

## PEER REVIEW HISTORY

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## ARTICLE DETAILS

<b>TITLE (PROVISIONAL)</b>	Spatially Exploring the Intersection of Socio-Economic Status and Canadian Cancer-Related Medical Crowdfunding Campaigns
<b>AUTHORS</b>	van Duynhoven, Alysha; Lee, Anthony; Michel, Ross; Snyder, Jeremy; Crooks, Valorie; Chow-White, Peter; Schuurman, Nadine

## VERSION 1 - REVIEW

<b>REVIEWER</b>	Gabrielle Dressler Warren Alpert Medical School at Brown University, USA
<b>REVIEW RETURNED</b>	15-Oct-2018

<b>GENERAL COMMENTS</b>	<p>The authors address an important gap in the current literature pertaining to medical crowdfunding. While others have argued that medical crowdfunding may disproportionately benefit individuals and groups of relative socio-economic, educational, and social privilege—thereby potentially exacerbating pre-existing inequities in the affordability of healthcare—few quantitative studies exist to support that speculation. Given my understanding of the methods, this manuscript takes a meaningful step towards clarifying the demographics of a very particular group who utilize crowdfunding platforms (Canadian residents fundraising for cancer-related healthcare needs).</p> <p>My broad suggestions for this paper are as follows:</p> <ul style="list-style-type: none"> <li>• The manuscript clearly outlines the medical crowdfunding landscape and the particular dominance of GoFundMe. However, the authors only state that the web crawler used to generate the dataset “scraped a major crowdfunding platform” (p. 5) without naming the platform. It could be useful to more explicitly situate the dataset within this established context.</li> <li>• It is significant that crowdfunding platforms tend to be for-profit companies that can both positively and negatively influence the success of individual campaigns. For example, GoFundMe alone has refused to allow certain kinds of campaigns on their site (Berman J. “Crowdfunding site won’t let crowds fund abortions,” The Huffington Post. 2014.), waived platform fees in certain cases but not others (Ali F. “GoFundMe denies waivers for Somali drought,” The Huffington Post. 2017.), and made donations directly to particular campaigns (Charlie Gard’s campaign page, Update #4, GoFundMe.com/please-help-to-save-charlies-life). This power structure (summarized in Dressler, G. &amp; Kelly, S. A. (2018). Ethical implications of medical crowdfunding: the case of Charlie Gard.</li> </ul>
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	<p>BMJ.) seems important to mention in a paper that addresses the intersection of inequity and medical crowdfunding.</p> <ul style="list-style-type: none"> <li>• The manuscript does not address the amount of money raised by the crowdfunding campaigns included in the dataset—neither the amount actually raised, nor the amount that campaigns set as their goal. It might be helpful to quantify the advantage afforded to those who “successfully” engage in medical crowdfunding, or to explicitly mention that the data do not describe that information. While the limitations section does note how “the campaign duration captured in the current dataset may not be representative of the overall success of the campaign” (p. 11), it might still be informative to compare the outcomes or targets of these campaigns to the few calculated averages that can be found in the literature (Gonzales, A. L., Kwon, E. Y., Lynch, T., &amp; Fritz, N. (2016). “Better everyone should know our business than we lose our house”: Costs and benefits of medical crowdfunding for support, privacy, and identity. <i>new media &amp; society</i>.; Berliner, L. S. &amp; Kenworthy, N. J. (2017). <i>Producing a worthy illness: Personal crowdfunding amidst financial crisis</i>. <i>Social Science &amp; Medicine</i>.) This is important in order to understand whether people of socio-economic privilege disproportionately utilize medical crowdfunding, disproportionately benefit from their campaigns, or both.</li> <li>• Relatedly, the discussion section briefly mentions a positive correlation “between the amount raised in a campaign and number of times the campaign was shared” (p. 9). This is an important finding that seems buried and warrants further discussion. Which campaigns were shared more? Does the number of shares align with trends in other measured variables?</li> <li>• In the discussion section, it would be helpful to restate that this research was conducted in the context of a universal health system to inform how these conclusions might apply to different systems (given that medical crowdfunding is utilized internationally).</li> </ul> <p>My smaller suggestions and questions include:</p> <ul style="list-style-type: none"> <li>• P. 3: The introduction draws a distinction between crowdfunding and “charitable crowdfunding” that isn’t otherwise mentioned. I would suggest either clarifying or removing this wording.</li> <li>• P. 8: The authors mention in the results section that “Canadians’ cancer-related crowdfunding campaigns were also commonly located in close proximity to city centres.” It might be helpful to quantify this distribution or describe it in more detail to bolster the discussion beginning on the bottom of page 9.</li> <li>• P. 9: In their discussion, the authors write that “Individuals in the highest income FSAs were found to be the heaviest users of medical crowdfunding.” The data report that the greatest percentages of campaigns come from quintiles 2, 3, and 4 (Table 3). While the use of crowdfunding is high in FSAs with high incomes, it seems important to address the contributions of quintile 2 to this conclusion.</li> <li>• P. 11: In the sentence that begins with “Further to this, postal codes are self-reported,” “misstate” should read “mistakes.”</li> <li>• Table 4: In the second quintile, 13979 should read 1397.</li> <li>• Table 6: It’s difficult to decipher the organizing principle here. I would suggest either organizing this by number of campaigns, alphabetically by province, or otherwise clarifying in the table title.</li> </ul>
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REVIEWER	Nora Kenworthy University of Washington Bothell
REVIEW RETURNED	17-Oct-2018

