Author's response to reviews

Title: Service usage and vascular complications in young adults with type 1 diabetes

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Version: 3 Date: 23 April 2014

Author's response to reviews: see over
Responses to review comments

Dear Editor, reviewers,

We have addressed each point raised by the reviewers as set out below. Further, the manuscript has undergone substantial revision throughout. Thank you for your helpful comments in improving this manuscript.

Mark McLean

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| 2. The data collection is retrospective and opportunistic - relying on what has been recorded in occasions of service or other presentations to the hospital service (such as Emergency visits). This could be problematic. It is possible that more screening has been performed, but has not been documented. Patients who have not had contact with the service will be missing from these data. Although data is provided to compare the sample size with the expected number of people with T1DM, there may be differences between those included and not. **We accept that there will be people we missed, but have expanded our** | The following text has been detailed: 

Participants were young adults (aged 16 - 30 years) with type 1 diabetes as a primary condition. We collated our database from patient occasions of service with HNEH services from 2008 onwards, and audited contacts during 2010 and 2011. In Newcastle participants were identified through ambulatory care clinic records and Emergency Department (ED) and hospital attendances. In regional areas, records of Community Health, local diabetes educators and pathology services were also searched. We endeavoured to identify all young people with type 1 diabetes in the Local Health District, but recognise that our database may miss any who did not use state public health services, whose management and outcomes may be dissimilar to those reported. | 7, 15 and 18

A chief limitation of this study was use of data originally collected as patient clinical healthcare records; all such studies are forced to rely on professional and legal accountability for clinical record-keeping, and the value attached to record quality in such situations of life-long care. Nonetheless study data will have been affected by factors affecting the quality of clinical record keeping. Whilst there was potential for
explanation of how our database was constructed, as I think we underestimated how comprehensive this was. We accessed a lot more than just hospital records.

3. I am concerned that this data collection seems entirely focused on activity within the hospital-based service. In the Australian health care system many patients receive the majority of their care in private practice settings from General Practitioners or specialists. It is possible that excellent care (including appropriate screening) has been provided but is invisible to this hospital-based audit process. The manuscript makes no mention of GP or private specialist care and whether this activity is captured in the audit.

We do not agree that many in this age range are supported by GPs or private endocrinologists for specialist care. Our experience with previous studies with this group indicate that General Practice is not where they look for diabetes care other than scripts, and few access private care. We acknowledge that this study does not include GP or private consultations.

Berkson’s bias on results, lack of access to General Practice (GP) or private practice data mean their service episodes were not reflected in these findings except as secondary report within case notes. However, few local GPs offered specialist support for type 1 diabetes; our previous qualitative study with this population reported their experience of GP diabetes care as predominantly age-inappropriate and non-specialist, and private endocrinologists as unaffordable [32]. Thus this may not have materially affected findings. The two-year time period of the study did not allow for trends across time, and the representative nature of these data can only be estimated by comparison to the earlier study, which revealed that little had changed over time [4]. Study co-morbidity definitions (specifically hypertension and nephropathy) were somewhat simplistic and data were not collected about acute illness and other co-morbidities that may affect screening and disease management. Furthermore, considering the high prevalence of type 2 diabetes in Aboriginal and/or Torres Strait Islander populations [33, 34] it is possible that a few may have been documented incorrectly with type 1 diabetes based on insulin administration. Nonetheless, the strengths of this study lie with the size of the cohort, the geographical size and range from which the cohort derives, and its near-complete population sampling within this under-researched age group.
4. Cases of hypertension are defined in the basis of a single recorded elevated blood pressure reading. This could be inappropriate if, for example, this single reading was obtained during a presentation to the Emergency Department.

*We agree, and we have stated this as a limitation.*

**Discretionary revisions**

5. Was data collected about significant co-morbidities which might affect compliance with screening guidelines? For example psychiatric co-morbidity, or related chronic illness such as cystic fibrosis.

*We specifically excluded diabetes secondary to other conditions. We have not considered the influence of other co-morbidities on screening attendance as they could equally be expected to increase or deter attendance.*

The following text has been detailed:

*Participants were young adults (aged 16 - 30 years) with type 1 diabetes as a primary condition.*

*..........data were not collected about acute illness and other co-morbidities that may affect screening and disease management.*
Monique Stone

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<td>Compulsory revisions</td>
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<td>1. The most interesting aspect of this study is the service use of these clients. The authors identified 707 records of the 830 estimated diabetics in this region. I would suggest this be moved to the results section, with an explanation about how diabetic services are delivered in this health sector. e.g. the transition process, is there someone to remind them of appointments or contact them if they fail to attend, when and where are the clinics, is there access to 24hr hotline for advice, do they pay to attend, do they have to wait long, is complications assessments performed at the clinic or do they have to go elsewhere. Do you have any data to estimate GP use (e.g. from medicare), is there are private endocrinologists or diabetes education services they may use?? How does the health services offered to young diabetic patients in the area compare to the national guidelines.</td>
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<td>We welcome this observation from the</td>
<td>This information is detailed in our previous paper published in Medical Journal of Australia and referenced in this publication.</td>
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<td>We do not have data on General Practice usage, and it would be very challenging to obtain this and differentiate GP attendance for diabetes care. However, the focus of this paper is type 1 diabetes specialist care – i.e. ability to review glycaemic management, titrate insulin, provide age-specific specialist information and complications screening. Our previous qualitative research with this target group, referenced in this paper, clearly indicated that participants did not report General Practice as providing this for them.</td>
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<td>Data in both the MJA and this paper indicate how services compare to guideline recommendations. However, it should be noted that the current Australian guidelines do not quantify service contacts – although guidelines of other nations are more specific about minimum contacts.</td>
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**Discretionary revisions**

