

## PEER REVIEW HISTORY

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## ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Policies Supporting Informal Caregivers Across Canada: A Scoping Review Protocol
<b>AUTHORS</b>	Khayatzadeh-Mahani, Akram; Leslie, Myles

## VERSION 1 – REVIEW

<b>REVIEWER</b>	Dr Fiona Morgan Senior Lecturer in Social Work, Institute of Community and Society, Faculty of Education, Health and Wellbeing, University of Wolverhampton, UK
<b>REVIEW RETURNED</b>	20-Jan-2018

<b>GENERAL COMMENTS</b>	<p>Overall this is an interesting article which sets out your intention to undertake a scoping review of the policy field of informal care in Canada. The objectives and scope of the intended study are very extensive but you comprehensively map out how you will fulfil them. My recommendation is for minor revisions to be made to your article which address all of the following points.</p> <p><b>Abstract</b>              In the abstract it states: 'but to fellow citizens with developmental disabilities or chronic diseases'. The wording used to describe disabilities varies cross nationally so some of the terms you use need to be clarified within the text. I assume your use of the term developmental disabilities is equivalent to the term used in the UK 'learning disabilities'. So the clarification that your term specifically relates to conditions which can cause cognitive impairments such as Downs Syndrome needs to be added.</p> <p>Your abstract and also the methodology section and conclusion frequently uses the pronoun 'we' or 'our'. From an academic writing perspective it is better not to write a first or third person account of what you have done or are intending to do. Instead state use more alternatives such as 'this article' or 'this scoping review'.</p> <p>You refer to 6) conducting consultations and in the dissemination section use the term 'knowledge users'. You need to be more explicit about what you mean here and the role of these people in the scoping review.</p> <p><b>Dissemination:</b> I don't think it is necessary to state you are going to attend conferences and write an article as that goes without saying. The more interesting points to highlight are your repository and policy briefs which are specific outputs of this project and which link directly to the listed strengths of your project. This issue relates to both your abstract and page 14 line 10 where you also discuss this.</p>
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	<p>Limitations: you state 'by limiting our search to English language documents we may miss some potentially important results'. Are all policy documents in Canada printed in English and French? Or if some are only published in French I think you need to be more explicit that your scoping review will 'exclude French language policy documents and literature which could have implications for your findings and aims' in relation to both your repository and policy briefs. You cannot for example state the repository 'will catalogue the full range of Canada's informal care support policies' because presumably some of the policies from Quebec would not be included.</p> <p>Introduction Page 3 Line 22: Use of the term 'senior' – this terminology to describe 'old people' is generally only used in North America. Consider using 'old age cohort' or specify the age range you are referring to 'cohort aged 65 or over' or similar when writing for an international audience.</p> <p>You need one sentence in the first paragraph of the introduction to set out what you mean by informal care-givers. Be explicit as to whether you include friends, family, neighbours, volunteers from community groups, anyone providing unpaid care? in your definition. You do not clarify this until page 4 line 31. So this needs to be brought forward into this first paragraph because otherwise it raises questions throughout the first few pages about who exactly your policy review is targeting.</p> <p>Page 3 Line 26: spelling error: 'In Canada, for instance, only 2% of elders, age 65 and older receiving publicly funded home care services are otherwise independent.' Change to 'aged 65 and over'. Moreover the whole of that sentence does not make total sense. Are you trying to say that only 2% of those receiving publicly funded home care services do not require any additional support from informal carers?. This needs to be clarified.</p> <p>Page 3 Line 33: I would add 'but ALSO in other contexts (e.g. developmental disability, chronic disease, childcare, drug abuse/addiction, teenage pregnancy, violence, and homelessness). You also need to be more specific: in the UK the term substance abuse is used to cover drugs and alcohol misuse. Also do you mean domestic violence? Also only include all these groups if your scoping review covers them all.</p> <p>Page 4 The following terminology is problematic, it would be deemed derogatory/dehumanising in a UK context to describe people as 'physically or mentally disabled, or addicted', they are people first and foremost and should not just be referred to by their 'issues'. If you are going to retain the term developmental disabilities (having described what you mean by this earlier) please replace the current wording with 'people with physical or developmental disabilities or substance misuse issues'.</p> <p>The first paragraph on page 4 also needs a sentence to recognise that a key reason for people becoming aware of 'informal care' is due to feminist academics and activists bringing the unpaid labour of women in the household to the attention of government and society in general.</p>
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	<p>Where you discuss the Carers (Recognition and Services Act) 1995 because of the lack of a clear definition of informal care earlier on, it is not clear if you realise that this Act provided carers (caring for family, friends, neighbours) with a right to an assessment of their needs if they requested one, this right did not apply to volunteers (paid or unpaid) from organisations providing care. Moreover the wording of the Act is 'provide a substantial amount of care on a regular basis'. There was no legal duty on the local government to provide such carers with any services and support to meet their assessed needs so it did not guarantee that they would be provided with 'social assistance' as you name it. I would also be careful with using 'social assistance' as a term. Generally this indicates state support in the form of cash benefits. In connection with that the Invalid Carers Allowance was first implemented in 1976 in the UK which was a cash benefit for single female carers and male carers, this was the first official recognition of informal carers in UK law.</p> <p>Page 5 line 8: you state: 'Indeed, many caregivers drop, or are forced, out of the labour force as they attempt to balance their responsibilities'. Replace with "dropout, or are forced, out of the labour force".</p> <p>Page 5 line 46: Can you state 'These territorial variations have led to the design and implementation of diverse policies in support of informal caregivers'</p> <p>Page 6 line 50: here you use the term 'neurodevelopmental disability'. You need to decide on a single term to describe these types of disability, which previously you have described as 'developmental disabilities' and stick to it throughout the article.