

## PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form ([see an example](#)) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below. Some articles will have been accepted based in part or entirely on reviews undertaken for other BMJ Group journals. These will be reproduced where possible.

### ARTICLE DETAILS

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| <b>TITLE (PROVISIONAL)</b> | Social media use among patients and caregivers: a scoping review   |
| <b>AUTHORS</b>             | Hamm, Michele; Chisholm, Annabritt; Shulhan, Jocelyn; Milne, Andrea; Scott, Shannon; Given, Lisa; Hartling, Lisa |

### VERSION 1 - REVIEW

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| <b>REVIEWER</b>        | Paul Wicks, R&D Director, PatientsLikeMe, UK<br><br>PW is an employee of PatientsLikeMe and owns stock / stock options in the company. PatientsLikeMe's R&D team receives research support from a number of pharmaceutical companies. |
| <b>REVIEW RETURNED</b> | 06-Mar-2013   |

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| <b>THE STUDY</b>                 | <p>1. Patients not representative because the total N of all the patients in the literature is probably only a few tens of thousands, as opposed to hundreds of millions of social media users. Not the authors' fault, but still.</p> <p>2. I noted two references in the intro that could be updated.</p>   |
| <b>RESULTS &amp; CONCLUSIONS</b> | I don't think there have been prior systematic reviews  |
| <b>GENERAL COMMENTS</b>          | <p>The authors have conducted a systematic review of the literature on the use of social media.</p> <p>Introduction:</p> <ul style="list-style-type: none"> <li>* There is a more up to date Pew report, and it might be ideal to find a more recent reference for hours spent on social media (Twitter hadn't yet exploded in 2010)</li> <li>* Para 2, it might be worth very briefly contrasting social media against "web 1.0" which favored expert static content</li> <li>* Second Life is dead - Farmville or World of Warcraft probably more current</li> <li>* Para 3 - Although as the authors show in referencing a work from 2002, such "potential" harms must be sufficiently rare that few have written about them despite their widespread use. Is it fair to say such fears are unfounded?</li> </ul> <p>Search Strategy:</p> <ul style="list-style-type: none"> <li>* When was the search conducted? A range is fine but time period crucial here.</li> </ul> <p>Study Selection:</p> <ul style="list-style-type: none"> <li>* Wait, mobile health can't be social? Tell that to WellApps, RunKeeper, etc. I don't think this is what you meant but be clearer. Presume you're mostly excluding tracking apps.</li> </ul> |

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|  | <p>* Why is a bulletin board OK but not a chat room? The only difference is asynchronous vs synchronous.</p> <p>* How did you deal with sites that incorporated multiple elements?</p> <p>Results</p> <p>* Ben Goldacre and others have commented that studies conducted by pharmaceutical companies tend to be more likely to find positive results than academic ones. Is the same true in social media?</p> <p>Discussion:</p> <p>* The authors end up doing something they criticise the literature for, i.e. being descriptive without further exploration. They present a top-level summary *describing* the proportions of studies in different categories, but give few examples or synthesise more complex abstract principles arising. Do benefits reported on TuDiabetes match those reported on PatientsLikeMe? What factors seem to be important in identifying a benefit?</p> <p>* This work does not relate to any of the important frameworks that have driven health social media such as the "E-Patient" movement (Tom Ferguson, ePatient Dave) or "Citizen Science" (as described by Melanie Swan).</p> <p>* A major limitation of this strategy is it assumes that people involved in social media want to publish research in the peer-reviewed literature and that is important to them. Facebook doesn't publish medical research, and yet it has transformed advocacy and community. Twitter doesn't publish medical research, and yet it has empowered the patient voice considerably. The published literature represents only a sliver of what is going on in practice, and as comprehensive as this review may be this is a limitation that should be recognised.</p> <p>Although citing all the studies that appeared in the references would be inappropriate, it would be a useful resource as an appendix to provide the studies identified to help other researchers explore further.</p> |
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| <b>REVIEWER</b>        | <p>Ted Eytan, MD MS MPH<br/>Kaiser Permanente - The Center for Total Health<br/>Washington, DC, USA<br/>twitter: tedeytan</p> <p>No competing interests (employee of Kaiser Permanente)</p> |
| <b>REVIEW RETURNED</b> | 20-Mar-2013   |

