Autism spectrum disorder

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Experimental statistics are official statistics which are published in order to involve users and stakeholders in their development and as a means to build in quality at an early stage. It is important that users understand that limitations may apply to the interpretation of this data.

These statistics have been labelled as experimental in order to allow for further work to be undertaken to assure users that these statistics meet the overall quality standards necessary to be designated as National Statistics. Information on how users should interpret these statistics are available throughout this chapter, in the Methods chapter of this publication, and in the accompanying Background Data Quality Statement.

NHS Digital will gather feedback to these statistics, their construction and interpretation from relevant experts, and following this announce details of how the assessment of these statistics will progress on the NHS Digital website during February 2017.

All official statistics should comply with the UK Statistics Authority's Code of Practice for Official Statistics which promotes the production and dissemination of official statistics that inform decision making.

Summary

- Autism spectrum disorders (ASDs), also referred to as autism, are developmental disorders characterised by impaired social interaction and communication, severely restricted interests, and highly repetitive behaviours.

- This chapter presents data on the profile of ASD among adults living in the English household population. This is the second time such data have been collected in England, after it was covered for the first time in the 2007 Adult Psychiatric Morbidity Survey (APMS).

- In the phase one interview ASD was screened for using the Autism Quotient (AQ-20). In the phase two interview, fuller assessments were carried out by clinically trained interviewers using the Autism Diagnostic Observation Schedule (ADOS) with a subset of participants with an AQ score of 4 or more. The results were weighted to generate a prevalence estimate for the population as a whole. This approach has been extensively validated. It should be recognised however that psychiatric diagnoses tend to be reached by professionals over multiple sessions involving probing and clinical judgement. Health surveys are a population research tool and should not be expected to provide the equivalent of a professional diagnosis. For further discussion of survey limitations see Chapter 14.

- The recommended threshold of a score of 10 or more (as well as meeting subdomain thresholds for ASD) on the phase two ADOS assessment was used to indicate a case.

- Data from the 2007 and 2014 surveys were combined to generate a larger sample for analysis. The APMS series has been designed so that samples can be combined in this way. Estimates based on the combined dataset are more robust than estimates based on the 2007 or the 2014 samples separately. 31 potential cases were identified in the combined phase two samples, which is small for subgroup analysis and means caution with interpretation is required. Had all participants completed a phase two interview (see above), we estimate that about 120 cases might have been identified in the sample as a whole.
• Using the combined sample, the prevalence of ASD was estimated to be around 0.8%. Survey estimates are always subject to sampling error. Given this, we estimate that if all adults in the population had been tested, the proportion identified with ASD would probably be between 0.5% and 1.3% (95% confidence interval (CI)). The size of this confidence interval is large, but similar to that for some other low prevalence disorders considered on APMS.

• Consistent with other research, estimated rates of ASD were higher in men (1.5%, 95% CI: 0.8% to 2.6%) than women (0.2%, 95% CI: 0.1% to 0.6%).

• ASD was associated with level of educational qualification, with rates being higher among people with no qualifications.

• People with ASD appeared to be no more likely than other adults to make use of treatment or services for mental or emotional problems.

### 6.1 Introduction

Autism spectrum disorders (ASDs) are developmental disorders characterised by widespread abnormalities of social interaction and communication, as well as severely restricted interests and highly repetitive behaviours (Wing 1997). As with other mental and behavioural disorders, they probably exist on a continuum. Presence of ASD can have a negative impact on learning and, at the more severe end of the spectrum, on the ability to live independently in adulthood (Howlin et al. 2004). Adults with the condition often experience isolation and adverse experiences such as being bullied and socially excluded (Brugha et al. 2014).

The cost of supporting an individual diagnosed with an ASD without intellectual disability is estimated as £0.92 million in the United Kingdom, with residential care, supportive living accommodation and individual productivity loss contributing the highest costs (Buescher et al. 2014). But quantifying a total cost of ASD is problematic because there have been no reliable estimates based on the number of adults in England with the condition with and without an autism diagnosis.
APMS 2007 was the first general population probability sample survey in any country to have assessed ASD in adults (Brugha et al. 2009b), with APMS 2014 being the second. Rates may be different in specific adult populations, such as among people who are homeless or living in prison. Rates were higher in men and in those without educational qualifications.

ASD is known to be strongly associated with the presence of learning disabilities and it has been estimated that 7.5% of adults with a learning disability may also have ASD (Cooper et al. 2004). The 2007 survey was extended to cover people with learning impairments, including those living in residential settings, and found rates to be higher in this group (Brugha et al. 2012). A secondary analysis of the APMS 2007 confirmed earlier indications that autism is associated with an increased risk of epilepsy (Rai et al. 2012).