</p> <p>P6-7: This sentence is too long please edit: "Given the vast and multidisciplinary nature of the literature on informal care (ranging from childcare, to drug abuse/addiction, to homelessness, to chronic disease, to neurodevelopmental disability, etc.), and thus far limited efforts to synthesize existing knowledge, a scoping review will allow us to: map existing knowledge and the main sources and types of evidence about different informal care policies in Canada, to develop a conceptual framework that classifies those policy instruments, to explore different policy objectives behind adopting/developing those policies, to investigate potential barriers and facilitators to implementation of diverse policy instruments, to explore the degree of success for those policies, to identify additional gaps in the literature, 54, and also draw out policy opportunities and lessons learned with our knowledge user partners."</p> <p>P7 line 13-17: I don't think you need to describe the 6 stages of your method in your text and have a Figure which basically repeats the same information. Remove the repeat wording from the text and just have Figure 1.</p> <p>P8 line 48: Your research question is stated as: "how do Pan-Canadian policies account informal care?" I find the phrasing of this question incomplete and lacking clarity for describing your project's overarching intention.</p> <p>P8 line 52/53: Given what you state here: "The knowledge users including content experts, policy makers, practitioners, and informal caregivers were then consulted to refine and finalize the research</p>
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	<p>questions”, you need to refer to my points relating to the ethical considerations of your study in relation to pages 13/14, particularly if informal carers are going to be included as knowledge users.</p> <p>Page 9 line 8 spelling error: What are the policies in support of informal caregivers across Canadian provinces and territories?</p> <p>Page 9 lines 13-17: You state “What policy issues have been targeted by the informal care support policies? (e.g. childcare, labour force participation, exotic diseases, elder care, drug abuse/addiction, teenage pregnancy, violence, developmental disability, homelessness, chronic disease)” You need to be more consistent throughout your article about describing the areas of informal care that you are going to be incorporating into your scoping review. I see here that you have added another category ‘exotic diseases’ what does this even mean? I think some further discussion is needed to justify some of these inclusion choices as some seem fairly limited in their connection to informal care (e.g. domestic violence, homelessness, exotic diseases) unless you are already aware of policies which support the informal carers of these groups already?. If you feel they are relevant then you need to explain why more explicitly (not necessarily in the methodology section but it could be incorporated in your introduction). Also use the same terms consistently throughout the article and please see my previous comments about some of these (violence, drugs).</p> <p>Page 9 line 19-25: You state “Who are the target populations of the informal care support policies? Children (e.g. exotic diseases, childcare) Adults (e.g. violence, drugs, chronic diseases) Seniors (e.g. aging population) If you are going to categorise various age groups you need to define the age ranges of each group here as well so there is consistency of approach when analysing across territorial areas.</p> <p>P9 line 39-40: you state “Is there any evidence of policy success for implementation of those informal care support policies as given by the authors?” It is unclear whether the ‘authors’ refer to the knowledge users too? If not you need to add mention of them separately here as my understanding was they would assist you with interpreting the success of the policies. However if they are considered to be authors alongside you, you need to make this role far more explicit in the article otherwise it gives rise to confusion (see my comments relating to ethics (p13-14)).</p> <p>P13 Ethics and Dissemination section: spelling error: “This scoping review aims to synthesize the existing Canadian evidence from a wide range of disciplines about informal care network policies”</p> <p>P13-14 You need to state in the ethics section whether or not you will be seeking ethical approval for your scoping study from your given institution. Clearly if you were only analysing documents this would not be necessary but your project refers to ‘knowledge users’ who will be communicating with you via email, workshops and teleconference as part of the process of interpreting the review documents and your analysis and potentially engaging in dissemination via YouTube and webinars. Elsewhere you also state; “The knowledge users including content experts, policy makers, practitioners, and informal caregivers were</p>
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	<p>then consulted to refine and finalize the research questions” If you are not intending on seeking ethical approval you need to state this explicitly and justify this decision as this seems like a blurred area to me as to whether these people constitute research participants or should be treated as such (particularly the informal carers who could potentially be considered vulnerable) or whether you consider, and they are aware, that they are authors alongside you in which case are they being named in the study?. You need to make their role clearer and more explicit. It is not clear if you are seeking quotes from them as part of their role which you would include in your review and dissemination outputs. If so issues such as anonymity, informed consent, data protection etc would also need to be considered if they are participants (rather than authors) and you would need to demonstrate an aware of these potential ethical issues in this section, particularly in relation to the involvement of the informal carers.</p> <p>Page 14 line 14: the phrasing of the end of this sentence needs to be amended: “We will further publish a series of policy briefs to be developed collaboratively with knowledge users about how to promote and better implement informal care policies through use of findings of this review”.</p> <p>Page 14 line 39: the wording of this sentence needs the highlighted addition: “One of the key findings of our review will be identification of successful informal care policies and potential barriers and facilitators to implementation of these policies which will provide a guide to policy makers and practitioners in shaping future evidence-based policies in eldercare in Canada and ultimately enhancing wellbeing of both the elder population and their informal care givers.”</p> <p>Appendix 4 – it does not seem necessary to include the project timeline as part of the article.</p> <p>Formatting the citations: There appear to be formatting issues in relation to how you have presented the numbered citations. According to the BMJ guidelines these should be contained in brackets and also there should be no space between the number and the preceding punctuation or word. Please double check this.</p>
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<b>REVIEWER</b>	MARY LARKIN The Open University, UK
<b>REVIEW RETURNED</b>	08-Feb-2018

