DIVISION OF PSYCHOLOGY AND LANGUAGE SCIENCES
CLINICAL EDUCATIONAL AND HEALTH PSYCHOLOGY

UCL

Perspectives on autism prevalence

AUDIT-50

ADAPT

10th May 2024

Dr Liz O'Nions

Epidemiologist | Bradford Institute for Health Research

Honorary Research fellow | University College London

Remarkable research for healthy ageing
THE DUNHILL MEDICAL TRUST

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Terminology

- **Administrative prevalence:** rate of recorded autism diagnosis

- **Community prevalence:** true rate of autism in people in a region (e.g. England), irrespective of whether they have a diagnosis.

Overview

- Autism as a continuum
- Differences in rates of diagnosis regionally & by service across England
- Passive vs. active approaches to autism identification
- What is the community autism prevalence & does it differ by age?
- Our estimates of under-diagnosis of autism in England

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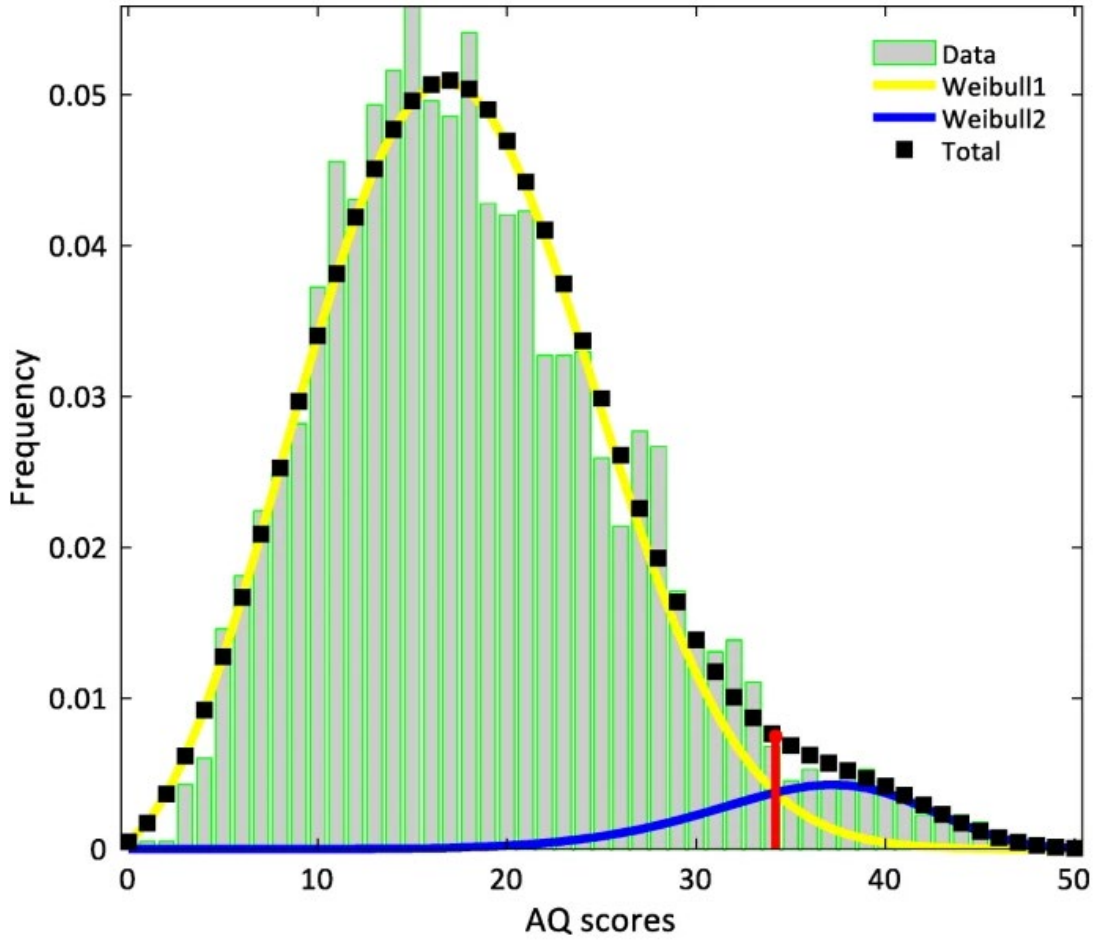
Autism as a continuum

- Current diagnostic practice conceptualizes autism categorically
- Autism characteristics are on a continuum: no “natural” diagnostic cut-point
- Diagnosis is a matter of clinical consensus
- Subject to change over time & variability between centres in terms of “conversion rates”.



Abu-Akel, A., Allison, C., Baron-Cohen, S., & Heinke, D. (2019). *Molecular autism*, *10*, 1-13.

