Author’s response to reviews

Title: Read coding patients with learning disabilities: Lessons from a cohort study

Authors:

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Author’s response to reviews: see over
Dear Andrea

**RE: Women with Learning Disabilities and Read Coding**

Please find enclosed the amended article. These are the amendments. Please note that reviewer Owen Barr did not like this article *at all*, so it has been difficult to work with his comment. However, the other reviewers’ comments have been much easier to use. In some parts, they commented on the same issue so these have been combined to result in one amendment.

- Linda Allan’s comment: Line one: Requires rewording - conflict does not exist over what a learning disability is - rather the conflict exists due to lack of agreement on definition. Line 1 has been changed to: “There is conflict over the definitions of the term ‘learning disability’ – as a result, there is no single definition (1,2)”

- Linda Allan states Line Three: Dispute that many parts of the world utilise ‘mental retardation’ – if this is the case - requires further referencing - international term is ‘intellectual disability’.

- Owen Barr stated: I am very surprised to see that term mental retardation is used officially within the UK. The following change has been made: Line 3 has been amended to: “… and in many parts of the world the phrase mental retardation was used for some time (2).” This statement is further supported by the addition of this phrase and reference: “For example, the American Association on Mental Retardation continued to use the term mental retardation until as recently 2006 (4).”

- Linda Allan: Para 2 - last line: If Crawford et al's phrase was utilised today most people with a ID would consider this highly offensive - explanation required of what is acceptable to people with a LD. I agree that the phrase at the end of paragraph two is highly offensive: “Crawford et al, (6)….“To emphasise this problem with definitions, this has been moved so that it is sandwiched between two statements that highlight this problem:

  “Oliver (5) points out that the problem of defining ‘disability’ is that the word is defined by people who do not have a disability. For example, Crawford et al, (6) suggest that definitions should include the phrase ‘significant sub-average intellectual functioning’ which represents, in the UK, an IQ below 74. It has taken some time to arrive at ‘respectful descriptions’ of people with LDs, (7).”

- Linda Allan: Para 3 - not clear of the value of this - is the author attempting to distinguish between learning disability & learning difficulty - if so would suggest rewording. This sentence has been added to paragraph 3 to aid clarity: “Confusion often arises over the use of the term learning disabilities, because it is often used to refer to conditions that are known as learning difficulties in the UK – such as dyslexia.”

- Linda Allan: Para 4 - Reference outdated - would suggest utilising more recent reference - plethora available. The reference in paragraph 4 has been updated.
Linda Allan: Para 6 - confusion of term - line 2 - learning difficulty / line 4 - learning disability. Paragraph 6 – Line 2: difficulties has been changed to disabilities. The following sentence has also been added: “The issue of services for patients with learning disabilities is also a Quality and Outcomes Framework target for all surgeries. Since 2006, practices have had to be able to produce a register of patients with learning disabilities.”

Linda Allan: Para 8 - There are many more advantages of Read code use. Paragraph 8 – Sentence amended to: “Among the advantages of the Read codes are that they are simple to implement and can aid searches.” The following sentence has also been added: “They also allow us to record data more consistently; retrieve it more easily and analyse more thoroughly.”

Linda Allan: No explanation given as to why the authors only included women within the age range of 25-64 (is this paper linked to a paper on cervical screening???) Population not given. Definition of Learning disability may be better moved to ‘background’. No statistical analysis / power given. No mention of study design / process / consent process or ethical approval. No rationale of why these read codes were selected and not others e.g. up to 40% of population will have epilepsy - why not search on this code or utilise some of the many other common genetic codes?

Angela Hassiotis: The authors allude to a previous project on cervical screening for this population. Information on that research would further elucidate the present report. In addition, I would like to know more about the practice size and the actual number of women in the cohort.

The methods section has been overhauled, combining both Angela’s and Linda’s comments to read as follows:

“A retrospective cohort study, using case control methods, was carried out to compare the uptake of cervical screening and the likelihood of being ceased, between women with and without learning disabilities. The use of Read coding was also explored as a part of this work to ascertain the most commonly used codes for learning disability. The study population included women aged 25-64 with learning disabilities in the PCT areas of Bury, Heywood and Middleton and Rochdale.

“Using Epi.Info Stat.Calc, we calculated that a sample size of 217 women with learning disabilities and 434 women without was required assuming prevalence of screening to be 80% and based on an OR of 2, and a sample ratio of 1:2 (women with learning disabilities to women without) Significance was set at 0.05 and power at 80%. Looking at Read coding for learning disabilities, we focused on the case group and we found that there were actually 267 women with learning disabilities who were in contact with the Learning Disabilities Teams or the GPs in the three areas.

“Design and Process

“This study was undertaken across Bury, Heywood-and-Middleton and Rochdale PCTs. There were 34 GP practices in Bury, 21 in Rochdale and 14 in Heywood-and-Middleton and work with these took place September-December, 2005. Patient data were stored on the database systems Vision, EMIS, EMIS PC4 and Torex.

“The following Read Codes (used for diagnoses and treatment) were used to identify women on GP systems identified as having learning disabilities. The reason for carrying out this second process of ascertainment was to ensure that as complete a list as possible, of women with learning disabilities, was obtained.
"The named learning disabilities are listed in Table 1.

... 

Ethics Committee: North Manchester LREC 05/Q1406/82

Obtaining Consent for Records to be Accessed

This study was carried out by accessing patient records. Although people caring for a woman with learning disabilities (carers), whether family or a paid employee, cannot consent on her behalf, the Mental Capacity Act (2005) advises that they (or nominated third parties) should be consulted to discover whether the person with learning disabilities would assent to joining any research project. A letter was sent to 267 women with learning disabilities requesting their permission to access their records. In the event that the women did not understand the letter, it was anticipated that they would pass it to their carer. In some cases, carers/parents contacted the PCT office to enquire further about the study.

The letter stated that if the women (or their carers) did not wish to give permission they should contact the study. 46 people contacted the office. The carers of four women withheld consent on the grounds that the woman could not consent. Of the 42 people who wished to find out more 37 were parents who stated that their daughters had never had a screening test but that the women assented to being included in the study for checking. Five were women with learning disabilities who wished to know more and gave their consent.

Angela Hassiotis: This method ensured that the practices received further support and assistance in ascertaining all of their practice patients who had a learning disability and to code them appropriately. This is a very important healthcare issue not only mentioned in Valuing People but also is a Quality and Outcomes Framework target for all surgeries.

The second paragraph of “Main Findings” has been amended to:

“The blanket use of generic codes means that it impossible to use GP records to easily identify any common types of learning disability or clusters. This could impede the provision of any specific specialist support that could be offered to patients, and the improvement of services, because the generic codes mask the situation. However, it should be noted that large ‘clusters’ were found at a number of practices, usually where there was a care facility nearby. “

Linda Allan: Discussion Highly dispute that this paper explores whether the DoH target of whether people with Learning disabilities registered with general practice have been read coded - this is a sample of 290 women only and makes no reference as to pattern of coding in men (more men will have a learning disability than women) The strengths and limitations of the study requires rewriting - no mention of the sample being only women . No mention of impact of only utilising a few read codes for example.

Angela Hassiotis added: In the discussion the first section "how this fits in" should be in a narrative rather than bullet point format and it should make some reference to current policy guidelines such as QOF. In the second section "main findings", I am unclear as to what the authors mean with "...could be associated with environmental factors". What are
those factors and their relevance to learning disability; how does that affect service provision? This paragraph needs further clarification.

The reference to environmental factors has been removed.

“How this fits in” has been amended, combining both Angela’s and Linda’s comments to add: “The Department of Health publication Valuing People (2001) sets out how the NHS may improve access to health services for people with learning disabilities – specifically women’s access to screening and examines how accurately their needs have been coded.” Plus: “The QOF target of every practice producing a register of patients with learning disabilities was introduced in 2006 – this study was carried out before this came into force.”

(Owen Barr also noted: I do not feel they have been clear about the definitions to be used and a number of conditions I identified in Table 1, are not always associated with learning disabilities, including Autism, Fragile X and Phenylketonuria. This is acknowledged as a weakness and explained in the limitations).

Under “Strengths and Limitations”, these amendments have been made: “A key weakness of this study is that it focused only on women – learning disabilities are more common among men. The Read Codes used in this Study were selected on advice from the Learning Disabilities Teams (LD Teams) and other PCT staff. It was not an exhaustive list. Other codes were omitted to ensure that women without learning disabilities were not considered among the figures (e.g. cerebral palsy is often included in lists). The use of Read codes can be problematic as one description can have two, even three codes. This could confound any audits or research as the codes inputted to GP records will vary according to which operator carries this work out. It is also possible that the selection of Read codes used may have distorted one aspect of the Study’s findings and weakened the work.”

- Linda Allan: Existing literature Reference quoted was work carried out prior to the new GP contract – the authors should acknowledge this and impact the contract will have had. To “Comparison with existing literature”, the following sentence has been added: “However, this assertion was made prior to the new GP contract and GPs now have a very good idea, in many cases very accurate idea of how many of their patients have learning disabilities.”
- Angela Hassiotis concluded: the title should bear the fact that the patients coded are a cohort of female service users with learning disabilities. The title has been changed to: “Women with learning disabilities and Read coding: Lessons from a cohort study”

Thanks for your time.

Fiona Reynolds