1. Another interesting aspect of the study is the number of unplanned hospital attendances. This could be highlighted.

   The use of health services by cohort members has been made a primary focus of the paper.

2. Low rates of HbA1c measurements being reported were mentioned. Were there any attempts to also examine the HbA1c values from HAPs at HNEH or the main private laboratories?

   The following text has been detailed:

   *Participants were young adults (aged 16 - 30 years) with type 1 diabetes as a primary condition. We collated our database from patient occasions of service with HNEH services from 2008 onwards, and audited contacts during 2010 and 2011. In Newcastle participants were identified through ambulatory care clinic records and Emergency*
Department (ED) and hospital attendances. **In regional areas, records of Community Health, local diabetes educators and pathology services were also searched.**

3. The described associated between vascular risk factors and complications are not novel. And there have been larger cohort studies that provided strong evidence for causality. This section could be omitted so the manuscript could focus more on health service delivery.

**We do not agree with this comment as our systematic review on this topic (currently under review with a sister publication) revealed few studies specifically of young adults with type 1 diabetes.**

4. On page 14 the authors state that the prevalence of retinopathy in their study was less than that described in 2000. Although this may be true, the low level of screening documented in this study potentially underestimates the true level of retinopathy in this population.

The following text has been detailed:

**Retinopathy prevalence was less than demonstrated for young adults in NSW between 1990 - 2000 [25], but consistent with more recent NSW adolescents’ data from 2005 - 2009 [26]. Whilst a reduction in prevalence over time may have been related to changes in diabetes management recommendations following the definitive Diabetes Control and Complications Trial [22] which made glycaemic control central, low levels of screening potentially under-estimates the true level of retinopathy in this cohort; also hypertension and nephropathy. Collectively these data are cause for concern, indicating early onset of co-morbid disease and increased risk of impaired quality of life and premature mortality.**
Deborah Holmes-Walker

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<td>The definitions used for hypertension and nephropathy overestimate the prevalence of the complications and the findings of relationship to age and duration of diabetes are not new and have been published in much larger and better studies. The conclusions however are well balanced and adequately supported and limitations of missing data is clear. Definition of hypertension over estimates presence of hypertension with classification based on a single measurement whereas treatment should be based on at least three BP measurements Similarly definition of nephropathy was at least one abnormal urine microalbumin this is not standard-should have three consecutive abnormal urines therefore overestimate of prevalence of nephropathy using this standard.</td>
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<td>We agree that the definitions used are somewhat ‘rough and ready’, and acknowledge this as a study limitation. However, with this low level of screening, we had little option: only 40 people, for example, received the three renal function assessments required for diagnosis of renal dysfunction, and these occurred over two years; few (less than one third over 2 years) had three or more blood pressure measurements recorded. We had no option but to report what we found. It is equally likely that the low level of screening under-estimates the prevalence. We also note that our systematic review found few studies specifically of young adults with type 1 diabetes, although there certainly are many larger and better studies of older adults.</td>
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What is notable in the service access data and its link to complications and a shorter report with this aspect of the data as the main focus would be more noteworthy for publication.

*The use of health services by cohort members has been made a primary focus of the paper.*

However some comment about the relationship between accessing of services and advancing age (resulting in reduced contact with services and advancing age is associated with increased prevalence of complications. Analysis of effect of age on service contact should be presented.

The following text has been detailed:

*There was a significant correlation between age and total number of planned contacts/two years (Pearson R=-0.339, p<0.001) and significant but weaker association with duration since diagnosis (R=-0.168, p<0.001; overall model fit R²=0.120). Multiple regression analysis demonstrated a significant relationship between increasing age and fewer planned contacts (Beta = -0.321, p<0.001), whilst the relationship with diabetes duration was not significant (overall model fit R²=0.118). A similar pattern was seen with unplanned service usage (Beta = -0.104, p<0.019); whilst still significant, this was much weaker, i.e. older age was more strongly linked with reducing use of preventive care than acute service usage.*

We noted the influence of increasing age on prevalence of complications.

I agree with the editor that the static measurements of HbA1c are not useful for correlating with nephropathy or hypertension but could be reported.

The following text has been detailed:

*Of those with any HbA1c measurement, median three measurements were documented (range 1 - 12) across the two year study period. In cohort members identified with*
separately. However the distribution of A1c is not dissimilar from other publications of this age group.