GENERAL COMMENTS	<p>This paper presents important exploratory research on a key question of interest to health researchers studying crowdfunding usage: How might crowdfunding overlap with geographies of socioeconomic status? It offers an important, but as the authors admit, rudimentary, analysis that is the first of its kind to geospatially analyze such data. The findings the paper offers are an important contribution to the literature, but as I describe below, the data could be more robustly analyzed and reported. I should note that I am not a geographer, and so some of these methods are relatively new to me, however I am a mixed methods researcher who collaborates with geographers on my current research, and I am familiar with the data collection and sampling techniques for crowdfunding research. I do hope that this paper will be reviewed by someone with more expertise in the spatial analysis methods described herein, which I will only touch on to the extent that my knowledge permits.</p> <p>This paper is clearly written and well-laid out, with few large structural or logical flaws. I do, however, recommend some significant revisions so that readers can better understand the methodologies used, the data collected, and the conclusions that can be drawn from them. I outline several of the larger recommendations below, and then offer some line-by-line edits for the authors' consideration as well.</p> <ol style="list-style-type: none"> <li>1. Sampling method description and limitations: One of my primary concerns with this paper is the detail with which the sampling techniques have been described. As outlined, this study would not be replicable because so much information is missing. Though the authors provide quite a bit of detail about technical tools used to parse the data, what they don't provide is an adequate description of how these tools were used, and how this might have impacted the sampling. There are many unanswered questions in this section, including: <ol style="list-style-type: none"> <li>a. What was the crowdfunding platform searched? This matters because of the significant differences in awareness and usage of different platforms in the public. Given the outsized market share of Gofundme, I think any study that uses another platform would have to seriously look at how the characteristics of users differ and thus impact the data. For example, our current research in the US indicates that users who chose to use YouCaring instead of Gofundme had specific reasons for doing so that were linked to awareness, literacy, and levels of education, among other potential factors.</li> <li>b. You state that you searched the database using key terms, but then indicate "cancer" was the only search term used. If so, why? There are many other terms patients use to describe cancer – tumor, sarcoma, leukemia, mass, etc. – that could mean you are missing a great deal of campaigns. How might only searching for 'cancer' impact your sample?</li> <li>c. Most crowdfunding sites use algorithms to rank the order of campaigns that are returned in search results. Many also limit the number of search results. How did you work with / around these algorithms?</li> </ol> </li> </ol>
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	<p>d. Did you pull every campaign that mentioned cancer between May 2012 and June 2016? How do you know you got them all? If you did not get them all, how do you know that your sample does not include just those that were most popular, successful, or had the greatest longevity or were returned first by the search results?</p> <p>e. You describe how “borderline terms” were flagged – what were these? Please provide and justify use.</p> <p>f. What other cleaning did you do to ensure the sample did not include unrelated campaigns, say for people who had died of cancer (but were fundraising for funerals), or even for non-human pets who had cancer (but I assume were not of interest to you)?</p> <p>g. How many “relevant campaigns” were identified?</p> <p>h. You mention “further cleaning and labeling” – of what sort? According to what methods? What “missing information or attributes” were you looking for?</p> <p>i. You note at the end of the sampling para that 1788 records were included in the study. But you give no sense of the overall sampling frame. How many cases were excluded? I have to note that this seems like an extremely small total number of cases. Can you provide some data on overall crowdfunding use and prevalence in Canada that shows this is an expected, reasonable number of campaigns to see in this period?</p> <p>j. You note that some campaigns were as old as from 2012. This seems like a very long time, though many campaigns do persist on sites for this long. I wonder, however, what sort of bias including quite old campaigns may introduce into your sample. For example, it might be likely that less successful campaigns are more likely to remove their content after a certain period of time, leaving only more successful campaigns. Or perhaps those with less education / technological awareness are less likely to remember / know how to take down their campaigns after a certain period of time.</p> <p>2. Other data specificity issues: You acknowledge several issues with data reliability and specificity in your conclusion – that you don’t really know the reported location of campaigns represents the patient’s location, that the geographic areas you are using may introduce significant ecological fallacies, and that the temporal frame of the study captures campaigns at one point in time which may misrepresent their success. At the end of the study you are clear about what these limitations are, and write that few of them can be overcome. But I am not necessarily inclined to agree, and in some cases I think the issues of data specificity may be greater than you describe.</p> <p>a. Location of campaigns: In addition to the issues you highlight, I would also ask how you know that the location a person reports is necessarily their permanent home. In our research we have found multiple people who have moved to urban areas for long-term treatment because of access / transportation issues, and thus the location they might report on their campaign is not their permanent address. As you even note on p. 9, people may be crowdfunding to relocate to an urban center. This might introduce some significant urban bias into your results. But I do think that some more exploratory, qualitative data collection could help you to better understand these data limitations, and potentially control for them. For example, by talking with crowdfunders directly you would know how many reside in the same place as the people they are crowdfunding for – or even know a rough measure of what proportion of people campaign for themselves vs. on behalf of others. This would allow you to at least create some known</p>