ASD has been assessed among children and young people, and two large-scale surveys estimated the prevalence of childhood ASD to be around 1%, 1, 2 and higher in boys than girls (Baird et al. 2006; Green et al. 2004). ASDs are more apparent and easier to study in children, in part because the diagnosis of autism should include presence of symptoms in childhood and parent and teacher observations of this are more likely to be accurate and available for this group. Because these studies have used different methodologies to APMS, the results are not directly comparable.

The number of reported (diagnosed) cases of autism increased steeply throughout the 1990s. It is quite possible that this was due to changes in public and professional awareness of the condition, different diagnostic definitions and practices, availability of services and referrals, and earlier age at diagnosis (Fombonne 2009). Nevertheless, the current evidence available does not rule out the possibility that the prevalence of ASD has increased (Rutter 2005).

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1 The prevalence of ASDs among children in South Thames was estimated by Baird et al. to be 116.1 per 10,000 (95% CI 90.4–141.8). A narrower definition of childhood autism, which combined clinical consensus with instrument criteria for past and current presentation, provided a prevalence of 24.8 per 10,000 (17.6–32.0).

2 Green et al. presented confidence intervals for the estimated prevalence of ASD among 5 to 10 year olds in England (1.13, 95% CI 0.65–1.39) and for 11 to 16 year olds (0.76, 95% CI 0.47–1.06).
6.2 Definition and assessment

Autism spectrum disorder (ASD)
The concept of autism gained recognition in the mid-20th Century and is still evolving (Frith 1991; Silberman 2015). It remains unclear whether ASDs 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 ASD, and the diagnostic criteria set out in the fourth Diagnostic and Statistical Manual (DSM-IV) (APA 1994) and the International Classification of Disease (ICD-10) (WHO 1993) are very similar. Both systems use the term pervasive developmental disorders (PDD) and require information on early childhood development for diagnosis. The fifth revision of the DSM (DSM-5) (APA 2013) has removed the requirement to endorse subtypes of ASD, such as Asperger's syndrome. It emphasises instead the importance of severity based on social communication impairments and restricted, repetitive patterns of behaviour, and whether with or without accompanying intellectual impairment. Furthermore, in DSM-5, individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's syndrome, or PDD not otherwise specified should be given the diagnosis of ASD. In this chapter, the terms autism and ASD are used interchangeably.

Assessment of ASD

Case assessment of ASD
In surveys of ASD in childhood, information on behaviour and early development has been collected from parents and teachers. For adults, the ideal scenario would involve assessments of directly observed current behaviour and information on both early development and on current day to day functioning over an extended period. This is not a practical option for a large general population survey of adults. Therefore, the assessment process used on APMS 2007, and replicated on APMS 2014, was based on a combination of self-report data collected at the phase one interview and a semi-structured assessment carried out by a clinically trained research interviewer at the phase two interview (Brugha et al. 2009a). This multi-stage case assessment for ASD is similar in structure to that used in the
APMS series since 1993 for the assessment of psychotic disorders. The APMS 2007 process involved a detailed validation assessment (Brugha et al. 2011b). It includes the following stages:

A. Phase one AQ-20 self-completion test

B. Selection of cases for phase two assessment

C. Phase two ADOS assessment of a subset of cases

D. Weighting to adjust for selection probabilities and non-response.

This approach has undergone an extensive programme of validation work supported by the NHS and Department of Health (Brugha et al. 2009a; 2011b; 2012; 2016). The validation programme has involved calibration of the ADOS with other research instruments for autism assessment; interviews with participants’ parents and other family members; comparison with further data collected from community, learning impairment, and patient samples; consensus ratings of participant vignettes with autism practitioners; and engagement with psychiatrists and epidemiologists with expertise in this field. The validation of the APMS process for identifying autism has been more extensive than that of other conditions covered on the survey. Further work is now planned to address recent developments in classification based on DSM-5 and drafting work for ICD-11.

A. Phase one interview: Autism Quotient

The full Autism Quotient, here referred to as the AQ-50, is one of few fully structured questionnaires designed to capture signs of ASD in adult participants (Baron-Cohen et al. 2001). The AQ-50 was reported in clinical populations to have good correspondence with a full ASD diagnosis (Baron-Cohen et al. 2001). Other available questionnaires tend to be either longer (Ritvo et al. 2008) or require data to be collected from a collateral informant, such as a parent (Constantino et al. 2003). A clinical diagnosis cannot be derived from the AQ-50; it is a test designed to identify potential underlying autistic traits.