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| <b>THE STUDY</b> | <p>The authors raise an important distinction in their review which is that most of the research has been done on "discussion groups" which sort of stretches the definition of social media as we see it today. I would delineate that more in the title.</p> <p>Also, the Conclusion in the abstract is very weak and hedge-y, and on the unclear side. As the authors state in the conclusion there is a substantial "promotion of social media" happening in society today so I think it's critical for the abstract to be clear that there is/is not sufficient evidence today. The audience reading this will be drawn to</p> |
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|                                  | the topic and will attempt to widely quote what is said here.   |
| <b>RESULTS &amp; CONCLUSIONS</b> | <p>A few things I would like to bring to the authors attention that will strengthen the accuracy of the paper:</p> <p>1. The Fox reference (#11) is about searching for medical information online. It misleads about online being dominant, in fact, Fox's work shows that the #1 place a person gets health information in 2012 is from a health professional, not online, and this has not changed for 10 years. See this infographic:<br/> <a href="http://www.tedeytan.com/2013/01/15/12286">http://www.tedeytan.com/2013/01/15/12286</a></p> <p>Also, if you dig deeper into Susannah's research you'll find that the % of people sharing experiences using social networks is quite low (in the 20% range) and this has not changed in almost 4 years.</p> <p>Survey data show that there is not a trend toward being more "social" with regard to health issues, even if people use the internet to look up information.</p> <p>2. I would revise the last sentence in the first paragraph of the discussion. Authors have not presented evidence that discussion forums are highly prevalent in the patient population at large, or that there is a dominance in seeking out "someone like me" - again, the Edelman Health barometer from 2011 shows that the #1 person people trust in health is their physician - see<br/> <a href="http://www.tedeytan.com/2011/11/14/9346">http://www.tedeytan.com/2011/11/14/9346</a></p> <p>It may be more accurate to state that a subset of patients are doing this online, but we cannot know which and for what reason.</p> <p>The challenge, as the authors allude to, is that these sites tend to be designed for the site designers (e.g the fallacy of "the user is just like me") so it bears mentioning that it's unclear what works from the perspective of a whole population versus the kind of people who go to discussion forums.</p> <p>This may be a long way of saying, there's no data here on how representative the people in these studies are of the population, and this is significant to people who work in population based health systems (as I do), who are being deluged with requests to implement these programs based on the experience of a select few.</p> <p>3. Figure 4 feels visually misleading to me. When I compare what is said in the text to how the figure appears, the eye is drawn to the upper right hand quadrant with big circles, but in total, the majority of the RCT's were not positive.</p> <p>4. There were 38 studies involving Facebook, Twitter, YouTube. I don't see a separate analysis of RCTs related to them, or it's unclear if there are any. I applaud the authors for making this distinction. It's significant. I would draw it out a lot more throughout the paper.</p> <p>5. Based on the Fox data above, it would be useful to understand how many of these studies involve health professionals in the mix, might be a topic for a future paper, however, I do know that TuDiabetes and TuAnalyze involve this connection via the Indigo personal health record.</p> |
| <b>GENERAL COMMENTS</b>          | Overall, a helpful addition to the literature. I am reviewing from the perspective of the audience who will use this work to make a   |

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|  | decision "should I move forward with implementing a social media program in my health system"? With that in mind, care to details about this audience perspective are warranted , so they can understand what this review says about social media in a whole population (not very much, it is about a selected group of people), and then how significant the results are for that group (not very, and not much data on what we cite as true social networking platforms). |
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### VERSION 1 – AUTHOR RESPONSE

| Reviewer Comments   | Authors' Response   |
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| <i>Editorial Comments</i>   |   |
| As covered in the review, please be clear in the methods on the date of the search (the abstract says 2000-2012). Just a thought - is the title correct? This isn't just about patient outcomes but is much broader (eg "Use of social media among patients and carers: a scoping review"). Something to consider.  | The date of the search (January 2012) has been added to the Search Strategy section. We've also revised the title to reflect the suggestion.                      |
| <i>Reviewer #1</i>  |   |
| 1. Patients not representative because the total N of all the patients in the literature is probably only a few tens of thousands, as opposed to hundreds of millions of social media users. Not the authors' fault, but still.   | We've updated our Limitations section to include a statement that "our included patient population may not be representative of social media users as a whole."   |
| 2. I noted two references in the intro that could be updated.   | Thank you for drawing this to our attention. These references have been updated.  |
| <p>Introduction:</p> <p>* There is a more up to date Pew report, and it might be ideal to find a more recent reference for hours spent on social media (Twitter hadn't yet exploded in 2010)</p> <p>* Para 2, it might be worth very briefly contrasting social media against "web 1.0" which favored expert static content</p> <p>* Second Life is dead - Farmville or World of Warcraft probably more current</p> <p>* Para 3 - Although as the authors show in referencing a work from 2002, such "potential" harms must be sufficiently rare that few have written about them despite their widespread use. Is it fair to say such fears are unfounded?</p> | <p>As above.</p> <p>Thank you for this suggestion. This has been added in.</p> <p>We've replaced Second Life with HumanSim to maintain a focus on healthcare.</p> |