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	<p>unknowns for your data, rather than having quite so many unknown unknowns.</p> <p>b. Temporal data on campaigns / campaign duration: So in many cases you do have relatively easy access to how 'old' a campaign is, and when their donations are given. And thus you could run some analysis to see at what general point campaign donations tend to plateau, and thus at what point we can reliably look at what they've raised as a gross measure of success without worrying that a campaign is simply too 'young.' I would strongly encourage you to do this so that your reporting of campaign success is more robust, especially since you also have some VERY old campaigns in the sample and it would be good to establish that those are not still getting donations and thus potentially skewing the data.</p> <p>c. Inclusion of race, gender, ethnicity, nationality, linguistic fluency measures, among others – these are incredibly important unknowns in your data, and I think you need more explanation as to why these were excluded and why it was not possible to include them. Given current debates about race, nationality, gender, and health disparities, it seems problematic to choose to exclude these.</p> <p>3. SES measures: you take measures for completion of post-secondary education, income, and home ownership as your measures for SES, but I think you need to justify this choice – in particular, the use of home ownership, since occupation is a more commonly used measure. Obviously all of these measures present some challenges (see Shavers 2007, etc), but the use of home ownership seems particularly perplexing to me, given the other challenges with geospatial rural / urban specificity in this paper. It seems quite likely that home ownership is a poor contributing factor of SES in certain areas, especially large urban areas where housing prices are high and renting is more common, of which there are several major examples in Canada. I think this choice of home ownership needs to be more explicitly justified and explained.</p> <p>a. A related point is that at several junctures throughout the paper you conflate education with technological skills, access, and literacy. (For example, on p. 9: "individuals who are better educated, more familiar with online technologies, and better able to express themselves online." This is very problematic, for several reasons. First of all, technological access and social media literacy are very different things, as many studies in communication and media studies have shown. And disparities in social media literacy occur across multiple social gradients, and not always alongside education in the way you might expect. Age, disability, geography, and cultural milieu can all play more powerful roles. Where I do think you could expand the analysis is in including a measure for technological access. Relying on education to provide this seems a huge leap that is not supported by the current data.</p> <p>4. Data analysis: While I recommend that a more expert statistician look at these results, even to my untrained eyes it seems very strange that no measures of statistical significance have been included in the results. This seems doubly strange when one takes into account how small the n is in specific geographic areas. To me, this is a huge oversight and I don't see how quantitative results should be published in a journal of this caliber without showing statistical significance.</p> <p>Other points I'd like the authors to consider:</p>
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	<p>1. I think you need to contextualize how these findings may or may not be unique to Canada given access to health care, other social support systems, or even factors like culture and histories of charitable giving. As we see crowdfunding cultures and practices evolving differently in different countries, it's important to think about how results may not be representative of other places where crowdfunding is particularly popular (especially the US, of course, but also developing countries or European countries where health system conditions and patterns of usage may be quite different).</p> <p>2. I am rarely one to pick on missing citations, but this paper leans very heavily (especially in the abstract and introduction) on an argument that all other writing on this topic has either been non-existent or "speculative." While it's true that empirical research on this question has been slim, it's not non-existent, and your claims on this count read as either disingenuous or poorly researched. See, for example, Lukk, Schneiderhan and Soares 2018, and Berliner and Kenworthy 2017, as starting points. In general, a more robust review of existing literature would be very helpful to readers. There are also numerous claims in the introduction and conclusion that desperately need citation – including passages such as "those studies that have been conducting using crowdfunding datasets have not addressed the issue of equitable access to care" (no citation, also worth noting that your study does not tackle this issue either – crowdfunding is not necessarily synonymous with access to care).</p> <p>3. Given the evolving ethical discussions around the use of "publicly" shared data on social media sites for research studies, I would strongly suggest a more concrete and detailed description of how data has been protected and human subjects protections taken into account, even if this was not mandated by your IRB. It would be especially nice to see authors like yourselves with ethics expertise explicitly addressing ethics of data scraped from the internet.</p>
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<b>REVIEWER</b>	KC Gary Chan University of Washington
<b>REVIEW RETURNED</b>	01-Feb-2019