<b>GENERAL COMMENTS</b>	<p>This is an interesting study. However, several aspects need revising in order to avoid the confusion that currently exists in this protocol. Where is the funding for this potentially big study coming from? This is an important practical consideration! My specific comments are:</p> <p>‘Grey’ Literature – need to say what this is</p> <p>The title does not reflect that they are going to draw out specific challenges for informal caregivers delivering elder care</p>
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	<p>There is too much to achieve in one study. It states that the the study looks at support for informal care in general and the implications of this for caregivers of older people. Working between these 2 aims often lead to confusion eg p11 (highlighted)</p> <ul style="list-style-type: none"> <li>• P6 - 2 sentences beginning with 'Given' - highlighted</li> <li>• P7 'As a scoping review builds on systematic review methods 57, it can also assist in determining the value of undertaking a full systematic review on this topic.</li> <li>• This sentence does not make sense? How does a scoping review build on systematic review methods? Is the intention to also conduct a systematic review?</li> <li>• The use of a scoping review needs much more justification as to why is it the best methodology</li> <li>• The research question - how do Pan-Canadian policies account informal care?" - does not reflect what they are trying to do in terms of searching for Canadian literature from across disciplines to identify the broad range of policy instruments different provinces and territories have adopted in relation to informal caregivers.</li> <li>• P8-9 – not clear how the more specific questions were developed. Have the consultation with the knowledge users taken place already?</li> <li>• The way the knowledge users are consulted needs to be clear eg individual, in a group?</li> <li>• The authors keep changing tenses eg p10 The MEDLINE search strategy produced 1508 records (12 August 2017) while the Web of Science search produced 4083 results (12 August 2017). Just before this they were saying what they will do. The change in tense the study has taken place already.</li> <li>• P10 how have they decided which databases to search for unpublished and grey literature?</li> <li>• We don't know that they have a research team until p11 ! This needs to be explained right at the beginning</li> <li>• P11 Why don't they look at existing scoping reviews of policies to support carers in other countries eg UK?</li> <li>• P12 and 13 'The data extracted will include ..' and 'conceptual framework with the following key elements'. How do they know this if the study has not been carried out</li> </ul>
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	<p>yet?</p> <ul style="list-style-type: none"> <li>• P12 – ‘establish a working group’. Who will be in this?</li> <li>• P13 – consultation workshop. Will this comprise different knowledge users to those consulted during the study?</li> <li>• P13 The main outputs of this knowledge synthesis are not consistent with what they say they aim to do</li> </ul>
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## VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Overall this is an interesting article which sets out your intention to undertake a scoping review of the policy field of informal care in Canada. The objectives and scope of the intended study are very extensive but you comprehensively map out how you will fulfil them. My recommendation is for minor revisions to be made to your article which address all of the following points.

Thanks for your positive feedback and your instructive comments throughout the text, which have been very helpful in making our revisions.

### Abstract

In the abstract it states: ‘but to fellow citizens with developmental disabilities or chronic diseases’. The wording used to describe disabilities varies cross nationally so some of the terms you use need to be clarified within the text. I assume your use of the term developmental disabilities is equivalent to the term used in the UK ‘learning disabilities’. So the clarification that your term specifically relates to conditions which can cause cognitive impairments such as Downs Syndrome needs to be added.

Thanks for this interesting comment. We removed the term ‘developmental’ from the abstract and throughout the text and decided to use the more general term ‘disability’ that includes both physical and cognitive (also called developmental, neurodevelopmental, intellectual, learning, mental or psychiatric) disabilities.

Your abstract and also the methodology section and conclusion frequently uses the pronoun ‘we’ or ‘our’. From an academic writing perspective it is better not to write a first or third person account of what you have done or are intending to do. Instead state use more alternatives such as ‘this article’ or ‘this scoping review’.

While we understand and appreciate the suggested rhetorical move to project greater neutrality and academic rigor, the disciplinary norms of the co-authors’ specific fields have shifted towards not just accepting first person formulations, but actively encouraging them as being more transparent and so allowing readers to ‘see’ the role that researchers play in the production of knowledge. As such we have, with respect, maintained the style as originally submitted.

You refer to 6) conducting consultations and in the dissemination section use the term ‘knowledge users’. You need to be more explicit about what you mean here and the role of these people in the scoping review.

