceptable' patients in the population at each year, a method in common with Taylor et al. (2013). The acceptable patient metric is based on registration status, recording of events in the patient record, and valid age and gender (Herrett et al., 2015). All patients with acceptable data registered on 30th June in the year of analysis were included in denominators. Patients who had died in that year or transferred out were included as they had the opportunity to be diagnosed. Patient numbers in the current study were 6,786,212 in 1998 ranging to 9,594,598 in 2018.

We assessed the incidence and how this varied between 1998 and 2018 for (a) all patients included in the analyzable sample, (b) by age band, (c) by gender, and (d) in SA vs BA. We used the index number to model change over time, which takes incidence at a baseline year (1998) as 100% and tracks the percentage increase or decrease from baseline in each subsequent year. Thus, if 100 people are given a diagnosis in the baseline year, 120 in year two, and 130 in year three, the index number will be 120 in year two, 130 in year three, and so on. The index number captured the trend in the number of *new diagnoses* given each year, not in the *prevalence* of autism, which would be a cumulative figure. An index number of 102 means a 2% rise in the incidence from the base year incidence, and an index number of 98 means a 2% fall. The index number is often used to show time trends in economics (Office for National Statistics, 2016).

We plotted the overall incidence index number by time (year) and checked model fit to ascertain what shape best described the trend. We fitted a least squares linear regression model with year as predictor and a log transformation of the autism index number as the outcome to ascertain the gradient, i.e. speed of any increase. Coefficients are reported in exponentiated form. The log transformation was satisfactory in overcoming heteroscedasticity, as evidenced by both residual and normal quantile postestimation plots.

In order to test for any moderating effects of age band in which diagnosis occurred and gender on increasing incidence as time passed, a multivariable regression was conducted to test the relationship between year (predictor) and index number (rate of change in incidence by year) with gender and age band included as well as the interaction terms between the predictor and putative moderators (gender and age band). In addition, the model included the interaction between gender and age band to see whether diagnosis of females in adulthood contributed more to the incidence pattern than in childhood.

Data sharing

This study is based on CPRD data and is subject to a full license agreement. Electronic health records are, by definition, considered sensitive data in the UK by the Data Protection Act and cannot be shared via public deposition because of information governance restrictions in place to protect patient confidentiality. Access to data is only available once approval has been obtained through the individual constituent entities controlling access to the data. The primary care data can be requested via application to the Clinical Practice Research Datalink.

Results

By 2018, 65,665 patients had a diagnosis of autism recorded in CPRD. Table 1 describes the patterns of age and gender by year for those with or without diagnosis of autism for each birth year. These show, as expected, a higher proportion of males than females in the sample with an autism diagnosis at baseline (81.6% were male in 1998), with a much larger proportion of patients assigned a diagnosis in younger age bands (in 1998, 91.4% of patients assigned an autism diagnosis were aged 19 years or younger, and 80.6% were under 12).

Incidence of autism

The overall time trend of new cases of autism diagnosis by year is illustrated in Figure 1. The figure, in contrast to Table 1, plots the trend in increasing incidence of new diagnoses, as a percentage increase from 100% modeled at baseline year in 1998: the index number. The figure starkly illustrates an overall 787% increase in recorded incidence of autism diagnosis over 20 years. The exponential model (log transformed outcome) was a very good fit to the data; $R^2 = 0.98$, exponentiated coefficient = 1.07, 95% CI [1.06, 1.08], $p < .001$.

The mean age of diagnosis rose, not only in the dataset as a whole, from a mean age of 9.6 years ($SD = 9.4$) in 1998 to 14.5 years ($SD = 12.7$) in 2018, but also rose within every specific age band (Table S1). Median and modal age of diagnosis also increased during the twenty-year period, although there was no change within the infant and preschool

Table 1 Demographic characteristics of patients with and without a diagnosis of autism, 1998 to 2018