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Differences in rates of diagnosis related to region/ service

In adults

Some NHS centres twice as likely to diagnose adults as autistic, study finds

https://www.theguardian.com/society/2024/mar/04/some-nhs-centres-twice-as-likely-to-diagnose-adults-as-autistic-study-finds

Landmark research suggests people have an 85% chance of positive assessment at some centres in England and 35% in others

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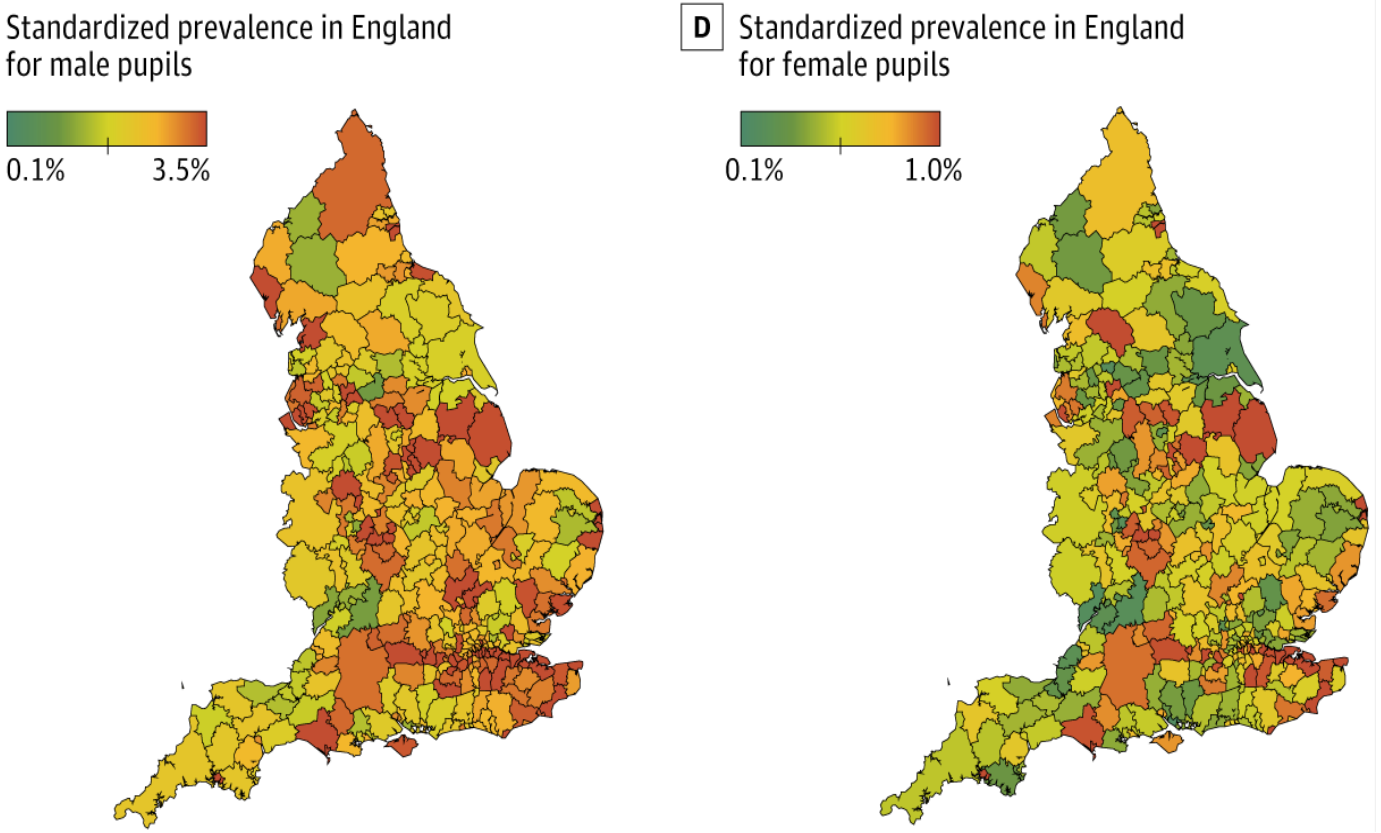
In children

Spring School Census 2017 from the National Pupil Database (NPD) in England

Variation in diagnosed prevalence by region among UK school pupils
n = 7,047,238 (Roman-Urrestarazu et al., 2021)

https://jamanetwork.com/journals/jamapediatrics/article-abstract/2777821



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How can we estimate autism prevalence? Tromans & Brugha, 2022

- Passively, using medical/ school records to see % with a clinical diagnosis.
- But we cannot assume equal access to assessment/ diagnosis.
- Actively, by going out into the general population and assessing people to see what % are autistic based on assessment tools.

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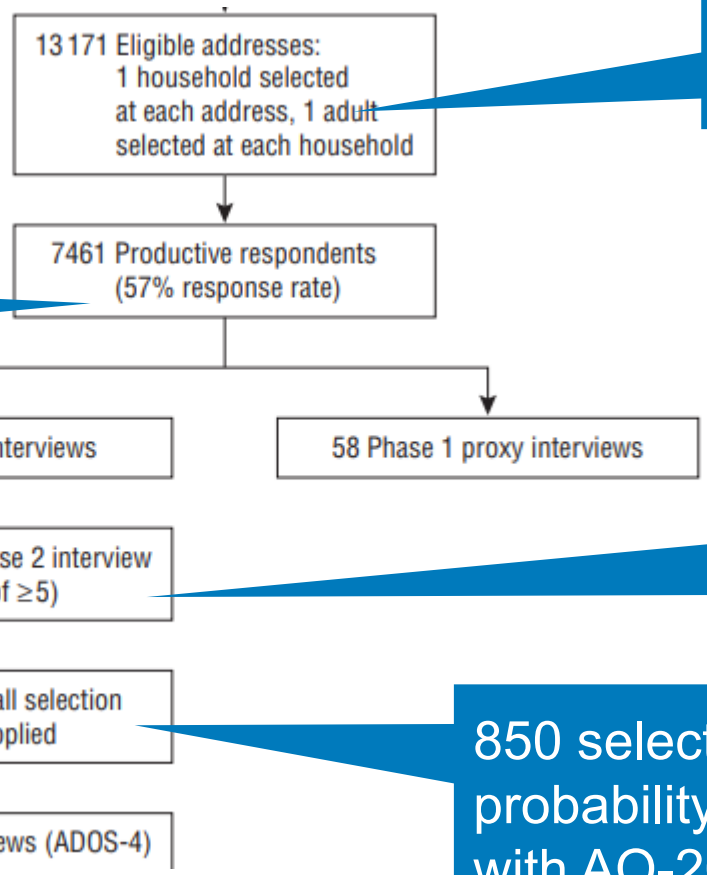
Actively identifying autism in the community: Brugha et al., 2011