The scoping review, with its synthetic approach, is the cornerstone of robust knowledge translation efforts as it transforms a great deal of scientific literature into a reliable form that is readable and relevant to knowledge users.<sup>1,2</sup> The Canadian Institutes of Health Research (CIHR), a federal/national agency that funds health research across Canada, defines a knowledge user as “an individual who is likely to be able to use the knowledge generated through research to make informed decisions about health policies, programs and/or practices”.<sup>3</sup> To increase the uptake of our review findings, we will engage diverse knowledge users including content experts, policy and decision makers, practitioners, and informal caregivers in the design, analysis, and dissemination of the review. By engaging a wide range of knowledge users in all stages of our review, we hope to co-produce knowledge and evidence that is useful and relevant to those who make real-world decisions and helping them make informed decisions. By adopting this knowledge co-production approach (also known as iKT or participatory research), our knowledge users function as active research partners in generating research from conceptualisation to implementation rather than passive recipients of research or research products. This, we believe, will enhance our understanding of the knowledge users context and needs, thereby increasing the policy-relevance of our research and enhancing integration of our review findings into policy and practice. It also increases knowledge users’ understanding of the research process.<sup>4,5</sup> We have tried to be more explicit about what we mean by ‘knowledge user’ and the role of these people in our scoping review. We have clearly outlined, throughout the method section, how we will be engaging our knowledge users in different stages of our review.

Dissemination: I don't think it is necessary to state you are going to attend conferences and write an article as that goes without saying. The more interesting points to highlight are your repository and policy briefs which are specific outputs of this project and which link directly to the listed strengths of your project. This issue relates to both your abstract and page 14 line 10 where you also discuss this.

Thank you for the advice: we have reduced our coverage of the usual channels of dissemination, and further highlighted our non-standard avenues.

Limitations: you state ‘by limiting our search to English language documents we may miss some potentially important results’. Are all policy documents in Canada printed in English and French? Or if some are only published in French I think you need to be more explicit that your scoping review will ‘exclude French language policy documents and literature which could have implications for your findings and aims’ in relation to both your repository and policy briefs. You cannot for example state the repository ‘will catalogue the full range of Canada’s informal care support policies’ because presumably some of the policies from Quebec would not be included.

We have adjusted the limitations section to reflect these observations, using ‘exclude’ rather than ‘may miss’ and clarifying that the review will reflect a search of ‘Canadian English language’ policy and commentary.

## Introduction

Page 3 Line 22: Use of the term ‘senior’ – this terminology to describe ‘old people’ is generally only used in North America. Consider using ‘old age cohort’ or specify the age range you are referring to ‘cohort aged 65 or over’ or similar when writing for an international audience.

Thanks for this interesting observation. We replaced the term ‘senior’ with ‘cohort aged 65 or over’ throughout the text.

You need one sentence in the first paragraph of the introduction to set out what you mean by informal care-givers. Be explicit as to whether you include friends, family, neighbours, volunteers from community groups, anyone providing unpaid care? in your definition. You do not clarify this until page



4 line 31. So this needs to be bought forward into this first paragraph because otherwise it raises questions throughout the first few pages about who exactly your policy review is targeting.

Thanks for raising this valid point. We added a sentence to the first paragraph of introduction to define informal care.

Page 3 Line 26: spelling error: 'In Canada, for instance, only 2% of elders, age 65 and older receiving publicly funded home care services are otherwise independent.' Change to 'aged 65 and over'. Moreover the whole of that sentence does not make total sense. Are you trying to say that only 2% of those receiving publicly funded home care services do not require any additional support from informal carers?. This needs to be clarified.

We re-wrote the sentence for better clarity.

Page 3 Line 33: I would add 'but ALSO in other contexts (e.g. developmental disability, chronic disease, childcare, drug abuse/addiction, teenage pregnancy, violence, and homelessness). You also need to be more specific: in the UK the term substance abuse is used to cover drugs and alcohol misuse. Also do you mean domestic violence? Also only include all these groups if your scoping review covers them all.

As per your other comment (below) and that of another referee we decided to avoid including many fields/areas of informal care and narrow down our search to two key areas of informal care including disability and elder care.

Page 4

The following terminology is problematic, it would be deemed derogatory/dehumanising in a UK context to describe people as 'physically or mentally disabled, or addicted', they are people first and foremost and should not just be referred to by their 'issues'. If you are going to retain the term developmental disabilities (having described what you mean by this earlier) please replace the current wording with 'people with physical or developmental disabilities or substance misuse issues'.

Thanks for this helpful comment. We made changes as per your suggestion.

The first paragraph on page 4 also needs a sentence to recognise that a key reason for people becoming aware of 'informal care' is due to feminist academics and activists bringing the unpaid labour of women in the household to the attention of government and society in general.

We added a sentence to the first paragraph to recognize of the paramount role of feminist activists and academics in increasing awareness of informal care.

Where you discuss the Carers (Recognition and Services Act) 1995 because of the lack of a clear definition of informal care earlier on, it is not clear if you realise that this Act provided carers (caring for family, friends, neighbours) with a right to an assessment of their needs if they requested one, this right did not apply to volunteers (paid or unpaid) from organisations providing care. Moreover the wording of the Act is 'provide a substantial amount of care on a regular basis'. There was no legal duty on the local government to provide such carers with any services and support to meet their assessed needs so it did not guarantee that they would be provided with 'social assistance' as you name it. I would also be careful with using 'social assistance' as a term. Generally this indicates state support in the form of cash benefits. In connection with that the Invalid Carers Allowance was first implemented in 1976 in the UK which was a cash benefit for single female carers and male carers, this was the first official recognition of informal carers in UK law.