<b>GENERAL COMMENTS</b>	<p>This is a timely paper addressing concerns of inequity caused by medical crowdfunding. The objective is clear and the authors have combined different data sets to analyze whether the association off aggregate social-economic variables and crowdfunding.</p> <p>I have some major concerns for Tables 2-5, regarding the presentation and interpretation of results.</p> <p>1. What is the leftmost column of Tables 2, 4, 5 represent? In Table 3, they represent median income and that are self explanatory, but it is not clear what do the numbers mean in other tables.</p> <p>2. A major concern is whether each quantile has (roughly) the same population size. It is alarming because some strata has more than 100 FSAs and others only 3 or 4. It is unclear how the quantiles are related from ArcMap. The conclusion being made (based on percentage total campaigns in each stratum) would be flawed if strata have unequal population.</p>
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	3. In Table 6, is population in 10000? Also, the row for Nunavut seems to obtain errors. The median income is certainly wrong, and the values of 0 in education and housing is also suspicious.
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## VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

Reviewer Name: Gabrielle Dressler

The authors address an important gap in the current literature pertaining to medical crowdfunding. While others have argued that medical crowdfunding may disproportionately benefit individuals and groups of relative socio-economic, educational, and social privilege, thereby potentially exacerbating pre-existing inequities in the affordability of healthcare, few quantitative studies exist to support that speculation. Given my understanding of the methods, this manuscript takes a meaningful step towards clarifying the demographics of a very particular group who utilize crowdfunding platforms (Canadian residents fundraising for cancer-related healthcare needs).

My broad suggestions for this paper are as follows:

The manuscript clearly outlines the medical crowdfunding landscape and the particular dominance of GoFundMe. However, the authors only state that the web crawler used to generate the dataset scraped a major crowdfunding platforms (p. 5) without naming the platform. It could be useful to more explicitly situate the dataset within this established context.

We now state explicitly that the GoFundMe was the platform scraped.

It is significant that crowdfunding platforms tend to be for-profit companies that can both positively and negatively influence the success of individual campaigns. For example, GoFundMe alone has refused to allow certain kinds of campaigns on their site (Berman J., Crowdfunding site won't let crowds fund abortions, The Huffington Post. 2014.), waived platform fees in certain cases but not others (Ali F., GoFundMe denies waivers for Somali drought, The Huffington Post. 2017.), and made donations directly to particular campaigns (Charlie Gard's campaign page, Update #4, GoFundMe.com/please-help-to-save-charlies-life). This power structure (summarized in Dressler, G. & Kelly, S. A. (2018). Ethical implications of medical crowdfunding: the case of Charlie Gard. BMJ.) seems important to mention in a paper that addresses the intersection of inequity and medical crowdfunding.

We have added these details to the background section.

The manuscript does not address the amount of money raised by the crowdfunding campaigns included in the dataset, neither the amount actually raised, nor the amount that campaigns set as their goal. It might be helpful to quantify the advantage afforded to those who successfully engage in

medical crowdfunding, or to explicitly mention that the data do not describe that information. While the limitations section does note how the campaign duration captured in the current dataset may not be representative of the overall success of the campaign (p. 11), it might still be informative to compare the outcomes or targets of these campaigns to the few calculated averages that can be found in the literature (Gonzales, A. L., Kwon, E. Y., Lynch, T., & Fritz, N. (2016). Better everyone should know our business than we lose our house: Costs and benefits of medical crowdfunding for support, privacy, and identity. *new media & society*.; Berliner, L. S. & Kenworthy, N. J. (2017). Producing a worthy illness: Personal crowdfunding amidst financial crisis. *Social Science & Medicine*.) This is important in order to understand whether people of socio-economic privilege disproportionately utilize medical crowdfunding, disproportionately benefit from their campaigns, or both.

The primary focus of this manuscript was on spatial attributes of crowdfunding campaigns. We agree that these suggested analyses would be of great value, but they are outside of the scope of this project. We feel that it would be a highly desirable project to take on in a follow up manuscript.

Relatedly, the discussion section briefly mentions a positive correlation between the amount raised in a campaign and number of times the campaign was shared (p. 9). This is an important finding that seems buried and warrants further discussion. Which campaigns were shared more? Does the number of shares align with trends in other measured variables?

We now highlight this finding in the abstract and discussion section of the paper and provide additional analysis.

In the discussion section, it would be helpful to restate that this research was conducted in the context of a universal health system to inform how these conclusions might apply to different systems (given that medical crowdfunding is utilized internationally).

We now note this context in the discussion section, including the need for investigation in other health system contexts.

My smaller suggestions and questions include:

P. 3: The introduction draws a distinction between crowdfunding and charitable crowdfunding that isn't otherwise mentioned. I would suggest either clarifying or removing this wording.

We have added clarifying language to the first paragraph.

P. 8: The authors mention in the results section that Canadians' cancer-related crowdfunding campaigns were also commonly located in close proximity to city centres. It might be helpful to quantify this distribution or describe it in more detail to bolster the discussion beginning on the bottom of page 9.



We feel that the maps generated through this project visually display this result. It was our aim to present this information visually given the study's nature as a spatial analysis.

P. 9: In their discussion, the authors write that "Individuals in the highest income FSAs were found to be the heaviest users of medical crowdfunding." The data report that the greatest percentages of campaigns come from quintiles 2, 3, and 4 (Table 3). While the use of crowdfunding is high in FSAs with high incomes, it seems important to address the contributions of quintile 2 to this conclusion.

