

PEER REVIEW HISTORY

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This paper was submitted to a another journal from BMJ but declined for publication following peer review. The authors addressed the reviewers' comments and submitted the revised paper to BMJ Open. The paper was subsequently accepted for publication at BMJ Open.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Primary care interventions to improve transition of youth with chronic health conditions from paediatric to adult healthcare: A systematic review
AUTHORS	Bhawra, Jasmin; Toulany, Alene; Cohen, Eyal; Moore Hepburn, Charlotte; Guttman, Astrid

VERSION 1 - REVIEW

REVIEWER	Brodie, Lynne Agency for Clinical Innovation, Primary and Chronic Care
REVIEW RETURNED	09-Dec-2015

GENERAL COMMENTS	<p>While I found the paper interesting and important in focusing attention on the need to better describe and evaluate primary care models for transition, it is not clear to me why the Triple Aim domains were used as a criteria for inclusion of papers in the study. For non North American readers I feel the paper would benefit from a little more detail as to why this approach was taken as it obviously limited the papers that could be included.</p> <p>Strengths include focusing attention on the need to consider primary health models for transition which is of increasing importance world wide as the cost of delivering health care in acute healthcare settings continues to rise. The philosophy of providing care as close to home as possible also provides a strong argument for primary health solutions being given increasing attention.</p> <p>The comment that there are no studies evaluating primary care transition models in common conditions such as asthma that are managed almost exclusively in primary care settings is an important one and a key area for future research.</p>
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REVIEWER	McDonagh, Janet University of Manchester, Centre for Musculoskeletal Research
REVIEW RETURNED	17-Dec-2015

GENERAL COMMENTS	<p>This is an interesting systematic review which considers transitional care in the primary care setting rather than the secondary care setting where much of the research has been undertaken to date.</p> <p>As in all such literature it is important for authors to use the terms</p>
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	<p>transition and transfer carefully in view of the confusion which such inconsistency serves to perpetuate. Although the authors clarify this on page 5, on Page 4, line 24-26 it is unclear as to what they mean: should the sentence here actually mean “..requiring transfer (the event) from paediatric to adult health care. Although there is no universally accepted age of transfer (the event)....”</p> <p>In view of the differences in the use of the term primary care between countries it would be worth including a brief reference to this in the introduction. In the UK primary care can potentially look after people from “cradle to grave” in contrast to primary care paediatricians in the US.</p> <p>It is difficult to understand why the Hankins study [2012] can be classed as primary care in that it was a paediatric haematology nurse who was the case manager and the adult service was an adult SCD program. In other countries such as the UK this would be very definitely considered an example of transition within secondary or tertiary care.</p> <p>It could also be argued that the Maestro project is a secondary care intervention which involves primary care rather than a primary care intervention per se. In view of this, the fact that only one study was based in a primary care setting could be emphasised more.</p>
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VERSION 1 – AUTHOR RESPONSE

	Reviewer’s Comment	Authors’ Response
Reviewer 1	<p>While I found the paper interesting and important in focusing attention on the need to better describe and evaluate primary care models for transition, it is not clear to me why the Triple Aim domains were used as a criteria for inclusion of papers in the study. For non North American readers I feel the paper would benefit from a little more detail as to why this approach was taken as it obviously limited the papers that could be included.</p> <p>Strengths include focusing attention on the need to consider primary health models for transition which is of increasing importance world wide as the cost of delivering health care in acute healthcare settings continues to rise. The philosophy of providing care as close to home as possible also provides a strong argument for primary health solutions being given increasing attention.</p> <p>The comment that there are no studies evaluating primary care transition models in common conditions such as asthma that are managed almost exclusively in primary care settings is an important one and a key area for future research.</p>	<p>Thank you for your feedback. We would like to clarify that the Triple Aim domains were <u>not</u> used as inclusion criteria for the systematic review. As described in the ‘Search Strategy’ section, all articles on interventions or evaluations regarding transition from paediatric-to-adult care in primary care settings were included in the search.</p> <p>The Triple Aim framework provides a conceptual approach for improving transition care. Another systematic review (Prior et al, 2014) used the Triple Aim domains as their inclusion criteria, however as noted in our manuscript subsection, ‘Data Synthesis and Quality Analysis,’ our study only used the Triple Aim domains as a framework to assess each study outcome for the final list of included studies.</p>