Thanks for these helpful insights. We re-wrote the first part of paragraph and added Invalid Carers Allowance Act.

Page 5 line 8: you state: 'Indeed, many caregivers drop, or are forced, out of the labour force as they attempt to balance their responsibilities'. Replace with "dropout, or are forced, out of the labour force".

The change was made.

Page 5 line 46: Can you state 'These territorial variations have led to the design and implementation of diverse policies in support of informal caregivers'

The change was made.

Page 6 line 50: here you use the term 'neurodevelopmental disability'. You need to decide on a single term to describe these types of disability, which previously you have described as 'developmental disabilities' and stick to it throughout the article.

As mentioned above, we removed the terms 'developmental' and 'neurodevelopmental' throughout the text and decided to use the more general term 'disability' that includes both physical and cognitive (also called developmental, neurodevelopmental, intellectual, learning, mental or psychiatric) disabilities.

P6-7: This sentence is too long please edit: "Given the vast and multidisciplinary nature of the literature on informal care (ranging from childcare, to drug abuse/addiction, to homelessness, to chronic disease, to neurodevelopmental disability, etc.), and thus far limited efforts to synthesize existing knowledge, a scoping review will allow us to: map existing knowledge and the main sources and types of evidence about different informal care policies in Canada, to develop a conceptual framework that classifies those policy instruments, to explore different policy objectives behind adopting/developing those policies, to investigate potential barriers and facilitators to implementation of diverse policy instruments, to explore the degree of success for those policies, to identify additional gaps in the literature, 54, and also draw out policy opportunities and lessons learned with our knowledge user partners."

We broke the sentence into two sentences.

P7 line 13-17: I don't think you need to describe the 6 stages of your method in your text and have a Figure which basically repeats the same information. Remove the repeat wording from the text and just have Figure 1.

We removed the repetitive text as per your suggestion.

P8 line 48: Your research question is stated as: "how do Pan-Canadian policies account informal care?" I find the phrasing of this question incomplete and lacking clarity for describing your project's overarching intention.

We made some adjustment to the question for better clarity. It now reads: "how is informal care being addressed in provincial, territorial, and federal Canadian policies?" As it is our overarching question we are trying to keep it broad and not very specific as expected from a scoping review.<sup>6</sup> We have four specific research questions outlined in the stage one of our review process.

P8 line 52/53: Given what you state here: "The knowledge users including content experts, policy makers, practitioners, and informal caregivers were then consulted to refine and finalize the research

questions”, you need to refer to my points relating to the ethical considerations of your study in relation to pages 13/14, particularly if informal carers are going to be included as knowledge users.

Thanks for raising this important issue. This review is part of a larger research project entitled: “Developing User-Centred Digital Supports for Informal Networks that Provide Care for Elders” for which we have received funding (AGE-WELL National Centre of Excellence) and an ethic approval from the University of Calgary Ethic Board (Ethic ID: REB17-0977\_MOD1). As part of this project, we are holding focus group discussions with the informal caregivers of the elderly (65 years old and over) and have clearly addressed ethical concerns such as issues of anonymity, informed consent, risk/benefit analysis, and data protection (data confidentiality, data privacy, data storage, retention and disposal). Our research participants sign the consent form prior to attending our focus groups. However, as this scoping review is broad, we are applying for a different source of funding. If we secure a new source of funding (which we feel is likely), we will seek new ethics approval, specific to this scoping review, from the relevant authority.

Page 9 line 8 spelling error: What are the policies in support of informal caregivers across Canadian provinces and territories?

Thanks, corrected.

Page 9 lines 13-17: You state “What policy issues have been targeted by the informal care support policies? (e.g. childcare, labour force participation, exotic diseases, elder care, drug abuse/addiction, teenage pregnancy, violence, developmental disability, homelessness, chronic disease)”. You need to be more consistent throughout your article about describing the areas of informal care that you are going to be incorporating into your scoping review. I see here that you have added another category ‘exotic diseases’ what does this even mean? I think some further discussion is needed to justify some of these inclusion choices as some seem fairly limited in their connection to informal care (e.g. domestic violence, homelessness, exotic diseases) unless you are already aware of policies which support the informal carers of these groups already?. If you feel they are relevant then you need to explain why more explicitly (not necessarily in the methodology section but it could be incorporated in your introduction). Also use the same terms consistently throughout the article and please see my previous comments about some of these (violence, drugs).

Thanks for this helpful comment. We decided to limit the areas of informal care to two key areas of elder care and disability to make the review more manageable.

Page 9 line 19-25: You state “Who are the target populations of the informal care support policies? Children (e.g. exotic diseases, childcare), Adults (e.g. violence, drugs, chronic diseases), Seniors (e.g. aging population). If you are going to categorise various age groups you need to define the age ranges of each group here as well so there is consistency of approach when analysing across territorial areas.

We re-wrote our review questions to align them with our review objectives. In the new set of questions, we did not include target population.