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|  | related to the interpretation of complex interventions in the Discussion on pages 13 and 14.   |
| <p>Results</p> <p>* Ben Goldacre and others have commented that studies conducted by pharmaceutical companies tend to be more likely to find positive results than academic ones. Is the same true in social media?</p>  | <p>Nearly all studies have been conducted in an academic context; therefore it is unclear whether the association between industry-funded research and positive results is also present in social media. We have added a statement to the Discussion that the fact that most tools were developed and evaluated by the same team may have had an impact on the positive findings reported.</p>   |
| <p>Discussion:</p> <p>* The authors end up doing something they criticise the literature for, i.e. being descriptive without further exploration. They present a top-level summary *describing* the proportions of studies in different categories, but give few examples or synthesise more complex abstract principles arising. Do benefits reported on TuDiabetes match those reported on PatientsLikeMe? What factors seem to be important in identifying a benefit?</p> <p>* This work does not relate to any of the important frameworks that have driven health social media such as the "E-Patient" movement (Tom Ferguson, ePatient Dave) or "Citizen Science" (as described by Melanie Swan).</p> <p>* A major limitation of this strategy is it assumes that people involved in social media want to publish research in the peer-reviewed literature and that is important to them. Facebook doesn't publish medical research, and yet it has transformed advocacy and community. Twitter doesn't publish medical research, and yet it has empowered the patient voice considerably. The published literature represents only a sliver of what is going on in practice, and as comprehensive as this review may be this is a limitation that should be recognised.</p> | <p>It will be very important to synthesize the findings in more detail, particularly in terms of the effectiveness of social media in health care. However, as this was a scoping review, our intention was to broadly describe the state of the literature, and use these results as a foundation for future evidence syntheses on specific clinical conditions and/or social media tools, and to identify the gaps that exist in the current state of the knowledge on this topic.</p> <p>We have added references to these movements in the discussion of the limitations of our scope of the review.</p> <p>Thank you for this comment. We have incorporated this suggestion into the Limitations section in the Discussion.</p> |
| Although citing all the studies that appeared in the references  | We've added a supplementary file   |

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| <p>would be inappropriate, it would be a useful resource as an appendix to provide the studies identified to help other researchers explore further.</p>   | <p>with the citations of the 284 included references.</p>   |
| <p><i>Reviewer #2</i></p>  |   |
| <p>The authors raise an important distinction in their review which is that most of the research has been done on "discussion groups" which sort of stretches the definition of social media as we see it today. I would delineate that more in the title.</p>   | <p>Thank you for this comment. While most studies included in the review were in fact based on discussion groups, we were still considering these tools to fall under the definition of social media. Our intention was to review all social media tools used, and the fact that discussion boards emerged as being so predominant in the literature was one of the results, rather than one of our objectives.</p> |
| <p>Also, the Conclusion in the abstract is very weak and hedgey, and on the unclear side. As the authors state in the conclusion there is a substantial "promotion of social media" happening in society today so I think it's critical for the abstract to be clear that there is/is not sufficient evidence today. The audience reading this will be drawn to the topic and will attempt to widely quote what is said here.</p>  | <p>The abstract has been updated to reflect stronger conclusions based on this study.</p>   |
| <p>1. The Fox reference (#11) is about searching for medical information online. It misleads about online being dominant, in fact, Fox's work shows that the #1 place a person gets health information in 2012 is from a health professional, not online, and this has not changed for 10 years. See this infographic: <a href="http://www.tedeytan.com/2013/01/15/12286">http://www.tedeytan.com/2013/01/15/12286</a></p> <p>Also, if you dig deeper into Susannah's research you'll find that the % of people sharing experiences using social networks is quite low (in the 20% range) and this has not changed in almost 4 years.</p> <p>Survey data show that there is not a trend toward being more "social" with regard to health issues, even if people use the internet to look up information.</p> | <p>We have clarified the wording in this paragraph.</p>   |
| <p>2. I would revise the last sentence in the first paragraph of the discussion. Authors have not presented evidence that discussion forums are highly prevalent in the patient population at large, or that there is a dominance in seeking out "someone like me" - again, the Edelman Health barometer from 2011 shows that the #1 person people trust in health is their physician - see <a href="http://www.tedeytan.com/2011/11/14/9346">http://www.tedeytan.com/2011/11/14/9346</a></p> <p>It may be more accurate to state that a subset of patients are</p>  | <p>We have edited this statement to reflect that the finding that discussion boards were used so commonly may reflect the popularity of these tools among patients and caregivers, but that it may also be an artifact of the behaviours or preferences of the site designers.</p>  |