This exploratory analysis is intended to reveal spatial aspects and patterns of crowdfunding campaigns. The data and analysis are not set out to explain every trend and therefore we do not feel it would be appropriate to focus on this specific quintile.

P. 11: In the sentence that begins with "Further to this, postal codes are self-reported," 'misstate' should read 'mistakes.'

We have corrected this typo.

Table 4: In the second quintile, 13979 should read 1397.

This has been corrected.

Table 6: It's difficult to decipher the organizing principle here. I would suggest either organizing this by number of campaigns, alphabetically by province, or otherwise clarifying in the table title.

The table was organized geographically, west to east. We have now organized it alphabetically by province.

Reviewer: 2

Reviewer Name: Nora Kenworthy

This paper presents important exploratory research on a key question of interest to health researchers studying crowdfunding usage: How might crowdfunding overlap with geographies of socioeconomic status? It offers an important, but as the authors admit, rudimentary, analysis that is the first of its kind to geospatially analyze such data. The findings the paper offers are an important contribution to the literature, but as I describe below, the data could be more robustly analyzed and

reported. I should note that I am not a geographer, and so some of these methods are relatively new to me, however I am a mixed methods researcher who collaborates with geographers on my current research, and I am familiar with the data collection and sampling techniques for crowdfunding research. I do hope that this paper will be reviewed by someone with more expertise in the spatial analysis methods described herein, which I will only touch on to the extent that my knowledge permits.

This paper is clearly written and well-laid out, with few large structural or logical flaws. I do, however, recommend some significant revisions so that readers can better understand the methodologies used, the data collected, and the conclusions that can be drawn from them. I outline several of the larger recommendations below, and then offer some line-by-line edits for the authors' consideration as well.

1. Sampling method description and limitations: One of my primary concerns with this paper is the detail with which the sampling techniques have been described. As outlined, this study would not be replicable because so much information is missing. Though the authors provide quite a bit of detail about technical tools used to parse the data, what they don't provide is an adequate description of how these tools were used, and how this might have impacted the sampling. There are many unanswered questions in this section, including:

a. What was the crowdfunding platform searched? This matters because of the significant differences in awareness and usage of different platforms in the public. Given the outsized market share of Gofundme, I think any study that uses another platform would have to seriously look at how the characteristics of users differ and thus impact the data. For example, our current research in the US indicates that users who chose to use YouCaring instead of Gofundme had specific reasons for doing so that were linked to awareness, literacy, and levels of education, among other potential factors.

We now clarify that GoFundMe was the platform searched.

b. You state that you searched the database using key terms, but then indicate "cancer" was the only search term used. If so, why? There are many other terms patients use to describe cancer – tumor, sarcoma, leukemia, mass, etc. – that could mean you are missing a great deal of campaigns. How might only searching for 'cancer' impact your sample?

We chose the key term 'cancer' as it is a higher order concept that will capture many subtypes. Furthermore, it is a term that will be more familiar and more likely to be used by crowdfunders and donors than subtype names. Our goal was to capture a large selection of cancer-related campaigns rather than an exhaustive sample of such campaigns, making the higher order term well suited to our aims.

c. Most crowdfunding sites use algorithms to rank the order of campaigns that are returned in search results. Many also limit the number of search results. How did you work with / around these algorithms?

We now clarify in the second paragraph that the scraping process searched for campaigns with Canadian postal codes. Thus, we did not use the internal search process and algorithms utilized by GoFundMe.

d. Did you pull every campaign that mentioned cancer between May 2012 and June

2016? How do you know you got them all? If you did not get them all, how do you know that your sample does not include just those that were most popular, successful, or had the greatest longevity or were returned first by the search results?

We now clarify that all campaigns mentioning cancer and originating from a Canadian postal code were scraped for that time frame. We cannot know that we scraped every such campaign, but as noted above we were not limited by GoFundMe's internal search results or algorithms.

e. You describe how "borderline terms" were flagged – what were these? Please provide and justify use.

This term was misleading and has been removed. The text now indicates that "Any ambiguous posts were read by the researchers to determine if they fit the classification and should be included."

f. What other cleaning did you do to ensure the sample did not include unrelated campaigns, say for people who had died of cancer (but were fundraising for funerals), or even for non-human pets who had cancer (but I assume were not of interest to you)?

We searched only campaigns in the 'medical' category and so were unlikely to have included many campaigns for funeral expenses or non-human animals as there are separate categories for these types of fundraisers. This is now clarified in the methods section.

g. How many "relevant campaigns" were identified?

The total number of scraped campaigns was roughly 1800 across all Canada postal codes. A small number were removed as incomplete as lacking data fields.

h. You mention "further cleaning and labeling" – of what sort? According to what methods? What "missing information or attributes" were you looking for?