P9 line 39-40: you state “Is there any evidence of policy success for implementation of those informal care support policies as given by the authors?” It is unclear whether the ‘authors’ refer to the knowledge users too? If not you need to add mention of them separately here as my understanding was they would assist you with interpreting the success of the policies. However if they are considered to be authors alongside you, you need to make this role far more explicit in the article otherwise it gives rise to confusion (see my comments relating to ethics (p13-14)).

As mentioned above, we re-wrote our review questions to align them with our review objectives. In the new set of questions, we removed the question related to the evidence of success.

P13 Ethics and Dissemination section: spelling error: "This scoping review aims to synthesize the existing Canadian evidence from a wide range of disciplines about informal care network policies"

Thanks, corrected.

P13-14 You need to state in the ethics section whether or not you will be seeking ethical approval for your scoping study from your given institution. Clearly if you were only analysing documents this would not be necessary but your project refers to 'knowledge users' who will be communicating with you via email, workshops and teleconference as part of the process of interpreting the review documents and your analysis and potentially engaging in dissemination via You Tube and webinars. Elsewhere you also state; "The knowledge users including content experts, policy makers, practitioners, and informal caregivers were then consulted to refine and finalize the research questions". If you are not intending on seeking ethical approval you need to state this explicitly and justify this decision as this seems like a blurred area to me as to whether these people constitute research participants or should be treated as such (particularly the informal carers who could potentially be considered vulnerable) or whether you consider, and they are aware, that they are authors alongside you in which case are they being named in the study?. You need to make their role clearer and more explicit. It is not clear if you are seeking quotes from them as part of their role which you would include in your review and dissemination outputs. If so issues such as anonymity, informed consent, data protection etc would also need to be considered if they are participants (rather than authors) and you would need to demonstrate an aware of these potential ethical issues in this section, particularly in relation to the involvement of the informal carers.

As described above, this review is part of a larger research project entitled: "Developing User-Centred Digital Supports for Informal Networks that Provide Care for Elders" for which we have received funding (AGE-WELL National Centre of Excellence) and an ethic approval from the University of Calgary Ethic Board (Ethic ID: REB17-0977\_MOD1). As part of this project, we are holding focus group discussions with the informal caregivers of the elderly (65 years old and over) and have clearly addressed ethical concerns such as issues of anonymity, informed consent, risk/benefit analysis, and data protection (data confidentiality, data privacy, data storage, retention and disposal). Our research participants sign the consent form prior to attending our focus groups. However, as this scoping review is broad, we are applying for a different source of funding. If we secure a new source of funding (which we feel is likely), we will seek new ethics approval, specific to this scoping review, from the relevant authority.

Page 14 line 14: the phrasing of the end of this sentence needs to be amended: "We will further publish a series of policy briefs to be developed collaboratively with knowledge users about how to promote and better implement informal care policies through use of findings of this review".

We removed the last part of sentence for better clarity.

Page 14 line 39: the wording of this sentence needs the highlighted addition:  
"One of the key findings of our review will be identification of successful informal care policies and potential barriers and facilitators to implementation of these policies which will provide a guide to policy makers and practitioners in shaping future evidence-based policies in eldercare in Canada and ultimately enhancing wellbeing of both the elder population and their informal care givers."

Thanks, amended.

Appendix 4 – it does not seem necessary to include the project timeline as part of the article.

We removed the timeline for the Appendix as per your valid suggestion.

Formatting the citations: There appear to be formatting issues in relation to how you have presented the numbered citations. According to the BMJ guidelines these should be contained in brackets and also there should be no space between the number and the preceding punctuation or word. Please double check this.

We amended citations to comply with the BMJ Open referencing style.

Reviewer: 2

This is an interesting study. However, several aspects need revising in order to avoid the confusion that currently exists in this protocol. Where is the funding for this potentially big study coming from? This is an important practical consideration!

This review is part of a larger research project entitled: “Developing User-Centred Digital Supports for Informal Networks that Provide Care for Elders” funded by AGE-WELL National Centre of Excellence in Canada.

My specific comments are: ‘Grey’ Literature – need to say what this is

Grey literature refers to both published and unpublished materials that are generally not peer-reviewed or indexed in bibliographic databases<sup>7</sup>. These include government reports, newsletters and bulletins, technical papers, working papers, theses, datasets, and proceedings of the seminars and conferences. Due to the paucity of peer-reviewed academic research in the area of policies in support of informal caregivers, the inclusion of grey literature or non-academic is especially important and valuable. These will also increase the breath, relevance and value of our review findings. For the grey literature, we will search the following websites: Dissertations & Theses A&I via ProQuest; OpenGrey; ISI Proceedings; Conference Proceedings Citation Index–Social Science and Humanities; Joanna Briggs and ProQuest Dissertations and Theses; PAIS Index - Public Affairs Information Service; Google Scholar; and Google. For specific Canadian grey literature we will search the following databases: Canadian Research Index; Canadian Electronic Library; Canadian Public Policy Index; and LabourSource (formerly Labour Spectrum). Other websites will be identified by the research team and knowledge users.