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| <p>doing this online, but we cannot know which and for what reason.</p> <p>The challenge, as the authors allude to, is that these sites tend to be designed for the site designers (e.g the fallacy of "the user is just like me") so it bears mentioning that it's unclear what works from the perspective of a whole population versus the kind of people who go to discussion forums.</p> <p>This may be a long way of saying, there's no data here on how representative the people in these studies are of the population, and this is significant to people who work in population based health systems (as I do), who are being deluged with requests to implement these programs based on the experience of a select few.</p> | <p>We have added a statement about the representativeness of the study population to the Limitations section in the Discussion.</p>  |
| <p>3. Figure 4 feels visually misleading to me. When I compare what is said in the text to how the figure appears, the eye is drawn to the upper right hand quadrant with big circles, but in total, the majority of the RCT's were not positive.</p>   | <p>We've revised the figure, switching the x and y axes, to have less of a visual emphasis on the top, right-hand corner.</p>  |
| <p>4. There were 38 studies involving Facebook, Twitter, YouTube. I don't see a separate analysis of RCTs related to them, or it's unclear if there are any. I applaud the authors for making this distinction. It's significant. I would draw it out a lot more throughout the paper.</p>  | <p>There was only one RCT that employed Facebook and Twitter as part of their intervention to promote a nutrition program. A statement has been added to the Results to indicate this.</p>                         |
| <p>5. Based on the Fox data above, it would be useful to understand how many of these studies involve health professionals in the mix, might be a topic for a future paper, however, I do know that TuDiabetes and TuAnalyze involve this connection via the Indigo personal health record.</p>   | <p>We have added a comment on page 14 to suggest future research in this area, including in-depth systematic reviews that include a description of the involvement of health care professionals.</p>               |
| <p>Overall, a helpful addition to the literature. I am reviewing from the perspective of the audience who will use this work to make a decision "should I move forward with implementing a social media program in my health system"? With that in mind, care to details about this audience perspective are warranted, so they can understand what this review says</p>  | <p>Thank you for your comments. We have added a statement to the key messages and Discussion section highlighting that further in-depth analyses are needed in specific clinical or topic areas to guide those</p> |



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| about social media in a whole population (not very much, it is about a selected group of people), and then how significant the results are for that group (not very, and not much data on what we cite as true social networking platforms). | who wish to implement a social media program for their constituents. |
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**VERSION 2 – REVIEW**

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| <b>REVIEWER</b>        | Ted Eytan MD MS MPH<br>Physician Director<br>Kaiser Permanente Center for Total Health<br>Washington, DC USA |
| <b>REVIEW RETURNED</b> | 09-Apr-2013  |

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| <b>THE STUDY</b> | <p>References: Elissa Weitzmann and TuAnalyze work (TuDiabetes is referenced in the body of the text but the research done using it is not referenced):</p> <p><a href="http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0019256">http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0019256</a></p> <p>My writeup of the article:</p> <p><a href="http://www.tedeytan.com/2011/07/28/8708">http://www.tedeytan.com/2011/07/28/8708</a></p> <p>The patients in the studies are not going to represent the general population, they will represent people who use social media in health issues, who probably have a much different readiness to change.</p> <p>Also, I think this sentence is still a little misleading:</p> <p>in September 2012, 72% of adult Internet users sought support and medical information online, 11 and in December 2012, 67% of Internet users were using social media.</p> <p>This implies that people are using social media for their health issues, which is not the case. If you read more carefully in Susannah Fox's work, the number is around the 25% range of people using social media for health.</p> <p>This is very important because in the talks I give, the audience makes this leap : using the internet + using social media + looking up online health info = using social media for health.</p> <p>The data do not bear this out, possibly because the difference between looking up info online and sharing it is quite vast. Note that this 25% number hasn't changed in 3 years - again, the thought is that without a private connection people don't want to share these details. That's why looking at the Weitzmann paper would be instructive, they are designing systems around this.</p> <p>Compare these numbers to 65% of Kaiser Permanente members are registered and actively using kp.org to communicate with their doctor - and this is for all members, not a self-selected group. Clearly people want to communicate about their health online, but in a trusted, safe place (with their doctor in our case). I am happy to provide this data if it adds context to the "why people really aren't using social media to talk about their health today."</p> <p>Overall the introduction is much stronger and clearer from the last version.</p> |
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| <p><b>RESULTS &amp; CONCLUSIONS</b></p> | <p>The abstract and the intro are much more clear than previously. The paragraph below seems like a bit of a backtrack from that.</p> <p>Much of the research to this point has focused on measures of communication between peers or on social support, but our sample also included trials measuring the impact of social media on health behaviour and status. With applications that directly target health outcomes, social media could present a cost-effective and wide reaching modality for administering certain types of interventions. This could be particularly advantageous when logistics make arranging in-person appointments difficult, for example in hard to reach populations, or when geography is an issue. These studies also suggest that social media has the potential to move beyond providing supportive online communities and could have widespread applicability and utility within the health care setting.</p> |
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### VERSION 2 – AUTHOR RESPONSE

References: Elissa Weitzmann and TuAnalyze work (TuDiabetes is referenced in the body of the text but the research done using it is not referenced):

<http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0019256>

My writeup of the article:

<http://www.tedeytan.com/2011/07/28/8708>

*We included studies of TuDiabetes in our review and while we do refer to the tool in the text, our intention with this scoping review was to provide a broad overview of the social media tools being used and their purposes, rather than delving into the research on any particular platform in detail.*

The patients in the studies are not going to represent the general population, they will represent people who use social media in health issues, who probably have a much different readiness to change.

*We have made this distinction on page 16.*

Also, I think this sentence is still a little misleading:

in September 2012, 72% of adult Internet users sought support and medical information online, 11 and in December 2012, 67% of Internet users were using social media.

This implies that people are using social media for their health issues, which is not the case. If you read more carefully in Susannah Fox's work, the number is around the 25% range of people using social media for health.

This is very important because in the talks I give, the audience makes this leap : using the internet + using social media + looking up online health info = using social media for health.

The data do not bear this out, possibly because the difference between looking up info online and sharing it is quite vast. Note that this 25% number hasn't changed in 3 years - again, the thought is that without a private connection people don't want to share these details. That's why looking at the

Weitzmann paper would be instructive, they are designing systems around this.

Compare these numbers to 65% of Kaiser Permanente members are registered and actively using [kp.org](http://kp.org) to communicate with their doctor - and this is for all members, not a self-selected group. Clearly people want to communicate about their health online, but in a trusted, safe place (with their doctor in our case). I am happy to provide this data if it adds context to the "why people really aren't using social media to talk about their health today."

*We have changed the sentence to read: "In 2011, looking for health care information was the third most common online activity<sup>10</sup> and in September 2012, 72% of adult Internet users sought support and medical information online.<sup>11</sup> In 2012, 67% of Internet users were using social media for any purpose<sup>12</sup> and 26% were using it for health issues.<sup>11</sup>" to clarify that online health seeking behaviour is not necessarily overlapping with social media use.*

Overall the introduction is much stronger and clearer from the last version.

The abstract and the intro are much more clear than previously. The paragraph below seems like a bit of a backtrack from that.

Much of the research to this point has focused on measures of communication between peers or on social support, but our sample also included trials measuring the impact of social media on health behaviour and status. With applications that directly target health outcomes, social media could present a cost-effective and wide reaching modality for administering certain types of interventions. This could be particularly advantageous when logistics make arranging in-person appointments difficult, for example in hard to reach populations, or when geography is an issue. These studies also suggest that social media has the potential to move beyond providing supportive online communities and could have widespread applicability and utility within the health care setting.

*This paragraph has been tempered, suggesting that these uses are dependent on evidence of effectiveness.*