	ASD diagnosis						No ASD diagnosis					
Year	*N*	% Male	% 0–5 years	% 6–11 years	% 12–19 years	% Over 19 years	*N*	% Male	% 0–5 years	% 6–11 years	% 12–19 years	% Over 19 years
1998	3,072	81.67	57.10	23.50	10.77	8.63	6,785,544	49.87	5.96	6.61	7.75	79.68
1999	3,948	82.09	53.95	25.08	11.88	9.09	7,023,959	49.94	5.89	6.57	7.85	79.69
2000	5,043	82.31	50.35	27.17	12.91	9.58	7,197,770	50.02	5.85	6.52	7.96	79.67
2001	6,290	82.51	47.63	28.33	14.01	10.03	7,366,131	50.08	5.86	6.43	8.09	79.63
2002	7,812	82.73	44.75	29.56	15.17	10.52	7,545,217	50.11	5.84	6.32	8.20	79.63
2003	9,488	82.62	42.51	30.60	15.74	11.16	7,702,452	50.14	5.86	6.24	8.31	79.59
2004	11,326	82.78	40.38	32.04	16.29	11.29	7,832,871	50.18	5.92	6.18	8.39	79.51
2005	13,158	82.73	38.89	32.75	16.93	11.43	7,935,910	50.17	6.01	6.16	8.40	79.43
2006	15,230	82.67	37.44	33.62	17.26	11.67	8,074,625	50.15	6.10	6.15	8.41	79.34
2007	17,353	82.80	36.24	34.34	17.75	11.67	8,211,364	50.10	6.18	6.19	8.34	79.29
2008	19,604	82.77	35.26	34.71	18.18	11.84	8,349,711	50.07	6.32	6.21	8.28	79.19
2009	22,217	82.62	34.47	35.06	18.49	11.98	8,453,071	50.03	6.41	6.30	8.21	79.08
2010	25,101	82.35	33.53	35.17	18.97	12.33	8,577,288	50.01	6.46	6.37	8.14	79.03
2011	28,302	82.01	32.72	35.19	19.41	12.68	8,665,355	49.88	6.55	6.46	8.13	78.85
2012	31,858	81.76	32.09	35.25	19.64	13.02	8,794,391	49.82	6.58	6.55	8.13	78.74
2013	36,022	81.27	31.54	34.94	19.89	13.63	8,733,804	49.77	6.69	6.76	8.18	78.37
2014	40,479	80.71	30.81	34.84	20.14	14.21	8,821,168	49.83	6.64	6.94	8.24	78.18
2015	45,462	80.07	30.23	34.58	20.32	14.86	8,986,878	49.81	6.53	7.02	8.38	78.06
2016	51,484	79.35	29.36	34.62	20.67	15.35	9,165,230	49.80	6.41	7.07	8.51	78.02
2017	58,224	78.48	28.58	34.69	21.04	15.69	9,358,837	49.78	6.26	7.10	8.62	78.02
2018	65,665	77.49	27.83	34.50	21.50	16.17	9,531,337	49.80	6.07	7.10	8.74	78.09

This table shows cumulative prevalence, taking into account diagnoses made prior to 1998.