https://jamanetwork.com/journals/jamapsychiatry/fullarticle/211276

Adult Psychiatric Morbidity Survey (APMS 2007); age 16+



13,100 Eligible addresses in England

7,400 respondents (57%)

Screening with AQ-20

5,100 eligible for phase 2 (score >=5)

850 selected, a random subset; probability of selection increased with AQ-20 score.

618 did ADOS module 4
19 scored 10+
None had a dx

Actively identifying autism in the community: Brugha et al., 2011

https://jamanetwork.com/journals/jamapsychiatry/fullarticle/211276

- Results weighted to adjust for selection & non-response bias
- Estimated prevalence : 9.8 per 1000: c. 1%
- Similar to contemporary child studies (e.g. Baird et al., 2006).
- Under-identificatiojn of autistic women (9:1 ratio; 1.8% vs. 0.2%)

Table 1. Weighted Cumulative Estimates of Respondents per 1000 Population for ADOS-4 Cut-offs

ADOS-4 Cut-off	Unweighted Base (n = 2828)	Weighted Base (n = 7333)	Weighted Estimate Rate per 1000 Population (95% CI)
≥7	32	108	14.7 (7.0-22.5)
≥8	26	88	12.0 (4.9-19.1)
≥9	20	75	10.2 (3.4-17.0)
≥10[a]	19	72	9.8 (3.0-16.5)
≥11	16	65	8.9 (2.2-15.5)
≥12	12	47	6.4 (0.6-12.3)
≥13	10	44	6.0 (0.2-11.8)

1%

1.5%

A less stringent ADOS-4 cut-off led to a higher prevalence

Actively identifying autism in people with ID: Brugha et al., 2016

- Previous survey only included people without moderate to profound LD
- Moderate to profound ID make up c. 0.3% of the population.
- Eligible individuals assessed in 64% of communal care establishments in a locality with ADOS (module 1).
- Including this group, estimated pooled prevalence around 1.1%