The full AQ consists of 50 items; to minimise participant burden on the already long APMS 2007 questionnaire, a shorter 20 item version was derived using data collected by two of the AQ authors in the development of the full schedule.
Details of the modelling undertaken to select the best subset of items are given in a separate technical report (Brugha et al. 2011b). The AQ-50 questionnaire is composed of items designed to assess five broad dimensions: social functioning, imagination, communication, attention switching and attention to detail. The 20 adopted items selected by the modelling procedure as the best predictors of a positive ASD assessment spread quite evenly across these categories: six were social functioning items; four, communication; four, attention to detail; three, attention switching; and three, imagination. The AQ-20 was discussed by an expert panel and tested in the cognitive piloting conducted as part of the APMS 2007 development work. Further modelling took place using a random sample of adults in contact with mental health services. This identified the 17 most predictive AQ items used in the 2007 survey, these were retained and three (which had performed poorly in the 2007 data) were replaced with items with improved prediction selected from the original AQ-50 (Tyrer et al. 2013). The revised 20 item version of the AQ is reproduced in full in the questionnaire in Appendix D.

A score was generated for each participant based on their responses to the 17 AQ items included in both the 2007 and 2014 surveys. Each response indicative of ASD was given one point, so that a higher score indicated greater likelihood that the person may have ASD. The AQ-20 is a self-completion questionnaire, and it was administered via a laptop computer in the phase one interview. Because it is a brief test and not a diagnostic measure, a clinical assessment was included in the phase two interview.

On APMS, the AQ was used only to exclude cases with an extremely low likelihood of having autism (those with an AQ score of between zero and three) and to inform the selection probabilities for phase two. It was not used to positively identify ASD.

**B. Selection of cases for phase two assessment**

A subsample of phase one participants was invited to take part in a second phase interview. Participants’ probabilities of selection for phase two were determined by their responses to questions at phase one, including their score on the AQ and whether they were male or female. Those with a higher AQ score had a higher chance of being selected, as did men. No one with an AQ score of zero to three was selected for a phase two assessment (unless they endorsed a psychosis criterion,
as psychotic disorder was also covered in phase two). All men with an AQ score of eight or more and all women with an AQ score of 11 or more were selected for phase two (except for those interviewed in the final two months of fieldwork, who were excluded). For men with an AQ score between four and seven and women with a score between four and ten, a subsample of those agreeing to recontact were selected for phase two, as outlined in the table below.

<p>| Probability of selection to phase two based on phase one AQ score |
|------------------|------------------|------------------|</p>
<table>
<thead>
<tr>
<th>Sex</th>
<th>Phase one AQ score</th>
<th>Phase two selection probability*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Men</td>
<td>0 to 3</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>4 to 7</td>
<td>0.157</td>
</tr>
<tr>
<td></td>
<td>8 to 10</td>
<td>1.000</td>
</tr>
<tr>
<td></td>
<td>11 or more</td>
<td>1.000</td>
</tr>
<tr>
<td>Women</td>
<td>0 to 3</td>
<td>0.000</td>
</tr>
<tr>
<td></td>
<td>4 to 7</td>
<td>0.045</td>
</tr>
<tr>
<td></td>
<td>8 to 10</td>
<td>0.245</td>
</tr>
<tr>
<td></td>
<td>11 or more</td>
<td>1.000</td>
</tr>
</tbody>
</table>

* Of those who agreed to take part in phase two.

It was not feasible for all phase one participants to have a phase two assessment, and this approach was designed so that those with the highest likelihood of a having autism (or psychosis) had the highest likelihood of being assessed, combined with being able to generate estimated rates of ASD for the population as a whole.

**C. Phase two assessment: Autism Diagnostic Observation Schedule (ADOS)**

The second phase interviews were carried out by clinically trained research interviewers from the University of Leicester. The assessment of conditions such as ASD required a more flexible interview than was possible at the first phase, and the use of judgement in rating clinical criteria for diagnostic classification.