Cleaning and labeling in this case refers to extracting the main content attributes and removing anything irrelevant like the footer. Specifically, we developed a template that automatically matches and extracts attributes within the collected web pages.

i. You note at the end of the sampling para that 1788 records were included in the study. But you give no sense of the overall sampling frame. How many cases were excluded? I have to note that this seems like an extremely small total number of cases. Can you provide some data on overall crowdfunding use and prevalence in Canada that shows this is an expected, reasonable number of campaigns to see in this period?

GoFundMe states that there had been 88,000 total campaigns across all categories started by Canadians by the end of 2016 (<https://medium.com/gofundme-stories/gofundme-in-canada-7512972a830>). Our data was collected in mid-2016, so fewer campaigns would have been created at that point. We were looking only for medical campaigns including the keyword 'cancer', and that were still accessible at that date (i.e., had not been previously concluded and removed). On this basis, we feel that 1,788 is a reasonable number of campaigns to have identified.

j. You note that some campaigns were as old as from 2012. This seems like a very long time, though many campaigns do persist on sites for this long. I wonder, however, what sort of bias including quite old campaigns may introduce into your sample. For example, it might be likely that less successful campaigns are more likely to remove their content after a certain period of time, leaving only more successful campaigns. Or perhaps those with less education / technological awareness are less likely to remember / know how to take down their campaigns after a certain period of time.

This issue is touched on in the limitations section. We have added a sentence noting the specific concerns raised here.

2. Other data specificity issues: You acknowledge several issues with data reliability and specificity in your conclusion – that you don't really know the reported location of campaigns represents the patient's location, that the geographic areas you are using may introduce significant ecological fallacies, and that the temporal frame of the study captures campaigns at one point in time which may misrepresent their success. At the end of the study you are clear about what these limitations are, and write that few of them can be overcome. But I am not necessarily inclined to agree, and in some cases I think the issues of data specificity may be greater than you describe.

a. Location of campaigns: In addition to the issues you highlight, I would also ask how you know that the location a person reports is necessarily their permanent home. In our research we have found multiple people who have moved to urban areas for long-term treatment because of access / transportation issues, and thus the location they might report on their campaign is not their permanent address. As you even note on p. 9, people may be crowdfunding to relocate to an urban center. This might introduce some significant urban bias into your results. But I do think that some more exploratory, qualitative data collection could help you to better understand these data limitations, and potentially control for them. For example, by talking with crowdfunders directly you would know how many reside in the same place as the people they are crowdfunding for – or even know a rough measure of what proportion of people campaign for themselves vs. on behalf of others. This would

allow you to at least create some known unknowns for your data, rather than having quite so many unknown unknowns.

We have added this issue about an urban bias into our existing discussion of limitations around determining the location of the campaign recipient versus the campaign organizer. We agree that qualitative data from crowdfunders will be useful to contextualizing and understanding the findings presented here and hope to conduct such work soon.

b. Temporal data on campaigns / campaign duration: So in many cases you do have relatively easy access to how 'old' a campaign is, and when their donations are given. And thus you could run some analysis to see at what general point campaign donations tend to plateau, and thus at what point we can reliably look at what they've raised as a gross measure of success without worrying that a campaign is simply too 'young.' I would strongly encourage you to do this so that your reporting of campaign success is more robust, especially since you also have some VERY old campaigns in the sample and it would be good to establish that those are not still getting donations and thus potentially skewing the data.

c. Inclusion of race, gender, ethnicity, nationality, linguistic fluency measures, among others – these are incredibly important unknowns in your data, and I think you need more explanation as to why these were excluded and why it was not possible to include them. Given current debates about race, nationality, gender, and health disparities, it seems problematic to choose to exclude these.

The primary focus of this manuscript was on spatial attributes of crowdfunding campaigns. We agree that examining these other elements would be very valuable, but they are outside of the scope of this project. Analyses of this type on a similar or likely smaller dataset should be pursued in the future and we hope this analysis helps makes the case for doing so.

3. SES measures: you take measures for completion of post-secondary education, income, and home ownership as your measures for SES, but I think you need to justify this choice – in particular, the use of home ownership, since occupation is a more commonly used measure. Obviously all of these measures present some challenges (see Shavers 2007, etc), but the use of home ownership seems particularly perplexing to me, given the other challenges with geospatial rural / urban specificity in this paper. It seems quite likely that home ownership is a poor contributing factor of SES in certain areas, especially large urban areas where housing prices are high and renting is more common, of which there are several major examples in Canada. I think this choice of home ownership needs to be more explicitly justified and explained.

a. A related point is that at several junctures throughout the paper you conflate education with technological skills, access, and literacy. (For example, on p. 9: "individuals who are better educated, more familiar with online technologies, and better able to express themselves online." This is very problematic, for several reasons. First of all, technological access and social media literacy are very different things, as many studies in communication and media studies have shown. And disparities in social media literacy occur across multiple social gradients, and not always alongside education in the way you might expect. Age, disability, geography, and cultural milieu can all play more powerful roles. Where I do think you could expand the analysis is in including a measure for technological access. Relying on education to provide this seems a huge leap that is not supported by the current data.