Prevalence of autism was higher in people with learning disabilities

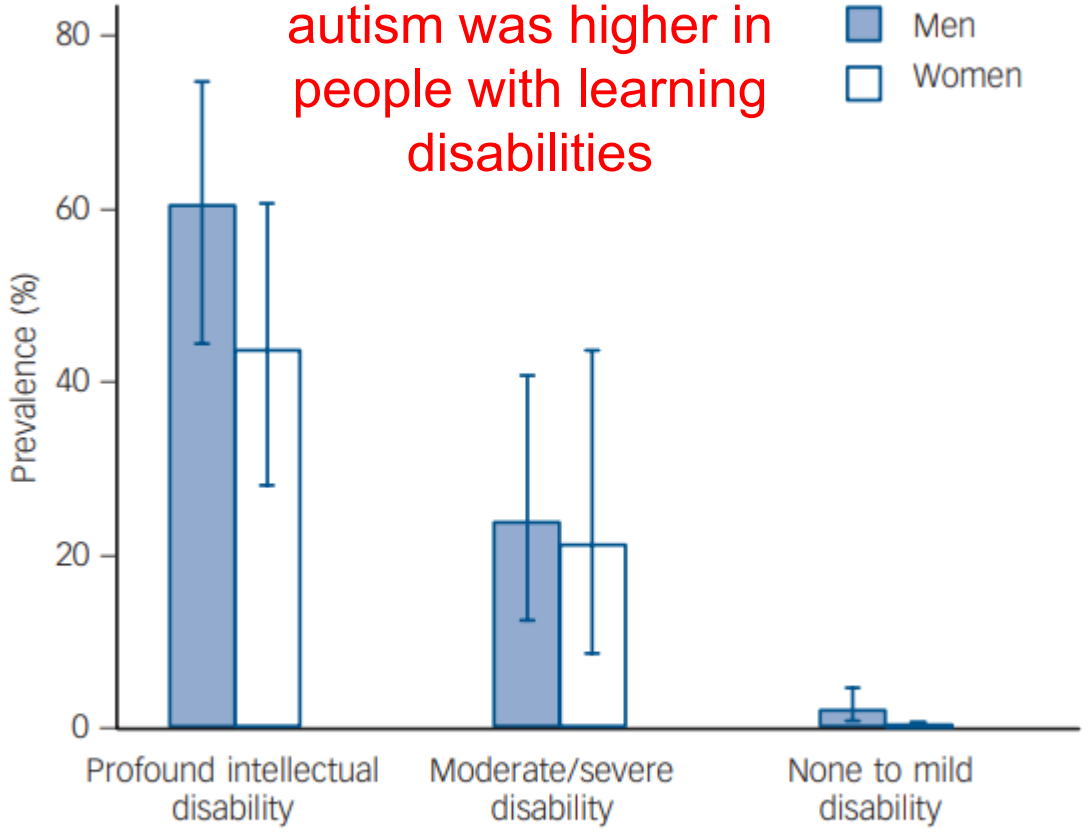
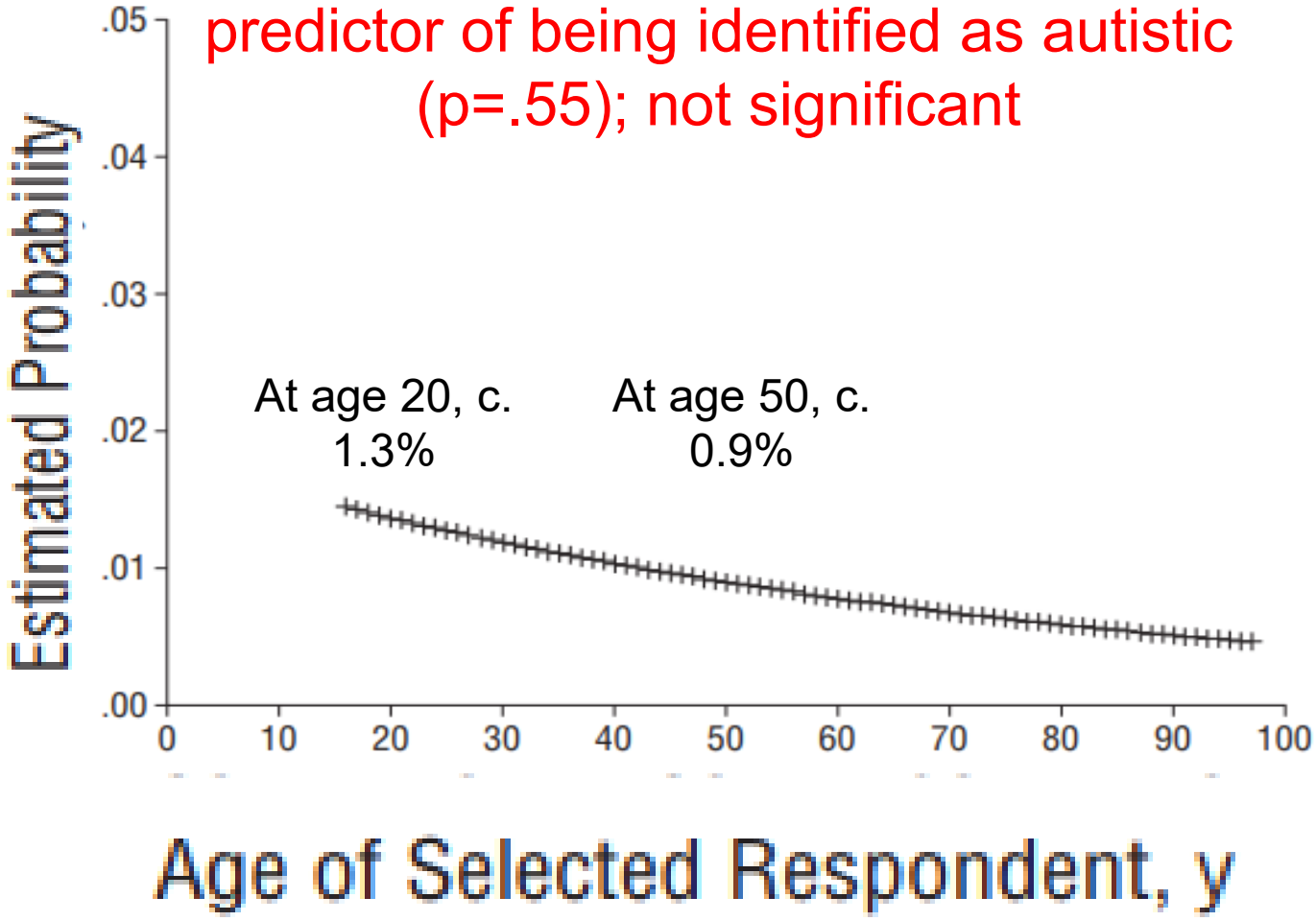


Fig. 1 Gradient of autism prevalence by intellectual ability; combined sample.

https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/epidemiology-of-autism-in-adults-across-age-groups-and-ability-levels/D4F48E07D1002DE6F75A67FF9A4FFCF7

Does prevalence differ by age? Brugha et al., 2011

P-value for age as a continuous predictor of being identified as autistic (p=.55); not significant



