Author’s response to reviews

Title: Physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis

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Author’s response to reviews:

Dear Editor,

Thank you for the opportunity to address the points raised by the two additional reviewers. With regard to your comments that the details of the associations of conditions are the more interesting point of the paper, and whether they have been found before: - we fully concur that the extent and early onset of multi-morbidity is the important message we are trying to convey. We have therefore slightly re-focussed the presentation of the results in the abstract. We can confirm that our literature review identified only two previous papers that have reported multi-morbidity in people with intellectual disabilities, but that both of these were focussed on studying elderly people with intellectual disabilities only, not the full adult age range, neither included a general population comparison group, and both were much smaller cohorts than ours. We reference both of these papers in our opening paragraph. We thank the reviewers for their consideration of the paper, and address the points as follows:

Reviewer 3:
No additional revisions required.

Reviewer 4:

1. the prevalence of intellectual disability is lower than expected (0.6% vs. 1% found in a meta analysis by Maulik et al, 2011 - doi:10.1016/j.ridd.2010.12.018) and therefore the comment by a previous reviewer that the study may be slightly under representative of those with Mild ID is justified. The slightly lower prevalence is to be expected but the authors should acknowledge this as limitation. However, the prevalence of 0.6% is generally higher than that found in studies relying on service definitions of ID, which is a strength
Response:

We are very familiar with the paper that the reviewer quotes. It does give an overall prevalence for intellectual disabilities of 0.921% for high income countries. However, in the details of the paper, it also separates out this figure for children/adolescents only, and for adults only. The adults only prevalence they report is 0.494% which is marginally lower than/very similar to our finding of 0.562%. Our study is of adults only.

There is a genuine difference in prevalence of intellectual disabilities between children and adults due to:

1. gradual skill acquisition over time, such that some children requiring additional educational support at school become fully independent without any need of extra support as an adult, and are not considered as having intellectual disabilities as an adult, and no longer meet either ICD-10 or DSM-5 criteria for intellectual disabilities in adulthood,

2. premature death of people with intellectual disabilities, so that prevalence rates drop with increasing age.

There are numerous other factors that impact on prevalence of intellectual disabilities over time and geographically, but we hope this is enough to make the point – the reviewer has provided the “headline” finding from the paper, and we trust that the details we have provided explain the discrepancy.

2. related to the above, it is possible that the authors may have missed some individuals with ID by using a fairly narrow list of read codes. In another primary care database study of health checks for individuals with ID in England it was found that a significant proportion of individuals with ID syndromes such as those with Fragile X syndrome or Down syndrome did not have a read code for intellectual disability (“mental retardation”). The authors should explain why they have chosen to use a narrow list of codes, or else give consideration to extending their ID definition by including an additional list of read codes, such as those for childhood autism and genetic ID syndromes, that has been used in other primary care database studies. A list of additional codes to use has been published previously as supplementary material http://www.thelancet.com/cms/attachment/2021261287/2041361619/mmc1.pdf. This may help to improve representativeness of their sample.

Response

We have added a sentence in the limitations section of the study to acknowledge this possibility with regards to adults with Down syndrome. We think this is a minor point unlikely to affect overall study findings as the date of data extraction was after GPs were financially incentivised to include people with intellectual disabilities on practice intellectual disabilities registers. Due to local factors, in a quarter of Scotland, this payment was made for each person included on the intellectual disabilities register, hence an incentive to include everyone. This area identified a rate of 0.46/1,000 patients, which was in the mid range of all of
Scottish Health Boards (0.4-0.6/1,000), suggesting similar practice across Scotland.

The reviewers list of codes includes adults with autism. We consider it would have been inappropriate to include adults with autism (and the various sub-classifications of autism) in our study, as the majority of adults with autism do not have intellectual disabilities. A recent English-wide study devoted to determining the prevalence of autism in adults found a prevalence rate of 1% excluding adults with intellectual disabilities and 1.1% including adults with intellectual disabilities (Brugha et al, 2012, Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey. The Health and Social Care Information Centre. http://www.hscic.gov.uk/catalogue/PUB05061/esti-prev-auti-ext-07-psyc-morb-surv-rep.pdf).

Only an estimated 65% of women with Fragile X have intellectual disabilities (more men have it), and about 65% with velo-cardiofacial syndrome have non-verbal disabilities. It therefore does not seem appropriate to have included these search terms in this study as some do not have intellectual disabilities.

People with some conditions listed on the code list the reviewer provides do not reach adult age e.g. Pataue syndrome, Cockayne syndrome. All the other conditions are exceedingly rare, such that it would not effect our overall study results even if they had been left off intellectual disabilities registers; the next most common condition on the list is Williams syndrome which is estimated to occur in 1 in 20,000 (there is some uncertainty of the exact rate), other conditions are much rarer.

3. It is not clear what read code lists have been used for important conditions such as coronary heart disease. Do they have a reference for these code lists, or could they give more information?

Response
We have amended the appendix to include the full data dictionary, rather than the previous abbreviated one. The Read codes used were from the QOF qualifying conditions definitions where available, and NHS Scotland Read Code groups where not.

4. One of the results is puzzling - the authors reported an OR of 2.2 for dementia in ID compared to the general population, based on a prevalence of 0.8% in ID, and 1.1% in those without ID. Although adjustment may have affected the reported OR, it still seems curious and a typo may be a possibility. The authors should check to confirm that the reported prevalence rates are correct.

Response
We have added a sentence to explain this as this information may initially seem puzzling. The information is accurate, and is due to the odds ratio being standardized by age (as well as gender and extent of neighbourhood deprivation) – the table does state that the OR is standardized. People with intellectual disabilities, particularly Down syndrome, are known to experience dementia at
much earlier age than the general population, and so this OR was an expected finding (and also provides indirect evidence that our codes for intellectual disabilities have not omitted people with Down syndrome). However the proportion of people with intellectual disabilities who have dementia at any one time is small, given the age distribution of the population with intellectual disabilities.

5. Finally, the authors make the following statement in the discussion: "The majority of adults with intellectual disabilities do not drink alcohol at all, although some misuse it, and at a slightly higher rate than the general population in this study." But I don't think they reported the data to support this statement?

Response
The data is reported in table 4.