We acknowledge that age, race, and many other factors could play an important role in the distribution of crowdfunding donations.

The development of the VANDIX measure of SES was based on a comprehensive survey of all Medical Health Officers (MHO) in the province of British Columbia. The MHO were asked which census variables they associated with better outcomes and general health in the province. A surprise finding was that the MHO were near unanimous in selecting home ownership as one such variable (see references below). When queried, the MHO identified home ownership as closely related to social capital, especially in rural areas. See: Bell, N., N. Schuurman, and M. V. Hayes. 2007. Using GIS-based methods of multicriteria analysis to construct socio-economic deprivation indices. *International Journal of Health Geographics* 6 (17); Bell, N., N. Schuurman, L. Oliver, and M. V. Hayes. 2007. Towards the construction of place-specific measures of deprivation: A case study from the Vancouver metropolitan area. *The Canadian Geographer* 51 (4):444-461.

We agree that education is not necessarily the same as having access to technology or the skills to use technology. However, it is certainly associated with the ability to leverage multiple tools in the service of health care for oneself and family. In this case, we are just listing characteristics: education, familiarity with online technology, and an ability to express oneself. We are not actually conflating the three attributes.

4. Data analysis: While I recommend that a more expert statistician look at these results, even to my untrained eyes it seems very strange that no measures of statistical significance have been included in the results. This seems doubly strange when one takes into account how small the *n* is in specific geographic areas. To me, this is a huge oversight and I don't see how quantitative results should be published in a journal of this caliber without showing statistical significance.

Spatial analyses take for granted that geographically close events are related. This is why statistical significance is not relevant to a spatial analysis.

Other points I'd like the authors to consider:

1. I think you need to contextualize how these findings may or may not be unique to Canada given access to health care, other social support systems, or even factors like culture and histories of charitable giving. As we see crowdfunding cultures and practices evolving differently in different countries, it's important to think about how results may not be representative of other places where crowdfunding is particularly popular (especially the US, of course, but also developing countries or European countries where health system conditions and patterns of usage may be quite different).

We now note this context in the discussion section, including how this context supports the need for more investigation in other communities.



2. I am rarely one to pick on missing citations, but this paper leans very heavily (especially in the abstract and introduction) on an argument that all other writing on this topic has either been non-existent or “speculative.” While it's true that empirical research on this question has been slim, it's not non-existent, and your claims on this count read as either disingenuous or poorly researched. See, for example, Lukk, Schneiderhan and Soares 2018, and Berliner and Kenworthy 2017, as starting points. In general, a more robust review of existing literature would be very helpful to readers. There are also numerous claims in the introduction and conclusion that desperately need citation – including passages such as “those studies that have been conducting using crowdfunding datasets have not addressed the issue of equitable access to care” (no citation, also worth noting that your study does not tackle this issue either – crowdfunding is not necessarily synonymous with access to care).

We agree that research in this area has been developing rapidly, including during the period after the relevant text was written, and was not adequately noted. We've now updated the introduction and discussion sections to better reflect this scholarship.

3. Given the evolving ethical discussions around the use of “publicly” shared data on social media sites for research studies, I would strongly suggest a more concrete and detailed description of how data has been protected and human subjects protections taken into account, even if this was not mandated by your IRB. It would be especially nice to see authors like yourselves with ethics expertise explicitly addressing ethics of data scraped from the internet.

In the first paragraph of the methods section we now detail that we consulted our local research ethics board regarding this study and, while not required by local regulations, did not publish any personally identifiable information about campaign recipients in this manuscript. We agree that more fulsome discussion of the ethical issues raised by working with crowdfunding data would be desirable in a manuscript dedicated to this issue, especially where personally identifiable information is used.

Reviewer: 3

Reviewer Name: KC Gary Chan

This is a timely paper addressing concerns of inequity caused by medical crowdfunding. The objective is clear and the authors have combined different data sets to analyze whether the association off aggregate social-economic variables and crowdfunding.

I have some major concerns for Tables 2-5, regarding the presentation and interpretation of results.

1. What is the leftmost column of Tables 2, 4, 5 represent? In Table 3, they represent median income and that are self explanatory, but it is not clear what do the numbers mean in other tables.

We now clarify that these are income quintiles.

2. A major concern is whether each quantile has (roughly) the same population size. It is alarming because some strata has more than 100 FSAs and others only 3 or 4. It is unclear how the quantiles are related from ArcMap. The conclusion being made (based on percentage total campaigns in each stratum) would be flawed if strata have unequal population.

Statistics Canada has developed FSAs to be comparable areas to be used for research purposes such as this. They are generally near homogenous population size across Canada, which explains why they can differ greatly in geographic area.

3. In Table 6, is population in 10000? Also, the row for Nunavut seems to obtain errors. The median income is certainly wrong, and the values of 0 in education and housing is also suspicious.