Age trend would also be impacted by premature mortality

Suggests broadly stable true prevalence

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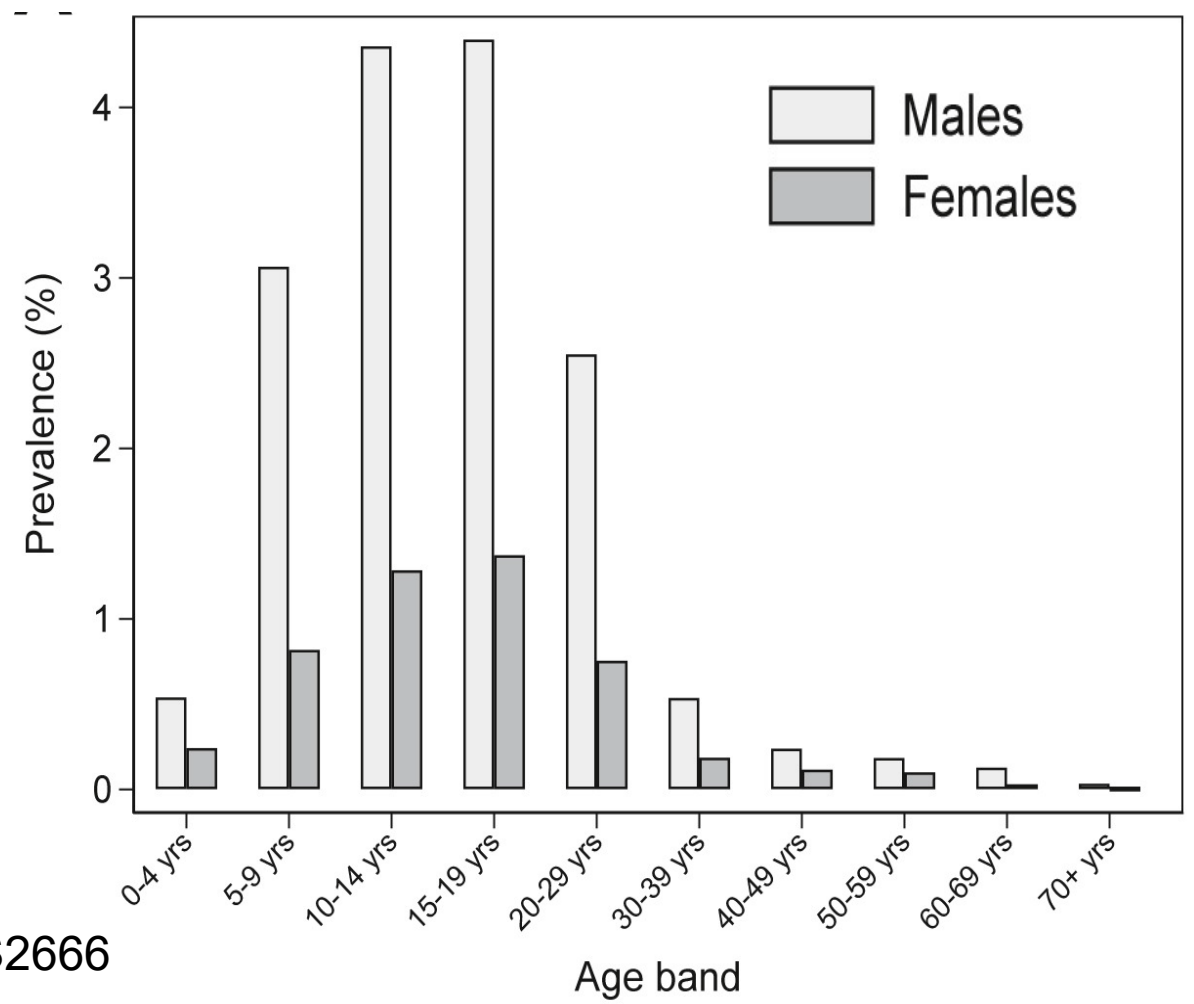
What conclusions could we draw?

- Stable community prevalence.
- 1% prevalence overly-conservative.
- No recent studies using up-to-date criteria.
- Children and young people (CYP) have best access to referral and assessment.
- We assume that the highest diagnosed prevalence in CYP would in fact apply to all age-groups, if there was equal access to assessment.
- c. 1% as a lower-bound; c.3% as an upper-bound figure of true prevalence.