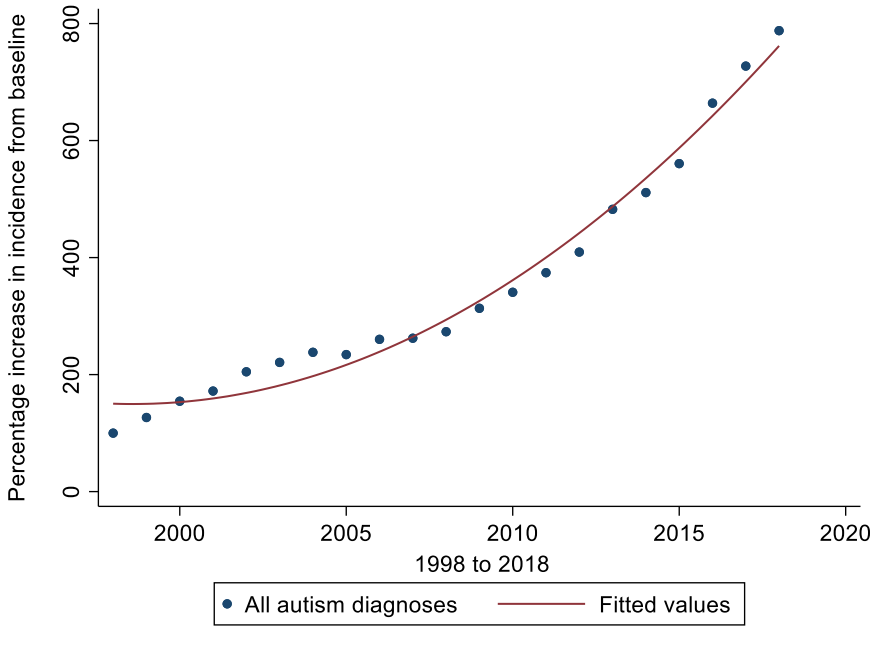


Figure 1 Percentage increase in incidence of autism diagnosis from 1998 to 2018

groups: median and modal age for those diagnosed in infancy remained 2 years for the entire 20-year period. The mean age at which males received a diagnosis across the whole dataset was 12.3 years old (*SD* = 11.5) and for females 14.9 years old (*SD* = 12.4). With the exception of one year in the 20-year period, within each year, the average age of diagnosis for females was greater than for males (Table S1).

Figure 2(i) illustrates the increases in rates of autism diagnosis by developmental stage. The increasing incidence of diagnosis was greater for adults and older children than for younger children. Compared with the youngest age band (0–5 years), being in an older age band strengthened the exponential relationship between year and increasing incidence of autism diagnosis (Table 2). One adult per 100,000 was diagnosed in 1998, versus twenty in 2018. Note the baseline in 1998 is held at the same level for all four groups; in reality, there were far more children and adolescents diagnosed year on year than adults.

Figure 2(ii) illustrates the relative pace of increase in diagnosis of males compared with females. Gender was a significant moderator of the increase in incidence over time; female gender predicted a bigger increase in incidence (exponentiated coefficient = 1.02, 95% CI [1.01, 1.03], $p < .001$). The gradient of growth in diagnosis for females has been, on average, increasing by more per year than that for males.

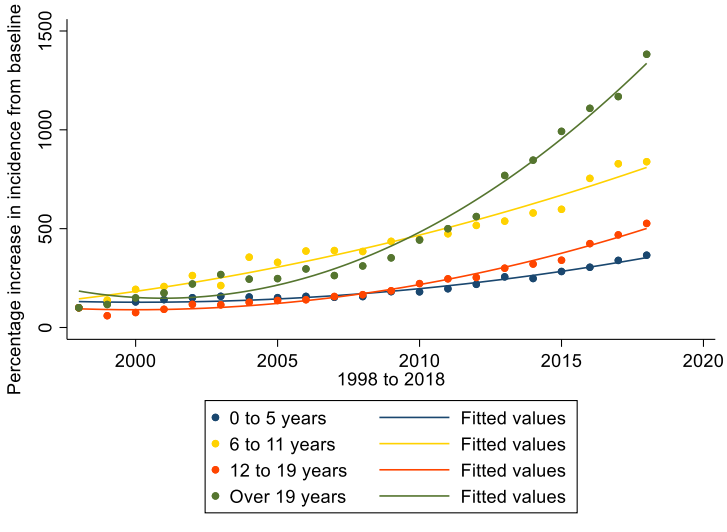
The breakdown of plots of percentage increase in diagnosis over time by gender and age band is given in Figure S1 and shows the pattern of rising diagnosis by gender at each age band. Being female was associated with increasing levels of diagnosis at adolescence compared with preschool. However, this was not the case in adulthood, where there was no gender difference (see Table 2).

The comparative time trend between those classed with SA and BA is shown in Figure 3. BA diagnoses increased more than SA up until 2013, when DSM-5 revisions led to recommendations to drop the diagnostic subcodes used to code BA and SA.

Discussion

The overall increase in incidence of diagnosis of autism is consistent with other reports from the United States and Europe (Boyle et al., 2011; Keyes et al., 2012; Maenner & Durkin, 2010; Parner et al., 2008; Smeeth et al., 2004). Previously, analysis of the GPRD between 2004 and 2010 for children age 8 indicated the incidence was stable (Taylor et al., 2013). Similarly, we found the number of incident cases in children age 8 remained stable from 2005 right through to 2009, but it did increase in 2010. This discrepancy may be because Taylor et al. excluded data from GP practices contributing data

(i) : Percentage increase in incidence of autism diagnosis from 1998 to 2018 by age-band.