The Autism Diagnostic Observation Schedule (ADOS), Module 4, was completed with 628 participants at the APMS 2014 phase two (and 618 at the phase two
of APMS 2007). It is a widely recommended ‘gold standard’ clinical research assessment instrument for autistic disorders that is used to collect information on adult functioning (Lord et al. 2002). The ADOS is a semi-structured clinical assessment of whether current behaviour is consistent with a diagnosis of an autistic disorder. In 2014, additional questions on restricted, repetitive patterns of behaviour and sensory differences were added to the second phase two interview. This was done due to their increased emphasis in DSM-5 and because the ADOS does not offer an adequate opportunity to measure restricted and repetitive behaviours, although such behaviours are coded on the ADOS if they occur. This additionally collected data is not reported on in the current chapter, but will be analysed in subsequent publications.

The ADOS and its algorithm have been validated in previous clinic based testing, but prior to APMS 2007 they had rarely been used with older adults or in a general population setting (Gotham et al. 2008). The methods and results of a quality assurance and validation study made use of clinician ratings and developmental interviews with parents and other informants to inform severity and clinical significance thresholds (Brugha et al. 2009a). That study found the ADOS performed well, and its results have informed the case threshold used in this report.

The ADOS consists of a series of tasks that evaluate communication, reciprocal social interaction (social functioning), creativity, imagination and stereotyped interests and restricted interests. These tasks are rated by the trained interviewer. The ADOS ratings that correspond to autism criteria are summed to produce an overall score. A score of seven or more is the threshold used to identify an inclusive category of ASD that is intended to correspond generally to the conceptualisation that underlies the term PDD (Brugha et al 2011b). The recommended threshold of 10 or more is applied in this report to indicate a case of autism, validated in the same population.

**D. Weighting to adjust for selection probabilities and non-response**

For the designation of an ASD outcome the following approach was used:

- For men with a phase one AQ score of four or more and women with a phase one AQ score of eight or more, and who had an ADOS assessment, the results of the ADOS were used.
• Men with a phase one AQ score of three or less and women with a phase two ADOS score of seven or less were designated ASD negative, regardless of whether or not an ADOS assessment was completed.

• Men with a phase one AQ score of four or more and women with a phase one AQ score of eight or more who did not have an ADOS assessment (e.g. due to non-selection, refusal or non-contact) were excluded from the analysis, and a weighting strategy was applied to take account of their absence and to address non-response biases.

For analysis of estimated prevalence of disorders assessed at phase two (autism and psychosis), the weighted phase two participants are added to the set of phase one participants who were not eligible for phase two, the prevalence being assumed to be zero for the not eligible group. Those not eligible are given their phase one weights. The sampling and weighting strategy is described in more detail in Section 14.7 of the Methods Chapter.

For the analyses presented in this report the 2007 and 2014 samples were combined to increase the sample size available for subgroup analysis. The survey series has been designed with the intention that samples should be combined, especially for analyses of low prevalence disorders or subgroups. This approach is also taken in the chapter on psychotic disorder.3

6.3 Results

Prevalence of autism in 2007 and 2014, by age and sex
The estimated prevalence of autism in 2014, using the threshold of a score of 10 on the ADOS to indicate a positive case, was 0.7% of the adult population in England (equivalent to a rate of 7 per thousand). The estimated prevalence of autism in the 2007 data (1.0%) was similar to the 2014 estimate; with largely overlapping confidence intervals.

3 Several papers published in peer-reviewed medical journals have analysed samples combined from across the survey series. See Appendix A for examples of these.
A total of 12 probable cases were identified in the 2014 sample, because a sub-sample of respondents was selected for a phase two interview. This small base means that great caution is required in interpreting the population distribution of autism. To improve how robust the estimates are, the 2007 and 2014 samples have been combined, yielding 31 participants identified with autism. Estimates based on the combined sample are more robust than those based on the separate 2007 and 2014 samples.

Using the combined sample, the prevalence of ASD was estimated to be around 0.8%. Survey estimates are always subject to sampling error. Given this, we estimate that if all adults in the population had been tested, the proportion identified with ASD would probably be between 0.5% and 1.3%. The size of this confidence interval is similar to that of some of the other low prevalence disorders considered on APMS.4

Estimated rates of ASD were higher in men (1.5%, 95% CI: 0.8% to 2.6%) than women (0.2%, 95% CI: 0.1% to 0.6%). Tables 6.1, 6.2

Figure 6A: Autism in 2007, 2014 and combined years, by sex
Base: all adults

For example, the estimated proportion of the population with signs of dependence on drugs other than cannabis is 0.8%, with a 95% confidence interval of 0.6% to 1.2%.
Some variation in prevalence of autism was evident with age, although there was not a clear pattern. Tables 6.1, 6.2

**Figure 6B: Autism in 2007, 2014 and combined years, by age**

*Base: all adults*

[Bar chart showing prevalence by age group and year.]