Our study: estimating underdiagnosis of autism in the UK

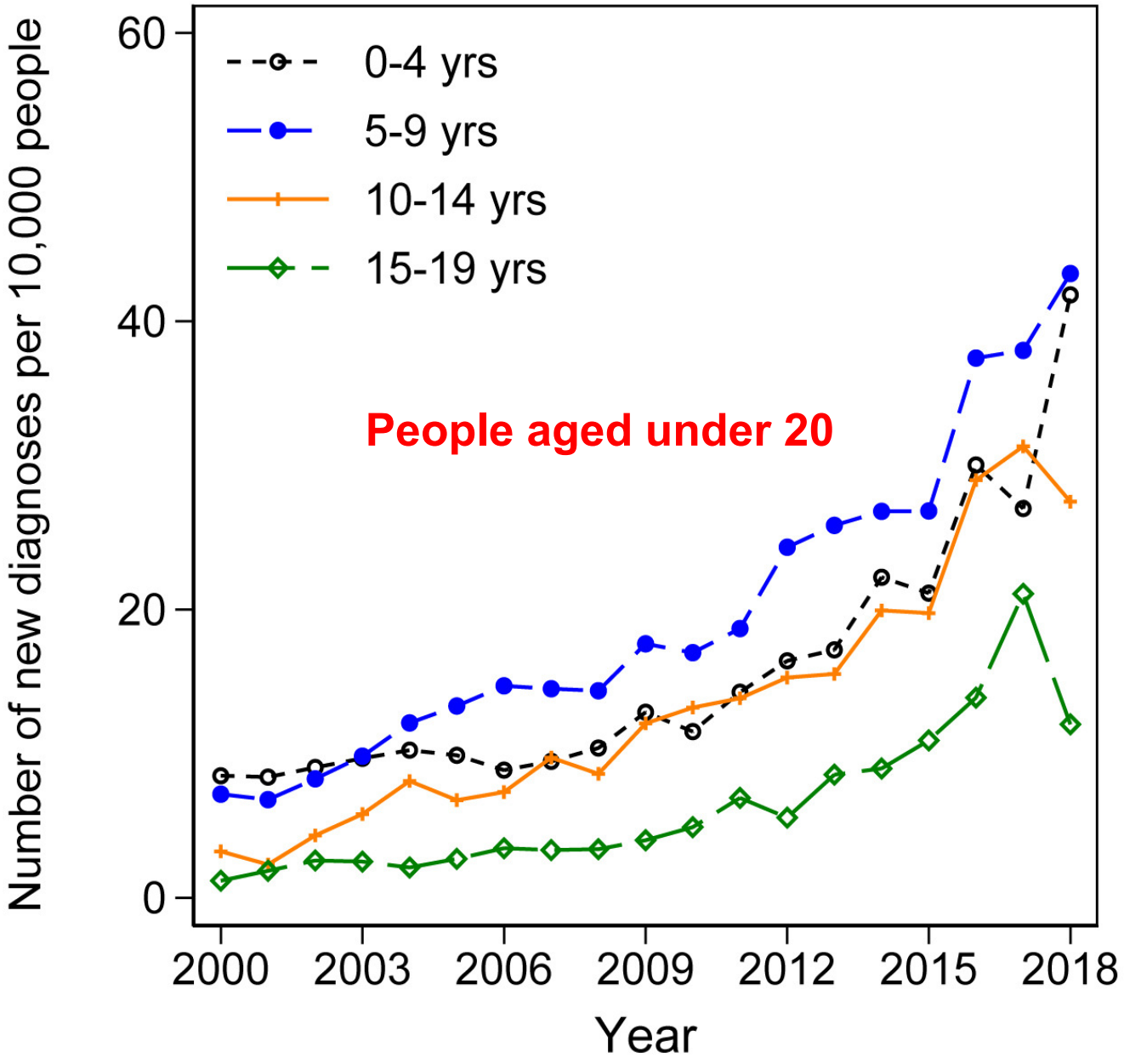
- Anonymised primary care (GP) data from 602,433 individuals in english primary care in 2018. GP data repository of health information.
- As of 2018, c.3% of 10- to 19-year-olds had a diagnosis (1 in 34).
- Highest diagnosed rate in any age-group:
- Males without ID = 4.1% (10-14 yrs)
- Females without ID = 1.2% (15-19 yrs)
- Males with ID = 41.1% (15-19 yrs)
- Females with ID = 23.7% (10-14 yrs)

% of people with an autism diagnosis as of 2018 stratified by sex



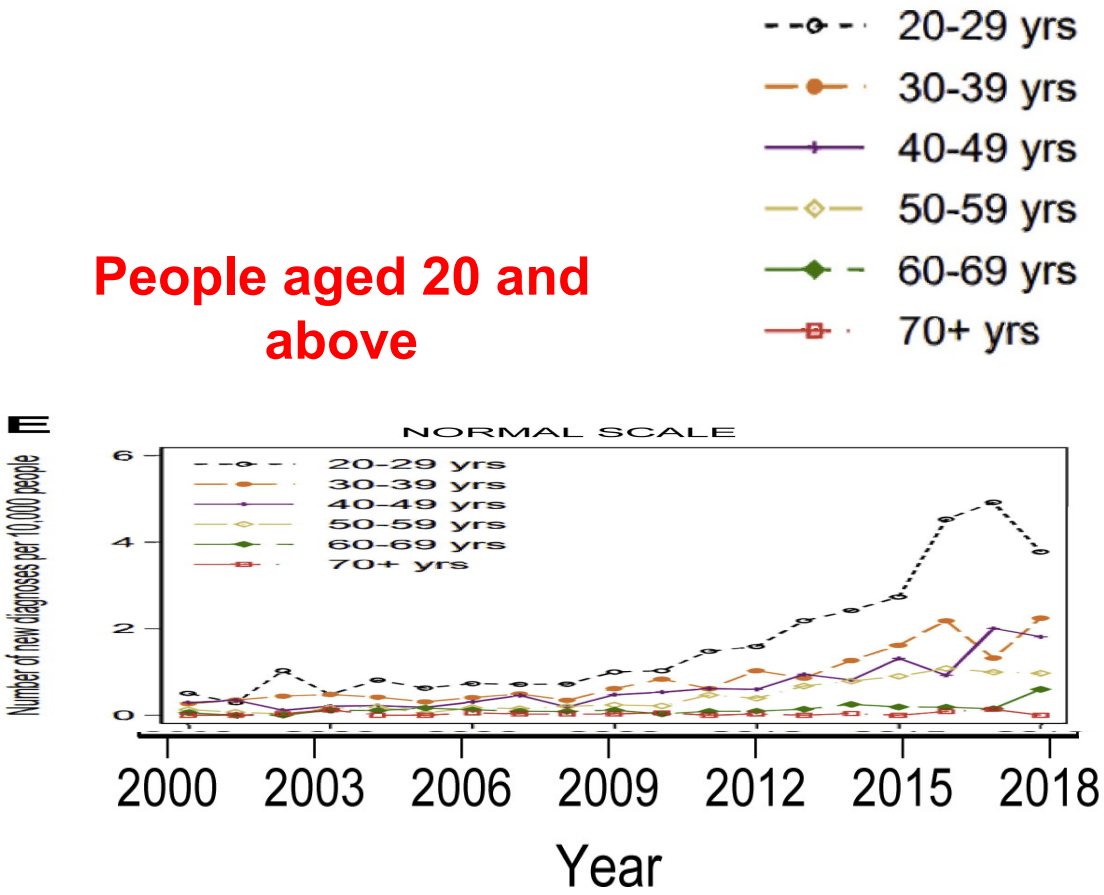
https://www.thelancet.com/journals/lanepe/article/PIIS2666-7762(23)00045-5/fulltext