(ii): By gender.

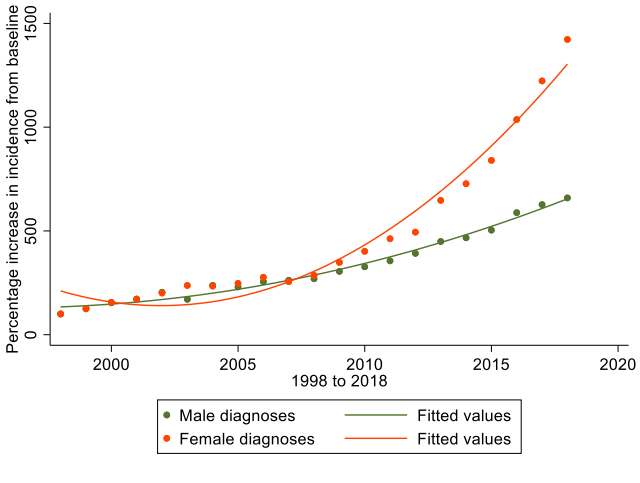


Figure 2 (i) Percentage increase in incidence of autism diagnosis from 1998 to 2018 by age band. (ii) By gender

Table 2 Moderating relationships between age band, gender, and increasing incidence of autism diagnosis

Moderator	Coefficient (exponentiated)	95% CI		*p*
		Lower	Upper	
Age band	(Preschool = reference)			
Childhood	1.03	1.01	1.05	<.001
Adolescence	1.04	1.04	1.05	<.001
Adulthood	1.06	1.05	1.07	<.001
Preschool × Gender	(Reference)			
Childhood × Gender	1.01	1.00	1.03	.321
Adolescence × Gender	1.03	1.01	1.05	.002
Adulthood × Gender	1.00	0.98	1.02	.665

Coefficient (exponentiated) refers to percentage incidence of autism compared with baseline in 1998 (1998 = 100%).

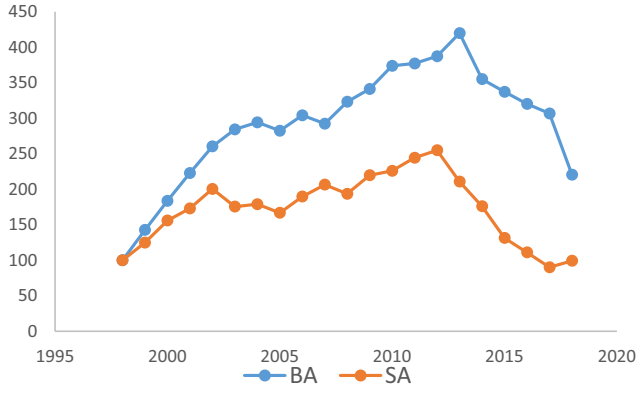


Figure 3 Percentage increase in incidence of autism diagnosis from 1998 to 2018 by diagnostic codes

after 1996, which we did not. Our current findings, taken over a longer period and with multiple age groups, indicate the overall trend is actually one of the increasing application of diagnosis over time.

The finding that increases in incidence of diagnosis were greater in adults and females suggests changes in identification and recording of autism diagnosis in these new cohorts (females, adults) as at least one contributor to these changes. There have been concerted campaigns to raise awareness of autism in both these groups, while there is no clear etiological explanation for why more adults and females might be developing autism compared with children and males.

The increase in age of diagnosis with time may be due to an increase in demand for assessment arising from greater public awareness of autism, combined with recent cuts to children's assessment services: diagnostic services risk being swamped. In 2020, NHS wait times from referral to diagnosis were reported as 352 days (1 year) for under 18s (NHS Digital, 2021), albeit services were hampered by the pandemic. Increased age of diagnosis in preschool age bands could be partly because diagnosis of autism in younger children is obviously complex and may need to go at the family's pace. Destigmatization of the label due to work by the neurodiversity movement and parent-led lobby groups may have contributed to rising demand for diagnosis in order to access support, in turn leading to changes in clinical practice. The inclusion of more cognitively able/BA individuals in the expanding spectrum (Keyes et al., 2012) has contributed to longer waiting lists as time has passed. As a larger proportion of cognitively able individuals are diagnosed with autism, the average age of diagnosis within each developmental stage may increase, as they do not present the immediate and complex needs of classic infantile autism and therefore tend to be referred and identified later (Hertz-Picciotto & Delwiche, 2009).