At the time the work was conducted last year, the Census profile for the FSA level was not published. To handle this, we selected the SES variables from the ADA level. Performing an intersection operation between FSAs and ADAs, SES variables were added to FSAs based on the percentage of area shared. By taking the weighted average of SES variables from the ADAs that intersect with each FSA, values such as those for shown for Nunavut are impacted by the error accumulation from this procedure, where populations are sparse. Likewise, if there were any issues with values in the ADA-level SES data, these will propagate to the weighted SES variables linked to the FSAs. This means that data issues from the ADA Census profile product or low populations contribute to and exacerbate errors.

The Nunavut values are correct with respect to this method applied. This is a systematic limitation that is exaggerated by the sparse population of Nunavut and affects all data reported in the tables at varying degrees. The geographically weighted method for adding SES variables to FSAs is accessible here: <https://github.com/alyshav/ArcPy-Calculate-Percent-Area-Shared-and-Compute-Weighted-Values>

## VERSION 2 – REVIEW

<b>REVIEWER</b>	Gabrielle Dressler Warren Alpert Medical School at Brown University Providence, RI, USA
<b>REVIEW RETURNED</b>	23-Mar-2019

<b>GENERAL COMMENTS</b>	Many thanks to the authors for their thoughtful responses to my recommendations. The authors sufficiently expanded their background section, thereby more explicitly situating their study within the existing literature on medical crowdfunding. They also broadened their discussion of previously described ethical concerns about medical crowdfunding, which provides helpful context when considering the implications of their work. Moreover,
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	<p>by clarifying the scope of their project, the authors adequately addressed my concerns about certain aspects of their analysis that I found to be incomplete or absent.</p> <p>However, given that I am neither a geographer nor a statistician, I hope that another reviewer with relevant expertise will be reviewing the changes the authors made to their methods and results sections.</p> <p>Lastly, the manuscript would benefit from a close edit, with particular attention to small typos.</p>
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<b>REVIEWER</b>	Nora Kenworthy University of Washington Bothell, USA
<b>REVIEW RETURNED</b>	31-Mar-2019

<b>GENERAL COMMENTS</b>	<p>The authors have done a very nice job responding to reviewers' points and clarifying aspects of the methodology that were missing in the previous version of the paper. However, a number of points that they have clarified in comments to the reviewer have not been added to the paper. I would still encourage the authors to include these clarifications about methodological approaches and justifications for specific measures. Given that this is one of the first papers to provide robust empirical evidence on this topic, I think it will garner significant attention from both other researchers and the public - both of whom should have access to this information if they have questions about how the study was conducted. If this material cannot be accommodated in the text itself, I'd suggest adding an online supplement with further information.</p>
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<b>REVIEWER</b>	Kwun Chuen Gary Chan University of Washington, USA
<b>REVIEW RETURNED</b>	17-Apr-2019

<b>GENERAL COMMENTS</b>	<p>I still find the numbers for Nanavut in Table 6 suspicious. Error accumulation shall also be an issue for Northwest Territories and Yukon (likely to a lesser degree). The population count in Population and Dwelling Count Highlight Tables, 2016 Census are similar for Nanavut, Northwest Territories and Yukon. I suspect the ADA SES variables may have significant quality issues and/or missing data problems. I guess this limitation should at least be mentioned.</p>
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## VERSION 2 – AUTHOR RESPONSE

Reviewer: 1

Many thanks to the authors for their thoughtful responses to my recommendations. The authors sufficiently expanded their background section, thereby more explicitly situating their study within the existing literature on medical crowdfunding. They also broadened their discussion of previously described ethical concerns about medical crowdfunding, which provides helpful context when

considering the implications of their work. Moreover, by clarifying the scope of their project, the authors adequately addressed my concerns about certain aspects of their analysis that I found to be incomplete or absent.

However, given that I am neither a geographer nor a statistician, I hope that another reviewer with relevant expertise will be reviewing the changes the authors made to their methods and results sections.

Lastly, the manuscript would benefit from a close edit, with particular attention to small typos.

We have reviewed the manuscript for typos.

Reviewer: 2

The authors have done a very nice job responding to reviewers' points and clarifying aspects of the methodology that were missing in the previous version of the paper. However, a number of points that they have clarified in comments to the reviewer have not been added to the paper. I would still encourage the authors to include these clarifications about methodological approaches and justifications for specific measures. Given that this is one of the first papers to provide robust empirical evidence on this topic, I think it will garner significant attention from both other researchers and the public - both of whom should have access to this information if they have questions about how the study was conducted. If this material cannot be accommodated in the text itself, I'd suggest adding an online supplement with further information.

We have added to the manuscript language justifying 'cancer' as a search term and the data cleaning process, both from the response letter.

Reviewer: 3

I still find the numbers for Nanavut in Table 6 suspicious. Error accumulation shall also be an issue for Northwest Territories and Yukon (likely to a lesser degree). The population count in Population and Dwelling Count Highlight Tables, 2016 Census are similar for Nanavut, Northwest Territories and Yukon. I suspect the ADA SES variables may have significant quality issues and/or missing data problems. I guess this limitation should at least be mentioned.

We have added our response to this point from the original revision letter to the limitation section.