Incidence of new diagnosis per 10,000 people: 2000 - 2018

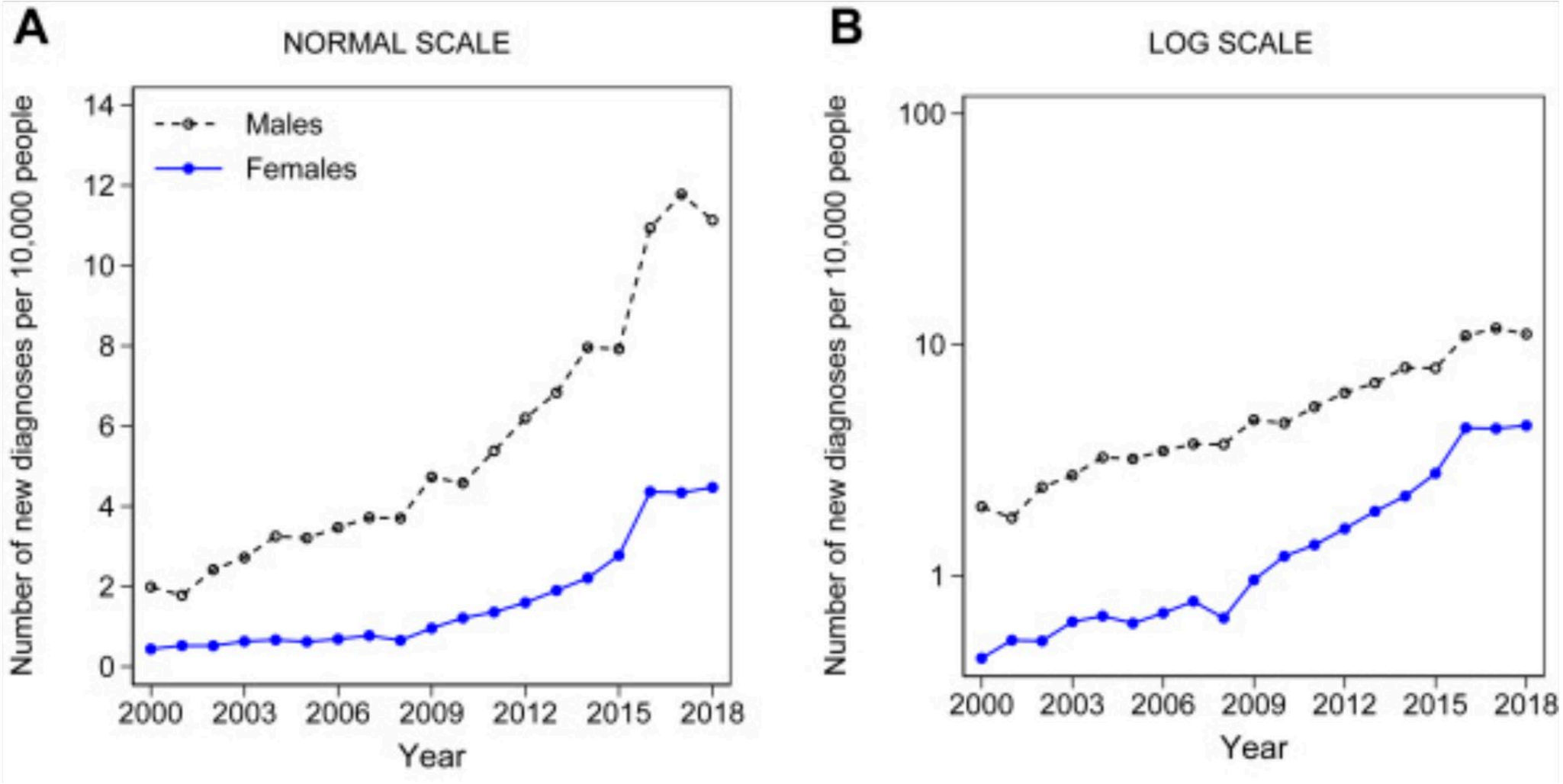


Anonymised primary care (GP) data from 5,586,100 individuals registered between 2000 and 2018 were included.