*We agree that we were hampered by the paucity of HbA1c measurements, and that what we had was not dissimilar to reports from other groups. The correlations are thus small points but part of a consistent pattern. Given the limitations of the data, we therefore feel it is worth noting.*

The regression results with pump therapy predicating hypertension may be spurious as there was a large amount of missing data and earlier in the data analysis there was no difference in prevalence of vascular complications between CSII users and non users with 40% missing data indicated.

The following text has been detailed:

*Findings with regard to the use of CSII were noteworthy. Whilst CSII users received overall significantly greater planned service use and assessments, hypertension and any vascular complication occurred more frequently in association with any usage of CSII. Results should be viewed with caution due to missing data but whilst findings were not in line with some studies [29] they were consistent with a previous NSW study which showed that while CSII use doubled during the study period, HbA1c in users deteriorated, rising from 8.4% to 8.6% [3]. It is tempting to speculate that perhaps people with poor control of blood glucose, and associated hypertension, may have been started on CSII in an attempt to improve control, but most of these young people were likely to have commenced use of CSII as children. Education at initiation of CSII for children is primarily to parents/ responsible adults. If the child/ teen was not targeted for education pre-transition from paediatric care, deficiencies in CSII knowledge were not likely to have been picked up or rectified if the young adult did not have a good relationship with a pump-specialist.*

| 16 and 17 |
| 16 and 17 |
Duration of diabetes may be longer in pump users compared with non users also service contact may be higher so patients on CSII may be more likely to have had urine collected or BP measured that non CSII patients- please comment as this finding is not found in other publications.

The following text has been detailed:

*The profiles of CSII and non-CSII users differed: CSII users were significantly older (mean age 21.5 versus 22.9 years; \( t = 5.011, p < 0.001 \)); had diabetes longer (mean 11.2 versus 9.8 years; \( t = 2.886, p < 0.004 \)); received more planned service contacts/ two years (mean 11.5 versus 6.25 contacts; \( t = 6.535, p<0.001 \)); more HbA1c measurements/ two years (mean 4.2 versus 2.6 measurements; \( t = 6.353, p < 0.001 \)); more BP measurements/ two years (mean 2.6 versus 1.5 measurements; \( t = 5.523, p < 0.001 \)); and more ACR measurements/ two years (mean 1.0 versus 0.7 measurements; \( t = 3.291, p < 0.002 \)).*

Measures of service contact- median of 1 per patient is not correct as there were a large number with no contact. Perhaps should report median contacts using baseline of patients contacting services i.e. some patients contacting service a lot and others not at all.

We are happy to do this if the reviewers and editor feel that median contact should be defined as excluding those with no contact i.e. range excludes 0.

The following text has been detailed:

*Unplanned service contacts were common; 308 (45.2%) and 326 (46.1%) members had at least one diabetes-related ED presentation and/ or hospitalisation during 2010 or 2011; of those with any unplanned contact an overall median of two contacts (range 1 - 22) occurred. Unplanned contacts occurred more frequently amongst those with evidence of retinopathy or nephropathy: for example, 90% of those with but only 61.4% of those without documented retinopathy had at least one unplanned service contact. A median eight (range 1 - 62) planned/ unplanned contacts were reported, with 178 and 184 (26.1% in each year) cohort members having no reported service contact, planned or unplanned, and 87 (12.8%) with no service contact over the two years.*

It is not clear that all patients type I diabetes or are there some type II diabetes managed on insulin – 40 ATSI patients noted in whom type II diabetes is more common.

See response to Reviewer One first comment, above.
**It is possible that a small number were misdiagnosed.**

This sentence on data analysis does not make sense- please explain more clearly: “For these (what does these refer to?) analyses only, absence of evidence of documented vascular complications, laboratory values and smoking were treated as absence of that complication or potential predictive factor.”

The following text has been detailed:

*Independent predictors of vascular complications were determined by logistic regression analysis, with separate models developed for hypertension, nephropathy and presence of any of the three vascular complications. For the analysis of these three models only, absence of evidence of documented vascular complications, laboratory values and smoking were treated as absence of that complication or potential predictive factor.*

For ACR results the percentages are confusing. Please include data of both proportion and percentage given large numbers of absent data (ie need baseline total as this seems to vary)

Relevant data have been provided in a table. The following text has been detailed:

*Low levels of screening and/ or documentation were evident, with findings indicative or suggestive of co-morbid disease (Table 2). The majority had no documented BP measurement, ophthalmic examination or ACR measurement during either 2010 or 2011, respectively.*

For HbA1c similarly include proportion as well as percentage data to determine baseline numbers from which data is reported

Relevant data have been provided in a table. The following text has been detailed:

*Low levels of screening and/ or documentation of risk factors were also evident (Table 3). Of those with any HbA1c measurement, median three measurements were documented (range 1 - 12) across the two-year study period.*

**Discretionary revisions**

**General editing: there are many**

Multiple amendments have been made to the text to improve clarity, particularly in
| paragraphs which need editing to include commas for sentences to make sense e.g. “Cohort members with rather than with no reported retinopathy were significantly older” and many similarly constructed sentences. | relation to comparing groups who have or do not have a complication. |