The title does not reflect that they are going to draw out specific challenges for informal caregivers delivering elder care

In this review, we do not aim to draw out challenges faced by informal caregivers delivering elder care. But, we aim to identify and synthesize Pan-Canadian policies in support of informal care. We have clearly outlined our aim in several instances throughout the text.

There is too much to achieve in one study. It states that the study looks at support for informal care in general and the implications of this for caregivers of older people. Working between these 2 aims often lead to confusion eg p11 (highlighted).

Thanks for this helpful comment. As per your suggestion and that of another referee, we decided to narrow down our review scope by limiting the areas of informal care to elder care and disability only. This will make our review more manageable.



- P6 - 2 sentences beginning with 'Given' – highlighted

We merged the two sentences.

- P7 "As a scoping review builds on systematic review methods, it can also assist in determining the value of undertaking a full systematic review on this topic". This sentence does not make sense? How does a scoping review build on systematic review methods? Is the intention to also conduct a systematic review? The use of a scoping review needs much more justification as to why is it the best methodology.

A scoping review can inform a systematic review<sup>8,9</sup>. The two key differences between scoping review and systematic reviews include: 1) a systematic review typically focuses on a well-defined question and includes specific study designs identified apriori while a scoping review addresses a broader topic and includes many different study designs. 2) A systematic review tends to answer a very specific and narrow research question and assesses the quality of studies for inclusion while a scoping review tends to answer to a broader research question and does not assess the quality of studies for inclusion<sup>6</sup>. We amended the sentence for better clarity.

- The research question - how do Pan-Canadian policies account informal care?" - does not reflect what they are trying to do in terms of searching for Canadian literature from across disciplines to identify the broad range of policy instruments different provinces and territories have adopted in relation to informal caregivers.

We made some adjustment to our overarching question for better clarity. It now reads: "How is informal care being addressed in provincial, territorial, and federal Canadian policies?" As it is our overarching question we are trying to keep it broad and not very specific as expected from a scoping review.<sup>6</sup> We have four specific research questions outlined in the stage one of our review process.

- P8-9 – not clear how the more specific questions were developed. Have the consultation with the knowledge users taken place already? The way the knowledge users are consulted needs to be clear eg individual, in a group?

We have revised our specific review questions (there are now 4 key questions) and have aligned them with our review objectives set out in the last paragraph of our introduction section. In the first paragraph of stage one: identifying the research questions we have clarified that we have sought views of knowledge users on our review questions via email at this stage.

- The authors keep changing tenses eg p10 The MEDLINE search strategy produced 1508 records (12 August 2017) while the Web of Science search produced 4083 results (12 August 2017). Just before this they were saying what they will do. The change in tense the study has taken place already.

The searches performed in MEDLINE and Web of Science in August 2017 were both sample/test searches to test our search strategy. We added 'sample search' to the text for better clarity. For the actual review, we will be searching a wide range of electronic databases, including MEDLINE and Web of Science, outlined in Appendix Table 2.

- P10 how have they decided which databases to search for unpublished and grey literature?

We have an information scientist (with a medical librarian background) in our team who has helped us in determining unpublished and grey literature. We have also sought views of an experienced librarian



who is in charge of the following sections at University of Calgary Library: Canadian Federal Government Information, Canadian Parliamentary (Legislative) Publications, Political Science, Public Policy, and Urban Policy documents and publications. He has been of tremendous help to us in identifying grey literature especially with our review focus being on Pan-Canadian public policies in support of informal care.

- We don't know that they have a research team until p11 ! This needs to be explained right at the beginning

In stage one of our review process (i.e. identifying research questions), we had referred to our research team: "Our research team has initially generated a list of potential research questions based on..."

- P11 Why don't they look at existing scoping reviews of policies to support carers in other countries eg UK?

To the best of our knowledge, there is no scoping review of policies in support of caregivers in any context/country, let alone in Canada which is the focus of our review.

- P12 and 13 'The data extracted will include ...' and 'conceptual framework with the following key elements'. How do they know this if the study has not been carried out yet?

These elements were developed upon our review objectives and questions. We anticipate to capture these elements in selected included studies. We added 'potential' before 'data extracted' and elements of conceptual framework in order to alleviate the degree of certainty in our statement. We have clearly outlined that "...list of extracted data will be modified as the research team becomes more familiar with the literature". We have also removed some elements to make the list more general, manageable, and aligned with our review objectives.

- P12 – 'establish a working group'. Who will be in this?

At this stage of the review and for the specific purpose of collating and summarizing the data, the working group will be composed of the research team including the lead researcher, a postdoctoral scholar, a research associate, and two graduate students. We will also seek the views of our knowledge users at this stage via email, teleconference, or web-conference to allow their inputs in reviewing the findings, before providing policy recommendations.

- P13 – consultation workshop. Will this comprise different knowledge users to those consulted during the study?

In line with our iKT (co-production) approach our main target audience for the workshop or policy roundtable is the knowledge users who have been engaged through various stages of our review process. These knowledge users have been involved in various stages of the review via non-personal interactions/communications (e.g. email, teleconference, web-conference) and had no chance to sit together in a face-to-face personal meeting. This way, these knowledge users feel they are active research partners in generating research from conceptualisation to implementation rather than passive recipients of research or research products. We may decide to include few new knowledge users and stakeholders in our consultation workshop/policy roundtable if those engaged during our review process do not sufficiently represent all various stakeholder categories we aim to reach out. For instance, if we secure only 2 policy/decision makers during our review process, we may decide to invite more policy/decision makers to our workshop.