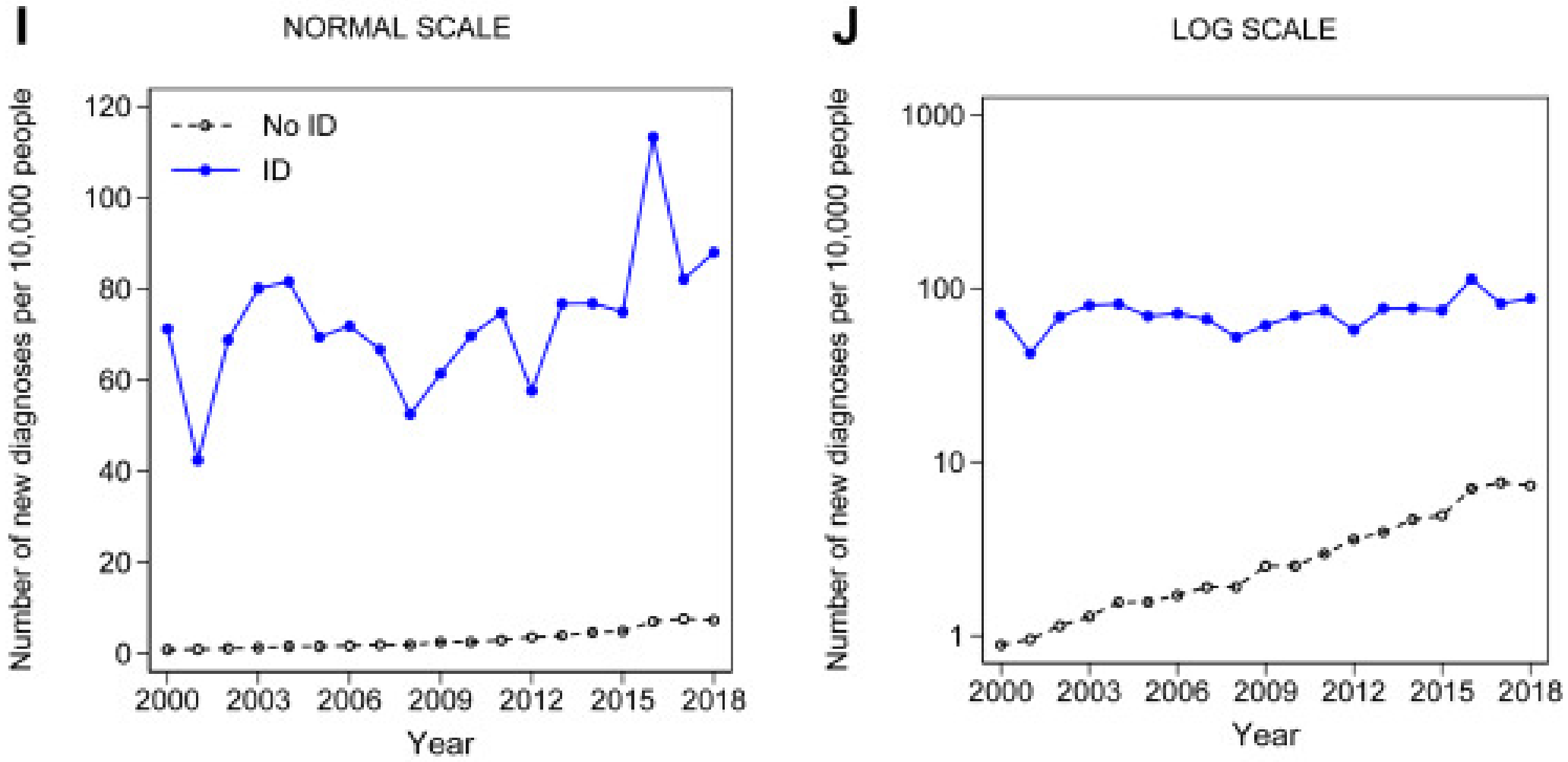
People aged 20 and above



Changes in rates of diagnosis for males vs. females: 2000 - 2018



Changes in rates of diagnosis by ID status: 2000 - 2018



Time trend for increase not evident in people a learning disability

Our conclusions

- Rates of new autism diagnoses have increased dramatically between 2000 and 2018.
- Adults are much less likely to be diagnosed than children.
- There are between c. 740,000 and 1.7 million autistic people in England out of a population of 56 million.
- Even assuming a true prevalence of c. 1%, 9 out of 10 autistic over-50s are undiagnosed.

Acknowledgements

- Prof. Josh Stott & Prof. Will Mandy

- Collaborators: Irene Petersen, Josh Buckman, Rebecca Charlton, Claudia Cooper, Anne Corbett, Francesca Happé, Jill Manthorpe, Marcus Richards, Rob Saunders, Cathy Zanker, Doug McKechnie, Dan Lewer, Celine El Baou.

- National Autistic Society-facilitated Experts by Experience Steering group.

- UCL Adapt Lab, UCL Primary Care and Population Health, and THINK group colleagues.