Reviewer 2	<p>This is an interesting systematic review which considers transitional care in the primary care setting rather than the secondary care setting where much of the research has been undertaken to date.</p> <p>As in all such literature it is important for authors to use the terms transition and transfer carefully in view of the confusion which such inconsistency serves to perpetuate. Although the authors clarify this on page 5, on Page 4, line 24-26 it is unclear as to what they mean: should the sentence here actually mean “..requiring transfer (the event) from paediatric to adult health care. Although there is no universally accepted age of transfer (the event)....”</p>	<p>The original statement reads: “Although there is no universally accepted age of transition, many jurisdictions use inflexible age cut-offs to delineate service boundaries, creating fragmentation and discontinuity in provision of care across a particularly vulnerable period [3,4].” While it is also true that there is no universally accepted age for ‘transfer,’ we purposefully used the term ‘transition’ to indicate the <i>process</i> or the time period within which transfer occurs.</p>
	<p>In view of the differences in the use of the term primary care between countries it would be worth including a brief reference to this in the introduction. In the UK primary care can potentially look after people from “cradle to grave” in contrast to primary care paediatricians in the US.</p>	<p>Thank you for your comment. We intentionally kept the primary care concept as broad as possible. Primary care in the United States can refer to both family physicians and paediatricians. In Canada as in the UK, the majority of time primary care is provided by family physicians, however not exclusively. Our search strategy did not limit to any specific primary care provider type regardless of age of patient serviced.</p>
	<p>It is difficult to understand why the Hankins study [2012] can be classed as primary care in that it was a paediatric haematology nurse who was the case manager and the adult service was an adult SCD program. In other countries such as the UK this would be very definitely considered an example of transition within secondary or tertiary care.</p> <p>It could also be argued that the Maestro project is a secondary care intervention which involves primary care rather than a primary care intervention per se. In view of this, the fact that only one study was based in a primary care setting could be emphasised more.</p>	<p>This systematic review included all studies that were either set in a primary healthcare setting, or involved primary care providers. Given that few studies are situated in primary care settings, the authors intentionally kept the search and inclusion criteria broad. As a result, both the Maestro study and the Hankins study fit within this inclusion criteria as one of the few studies that involved primary care providers in the transition process. For example, the paediatric haematology nurse facilitated connection with relevant primary care providers in the adult healthcare setting.</p>

VERSION 2 – REVIEW

REVIEWER	Dr Janet E McDonagh University of Manchester, UK
REVIEW RETURNED	18-Mar-2016

GENERAL COMMENTS	<p>This is an interesting systematic review which considers transitional care in the primary care setting rather than the secondary care setting where much of the research has been undertaken to date.</p> <p>As in all such literature it is important for authors to use the terms transition and transfer carefully in view of the confusion which such inconsistency serves to perpetuate. Transition is definitely the process but not just “the time period within which transfer occurs “ as the authors state in their response. Transition ideally starts many years before transfer and continues after transfer. Some even advocate transition starting at birth in congenital or genetic disorders. So I still would argue that there is a need for clarity in the terminology used.</p> <p>Also, the phrase in the abstract “transition-age youth” is confusing when transition is usually advocated to start in early adolescence (eg in the AAP guidance and UK guidance) and not in the mid/late adolescent age range. It is the event of transfer which tends to take place in the 16-21 age range</p> <p>I would suggest rephrasing as youth aged 16 years and over – but somewhere also give the rationale as to why this age range was adopted.</p> <p>An additional limitation worth adding would be the differences in what primary care actually constitutes in different countries eg In the UK primary care can potentially look after people from “cradle to grave” in contrast to primary care paediatricians in the US.</p> <p>Page 4 – the authors raise the issue of the impact of adolescent development. There are several papers which may be worth referencing with respect to this as it is often this developmental concept which is forgotten in transitional care programmes but also not fully understood by health professionals: Scal P. Improving Health Care Transition Services: Just Grow Up, Will You Please. JAMA Pediatr. 2016 Mar 1;170(3):197-9.</p> <p>Farre A, Wood V, McDonagh JE, Parr JR, Reape D, Rapley T; Transition Collaborative Group. Health professionals' and managers' definitions of developmentally appropriate healthcare for young people: conceptual dimensions and embedded controversies. Arch Dis Child. 2016 Mar 4. [Epub ahead of print]</p> <p>Discussion as to why so little research has taken place within this area of care in primary care.</p> <p>As mentioned in the original review, It is difficult to understand why the Hankins study [2012] can be classed as primary care. The authors state that it was involved to the extent that a case manager (who was a specialty nurse (paed haem) helped establish patient's relationship with an adult medical home or health care provider. Is it was secondary care-led seeking to involve primary care. In other</p>
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	countries such as the UK this would be very definitely considered an example of transition within secondary or tertiary care. Likewise the Maestro project which involves primary care rather than a primary care intervention per se. In view of this, the fact that only one study was based in a primary care setting could be emphasised further.
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REVIEWER	Lynne Brodie Agency for Clinical Innovation Transition Care Network, NSW Ministry of Health NSW Australia
REVIEW RETURNED	22-Mar-2016

GENERAL COMMENTS	Thank you for your response to the questions raised in my previous review. I'm now much clearer about the use of Triple Aim in your design. Engaging with Primary Care around transition remains a challenge in Australia as many of the young people with complex chronic illnesses use their paediatrician as a general practitioner and the 'double hit' you describe when they transition is one that we are very familiar with. I look forward to an increase in the evidence around the role of primary care in future systematic reviews and am confident that researchers will benefit from the rigorous methodology you have undertaken.
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VERSION 2 – AUTHOR RESPONSE

Reviewer: 1

Thank you for your helpful feedback. Please find our responses to your comments below:

The first paragraph (sentences 2-4) of the Introduction has been rephrased to further clarify the differences between the terms transition and transfer.

The 'Participants' section in the Abstract has been rephrased as suggested by the reviewer.

The limitation regarding differences in primary care across jurisdictions has been added to the Strengths and Limitations section.

Thank you for bringing the Scal 2016 and Farre et al 2016 articles to our attention. We have included both references in our Introduction section. We describe our impression of why so little research has been done in primary care in the Introduction (paragraph 2) and Discussion (paragraph 2).

Regarding study selection, additional text has been added to the 'Results' section of the Abstract, as well as sentence 2 in the Discussion section to further emphasize the point that only one study was situated in a primary care setting.

Reviewer 2

Thank you for your thoughtful feedback and comments.