Trends in age bands

Many texts and guidelines argue that the earlier diagnosis is made the better, so children can receive early intervention before critical developmental stages elapse (e.g., language acquisition). Reports show decreases in the mean and median ages at which childhood autism diagnoses are made in California (King, Fountain, Dakhlallah, & Bearman, 2009) and Denmark (Parner et al., 2008), yet we found the opposite, suggesting that the stated policy goal of earlier recognition is not being achieved. Adults were an under-recognized group in the UK and lobbying successfully led to implementation of the Autism Act. Similar legislation has recently extended to children, and it remains to be seen whether the age of diagnosis subsequently decreases. Our finding of a marked increase in adult diagnoses compared with other age bands, which accelerated after 2009 when UK adult autism diagnostic assessment services were made statutory, suggests the new adult diagnostic assessment services are having an impact. However, wait times for assessment can be long. If private care is being utilized to avoid waiting for diagnosis, the actual increase in diagnosis may be even higher, since such diagnoses may not be fed back to GPs.

Trend by gender

A meta-analysis of over 50,000 participants with autism showed that in population-based studies of

people with autism there are three males to every female, whereas in clinic-based samples the ratio is nearer four to one (Loomes et al., 2017). This suggests that females with autism are less often identified and diagnosed. Some researchers suggest this is possibly because they are better able to mask autistic difficulties (Hull et al., 2017). Others propose that the behavioral characteristics of autism may be different in females compared with males, while the diagnostic criteria are based on symptoms seen in males (Kirkovski, Enticott, & Fitzgerald, 2013). Autism is popularly conceptualized as a 'male' disorder. Such understandings may have led to gender stereotyping by education professionals, clinicians, and parents when identifying children with severe symptoms. In response to these research narratives, there has been a drive toward referral of more females. Our findings, showing a marked growth in female diagnoses compared with males, suggest such initiatives have been having an effect. If girls tend to be missed, we would expect perhaps to see a steeper rate of female diagnoses in older age bands compared with early childhood, and this was true in adolescence but not in adulthood. However, females were on average diagnosed at older ages than males at almost every time point (Table 1) which does support this interpretation.

In their review of sex and gender differences, Lai and Szatmari (2020) found diagnosed females showed fewer restricted/repetitive behaviors/interests/activities and were more likely to have better cognitive development, less intense autistic symptoms and displayed a greater reduction in symptoms over time than males. Despite this, their review suggests females may experience more challenges at adolescence than males, perhaps prompting the need for a diagnosis, which might partly explain the observed disproportionate rise in female diagnosis at adolescence. Intriguingly, Figure S1 indicates a steeper increase in female diagnosis at adulthood in the last two years of the time trend. Future research could determine whether this pattern is sustained.

Trend by SA/BA

The pattern of SA/BA diagnosis (Figure 3) was as expected: the rate of broad autism (BA) diagnosis, mostly accounted for by our coding of Asperger's included in BA, increased more than SA up until 2013. The subsequent drop-off is very likely due to the reduction in ongoing use of 'Asperger's' and 'autistic disorder' as distinct labels after 2013 DSM-5 revisions came into effect, replacing these codes with the more generic 'autism spectrum disorder' and 'autism', which accounted for a growing majority of the increasing incidence of diagnosis after 2013. The picture given in Figure 3 is revealing, yet is limited by the many missing cases as only around a third of all cases in CPRD could be classified as SA or BA. The figure broadly suggests a larger part of the rise in diagnosis rates in the UK was attributable to diagnosis of individuals without severe autism, up until 2013. After this timepoint, it was not possible to distinguish by diagnostic subcodes, although the trend may well have continued. Given the limits imposed by missing data and that actually the bulk of diagnoses cannot be attributed to SA or BA, combined with issues about changes to diagnostic codes that were applied given changing DSM criteria, we decided not to formally test the BA/SA comparison.