**Variation by other characteristics in combined 2007 and 2014 data**

**Ethnic group**

None of the 31 adults identified with autism in the APMS 2007 and 2014 samples was a participant from a minority ethnic group. However, due to the small number of minority ethnic respondents in the sample as a whole, caution is required in interpreting whether or not autism is associated with ethnic group. No table is presented for this analysis.
Region

There was no significant variation in the prevalence of autism across the four NHS England regions. Table 6.3

Education

Presence of autism was associated with the highest educational qualification that people had achieved. Overall, the rate was lowest among those with a degree level qualification (0.2%) and highest among those with no qualifications (1.5%). 3.2% of men without qualifications were identified with autism. Table 6.4

Figure 6C: Autism, by highest educational qualification: 2007 and 2014 combined

Base: all adults

Employment status

Analysis by employment status was run on those aged 16–64, to exclude people who are retired constituting most of the economically inactive group. There was no significant variation in the proportion of adults identified with autism according to whether they were employed, unemployed or economically inactive. Table 6.5
Treatment and service use
As mentioned above, even when the 2007 and 2014 APMS samples were combined, there were just 31 adults identified with autism. This of necessity limits the scope of analysis.

People identified with autism were no more likely than those without autism to use any of a range of different types of treatment or services for a mental health reason. In fact, in terms of use of health services for a mental health reason, it even appears that people with autism were less likely. Healthcare services included use of inpatient or outpatient health services within the last three months for a mental health reason or discussing a mental or emotional problem with a GP within the last year. 3.7% of adults identified with autism reported this, compared with 11.6% of those who without autism. Table 6.6

Physical and mental comorbidity with autism is considered in Chapter 13.
6.4 Discussion

The estimated prevalence of autism in adults in private households in England was estimated to be around 0.8% (95% CI: 0.5% to 1.3%) based on the combined samples for the 2007 and 2014 APMS. There was no significant difference between the rates of autism identified in 2007 and 2014. In these surveys adults were interviewed if they were able to participate fully. However, adults who would be unable to participate in the APMS because of learning disabilities were also represented in a recent extension to the 2007 APMS (Brugha et al. 2012). No significant change in the prevalence of autism was found when the population of adults with learning disabilities was accounted for in the analysis.

There was no clear pattern in the distribution of autism by age. Rates were higher in men than women, as found in most research on autism (Brugha 2011a). However, it has been suggested that assessments for autism may draw more on how the condition manifests in men, and this may lead to under identification of autism in women (Trubanova et al. 2014). Autism was much more common among people, especially men, without any qualifications, and rates were lower in those with a university degree. No one from an ethnic minority group was identified with autism in either the 2007 or the 2014 APMS. This is likely to be due to the small sample size.

Among 16 to 64 year olds, employment status was not significantly related to whether or not someone was identified with autism. This finding took into account the ‘economically inactive’ group, which includes students, and those looking after home, long term sick or disabled, or in early retirement. Employment and autism is a complex topic that needs more detailed study, including research which considers people in whom autism is unrecognised (that is, present but not diagnosed).

Adults in the survey identified with autism were no more likely than adults without autism to use treatment or services for a mental health reason. And in fact, adults with autism appeared even less likely than those without to use health services for a mental or emotional reason. In contrast, every other mental health condition examined in this and previous APMS has been shown to be associated
with increased use of treatment and health services. Other work shows that adults with mental disorders receive attention from services because mental health problems are recognised needs (Spiers et al. 2016). This recognition of need does not appear to extend to adults with ASD.

Adults with autism have enduring problems with communication and social understanding. There are no effective medical treatments for autism in adulthood. However care services for identifying and supporting them are being developed lead by local authorities throughout England. These services are based on the principle that carers and health and social care staff can recognise and accept the presence of the condition, and learn how to understand and communicate with those who have it. Clinical experience of providing informed social care of this kind to adults given a diagnosis of ASD could lead to real improvements in quality of life.

6.5 Tables

**Prevalence**

Table 6.1  Autism in 2007 and 2014, by age and sex

Table 6.2  Autism (2007 and 2014 combined), by age and sex

**Characteristics**

Table 6.3  Autism (observed and age-standardised), by region and sex

Table 6.4  Autism (age-standardised), by highest educational qualification and sex

Table 6.5  Autism (age-standardised), by employment status and sex

**Treatment and service use**

Table 6.6  Treatment and service use, by autism

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5 www.improvinghealthandlives.org.uk/projects/autsaf2014results
6.6 References


This chapter should be cited as: