Reviewer's report

Title: Pediatric Complex Chronic Conditions Classification System Version 2: Updated for ICD-10 and Complex Medical Technology Dependence and Transplantation

Version: 1 Date: 3 March 2014

Reviewer: Eyal Cohen

Reviewer's report:

Thank you for the opportunity to review this manuscript. The CCC classification system is simple to use, logical, transparent, and has been very informative in broad types of health services research related to pediatric chronic disease. Updating it to ICD10 is a laudable task, and the authors should be commended for presenting a very clear manuscript outlining the changes they made and the comparability testing they have conducted.

Major Compulsory Revision:

My main concern with the manuscript is the decisions that were made to update some of the diagnoses included/not included in the CCC framework for CCC v2. The authors note that some diagnoses in CCC v1 do not meet the conceptual definition of CCC (lasting 12 months, requiring specialized care and probably hospitalization). However, it is not clear why some diagnoses were removed (e.g. benign malignancies), while others that do not necessarily meet the conceptual definition of a CCC were not (e.g. some of the benign cardiac lesions like patent ductus arteriosus, which frequently spontaneously closes). Similarly, diabetes mellitus is now included, adding a substantial number of children with a condition that generally does not frequently lead to hospitalization. The new category of neonatal CCC also raises similar questions, as many of the neonates who develop chronic problems (again using the conceptual framework of expected to last 12 months or more), will likely do so by virtue of complications (e.g. cerebral palsy) rather than the initial diagnosis (prematurity).

I am not surprised that temporal trends in death have not changed with the two versions as death is relatively uncommon for the majority of children classified as having a CCC, and the high risk conditions for death are likely very well captured in both versions. However, the changes that lead to a 19-33% [?or is it 23-36% .. see comment below] increase in patients captured as having CCCs can be problematic in comparing studies with CCC v2 to data using CCC v1. The authors state in their conclusion that the new system is ‘more comprehensive’. That may be true, but the potential trade-off of this is decreased specificity of the CCC classification scheme and, ultimately, challenges in comparing data using this new version to the impressive body of literature that the authors cite that has been conducted with CCC v1.
Minor Point:

Abstract (and Results p. 10): If I am reading them correctly, the numbers presented for changes in patients categorized as CCCs seem a bit discordant with the data in Table 2. In the text in KID 2009, it is 2.5 % absolute and 23% relative increase. In the Table, it seems like 2.1% and 19%. For NEDS 2010, the numbers in the text (0.7% absolute and 36% relative) differ slightly from the Table too (33.3% relative increase).

Introduction: Although the US is moving to ICD10 now, would suggest pointing out that ICD10 is already used widely internationally.

Discretionary Revision:

Figure 1: It is clear in color, but for those who print up manuscripts in black and white, it may be easier to see if some of the lines used are presented as dashes, etc.

Level of interest: An article of importance in its field

Quality of written English: Acceptable

Statistical review: No, the manuscript does not need to be seen by a statistician.

Declaration of competing interests:

I declare that I have no competing interests