- P13 The main outputs of this knowledge synthesis are not consistent with what they say they aim to do.

The two key outputs of our review are closely aligned with our review objectives as outlined below:

“The main outputs of this knowledge synthesis will be 1) a conceptual framework that classifies policy instruments that support informal care or integrate them into formal systems of care, 2) potential barriers and facilitators for implementing those policies”.

“In this review, we are going to address the following five objectives: 1) to analyze and synthesize existing Canadian evidence through a comprehensive review of grey and academic literature on policy instruments to support and integrate informal caregivers across Canada, 2) to develop a conceptual framework that classifies diverse informal care policies, 3) to explore different policy objectives behind adopting/developing those policy instruments (e.g. wellbeing, satisfaction, efficiency, effectiveness), 4) to explore potential barriers and facilitators to implementation of diverse policy instruments, and 5) to identify, in conjunction with our knowledge user partners, the approaches, methods, and lessons learned in the broader literature that are applicable to the specific challenges of informal caregivers delivering elder care”.

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## VERSION 2 – REVIEW

<b>REVIEWER</b>	Dr Fiona Morgan Senior Lecturer in Social Work, Institute of Community and Society, University of Wolverhampton, UK
<b>REVIEW RETURNED</b>	29-Mar-2018
<b>GENERAL COMMENTS</b>	Thank you for your very thorough response to my initial comments to your article and for addressing the vast majority of these satisfactorily.

	<p>There are only 3 remaining issues in your revised script that I consider to need a further revision which is the only reason I have not yet accepted the article. I would welcome the editor's view on the comment relating to the ethics issue and their view can take precedence if they feel that the article does not require this addition. The other two points are very minor, Point 2 is optional but the errors relating to Point 3 do need to be addressed.</p> <p>1. While you have satisfied me in your comments that you have received ethical approval for your study as part of the wider project and will undertake a separate ethics application if you do receive further funding for your specific project, this has still not been explicitly stated in either your main article or abstract even though you have amended the subheadings to state Ethics and Dissemination. To my mind this requires a sentence in the main article at least to confirm that this action was taken so readers can be reassured about the involvement of the participants in the project. This could be added to your Patient and Public Involvement section due to its relevance to this discussion and then you can remove the 'Ethics' wording from the Ethics and Dissemination section. As I said above I am happy for the editor to decide on the necessity of this point.</p> <p>2. I think it would be helpful in the abstract to mention the use of your integrated knowledge translation approach in relation to your knowledge users as this forms part of your methodology.</p> <p>3. There are some errors when discussing the UK system. If you wish to name the legislation which brought in Invalid Carers Allowance (now just known as Carer's Allowance) it is the Social Security (Invalid Care Allowance) Regulations 1976. This brought in an income tested as opposed to means tested benefit as savings are not taken into account. The initial benefit was for single female carers (not married) and male carers (marital status not specified for them) only. It is up to you how much detail you provide as long as it is accurate.</p>
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## VERSION 2 – AUTHOR RESPONSE

### Response to Comments of Reviewer 1:

1. While you have satisfied me in your comments that you have received ethical approval for your study as part of the wider project and will undertake a separate ethics application if you do receive further funding for your specific project, this has still not been explicitly stated in either your main article or abstract even though you have amended the subheadings to state Ethics and Dissemination. To my mind this requires a sentence in the main article at least to confirm that this action was taken so readers can be reassured about the involvement of the participants in the project. This could be added to your Patient and Public Involvement section due to its relevance to this discussion and then you can remove the 'Ethics' wording from the Ethics and Dissemination section. As I said above I am happy for the editor to decide on the necessity of this point.

Thanks for this comment. We included a statement to the Ethics and Dissemination section of the manuscript, both in the abstract and the main text, to articulate that our study has received ethics approval from the University of Calgary Conjoint Ethics Board.

2. I think it would be helpful in the abstract to mention the use of your integrated knowledge translation approach in relation to your knowledge users as this forms part of your methodology.

Although we mentioned the use of an integrated knowledge translation approach in the Ethics and Dissemination section of our abstract, following your helpful comment, we transposed this sentence to the Method section.

3. There are some errors when discussing the UK system. If you wish to name the legislation which brought in Invalid Carers Allowance (now just known as Carer's Allowance) it is the Social Security (Invalid Care Allowance) Regulations 1976. This brought in an income tested as opposed to means tested benefit as savings are not taken into account. The initial benefit was for single female carers (not married) and male carers (marital status not specified for them) only. It is up to you how much detail you provide as long as it is accurate.

Many thanks for this instructive comment. We have revised the text as follows:

In the UK, the implementation of the Social Security (Invalid Carers Allowance) Regulations of 1976, and the Carers Recognition and Services Act (also known as Carers) of 1995 saw informal caregivers become the specific object of formal policy efforts. The Invalid Carers Allowance, now known as Carer's Allowance, was an income-tested support delivered as a cash benefit to single female carers (not married) and male carers (marital status not specified for them), and represented the first official recognition of informal caregivers in UK law.