As autistic traits are normally distributed (Steer, Golding, & Bolton, 2010), and the observed trend is one of the diagnosing cases with more typical cognitive ability or less severe traits over time (Arvidsson et al., 2018), a small shift in the cutoff threshold for diagnosis could lead to a relatively large increase in the number of cases, as there are simply more individuals nearer the population mean than at the severe end of the spectrum. This may contribute to the exponential pattern observed.

Strengths and weaknesses of the study

The main strength of this analysis is the extensive and large dataset, broadly representative of the UK population that avoids the biases of specialist clinic-based studies. However, the database has inherent limitations around data completeness. Although validation studies show what data there are are of good quality (a recent study reported 91.9% positive predictive value for autism codes in the CPRD; Hagberg & Jick, 2017), there is likely missing data due to private diagnoses and incomplete recording in primary care. The patient groups missing from primary care records include prisoners, private patients, some residential homes, and the homeless. Linkage of mental health data from Child and Adolescent Mental Health services would not improve our ability to compare time trends because the routine data available are patchy: data from some services are not submitted or are incomplete, and other pathways, such as community pediatrics and diagnoses, are often made in private clinics in the UK, which are not included in the data.

Because of this potential for missing data, we chose not to concentrate on absolute incidence or prevalence rates, rather keeping the analysis focused on a comparative trend in diagnosis over time. Whether autism is actually recognized, that is, diagnosed in the first place, is a distinct issue that could also lead to underestimates of population prevalence when using GP data. We therefore argue against publishing UK autism prevalence estimates based on GP data, which could be misleading. Instead, we advocate caution (not reporting absolute point prevalence estimates due to possibility of missing cases in clinical records) and a comparative approach (covering all age ranges) showing patterns and trends in identification.

Our analysis suggests the makeup of the diagnosed autistic population is shifting along with the increasing incidence. There are now larger proportions of females and adults in the UK population with an autism diagnosis and, until DSM-5 revised the codes, our subcode analysis indicated an increasing proportion of diagnoses of broad, less severe autism. We suspect that this is an artefactual change (a shift in who is considered to have autism). Our finding that different groups have shown different rates of increase is consistent with this interpretation. However, we cannot discount the possibility of accompanying 'real' increases, that is, more individuals having symptoms of autism as time has passed.

Narratives about diagnosis are likely to be further reinforced by clinical recognition and identification itself. As more females, for example, are diagnosed, there are more women identified with autism who make a vocal contribution about how they missed out on diagnosis when younger, and more females with autism are talked about and seen, thereby reinforcing narratives about female autism and spurring further research and clinical recognition. Thus, the rise fuels the rise, in the sense that the more often a diagnosis is applied, the more people rally around its banner and advocate for more diagnosis (Russell, 2020).

Our findings need replication in other datasets, particularly those linked between primary and secondary care. Further research could usefully examine the influence of factors that may affect accessibility to diagnosis (e.g., rurality), as well as socioeconomic status or ethnicity as these were associated with autism in England in an analysis of educational records (Roman-Urrestarazu et al., 2021). Additional research is also required to establish whether diagnosis is followed by any support, which data linkage might allow researchers to explore.

Supporting information

Additional supporting information may be found online in the Supporting Information section at the end of the article:

Appendix S1. List of available codes categorized as 'autism'.
Table S1. Mean and SD age of diagnosis by year of recording.
Figure S1. Percentage increase in incidence of autism diagnosis from 1998 to 2018 by gender at each age band.

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Key points

- Previous UK studies have conflicting findings as to whether rates of autism diagnosis are increasing.
- Ours is first study to analyze the time trend of autism diagnosis in a population-based UK clinical cohort by developmental stage, level of severity and by gender, over a twenty-year period.
- Results show an exponential increase in use of autism diagnosis over time.
- New subpopulations previously seldom considered for autism diagnosis (females, adults) have steepest growth in diagnosis rates.
- Differing rates of increase between subgroups suggest effects are primarily due to increased recognition, although an actual increase in autism incidence cannot be ruled out.
- 2009 UK policy to invest in adult assessment centers may underpin rise in adult diagnosis.
- Rising age at diagnosis in infancy and childhood suggests policy to improve early recognition of autism has had limited effect.

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