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Perspectives of People With Cancer or Hereditary Cancer Risk on the Use and Value of Online Peer Support

Jill Holdren, MA,¹ Karl Surkan, PHD,^{1,2} Andrea Downing, BA¹

¹The Light Collective, Eugene, OR; ²Department of Women's and Gender Studies, Massachusetts Institute of Technology, Cambridge, MA

Purpose	People with cancer routinely seek information and support in peer groups online. While peer communities constitute a major component of the health care landscape, they exist in isolation from clinical and research institutions. This study aimed to explore how and why cancer patients utilize online peer support groups and how they might be improved.
Methods	A convenience sample of members of 6 closed Facebook cancer peer support groups (n=291) participated in an online needs assessment survey. We further conducted semi-structured interviews with 14 members and 6 moderator-patients, hand-coding the free-text responses and interview transcripts.
Results	Group participation was largely motivated by the desire to exchange information (79%) and to connect with others sharing the same condition (76%). Among study participants, 40% indicated they did not get information or support from any other online or offline organizations, 60% indicated they had few concerns with Facebook peer support groups, 84% indicated it was at least somewhat important that their health information and posts remain private, and 75% desired more input from experts in order to access evidence-based information and curb misinformation. About half wanted more group moderation, and moderators themselves expressed an urgent need for training and support.
Conclusions	While online peer groups are a commonly utilized care component for many people with cancer or hereditary cancer risk and serve as a primary source of condition information, many participants desired more expert involvement in and moderation of groups. Privacy and security of health information was another key need expressed. (<i>J Patient Cent Res Rev.</i> 2023;10:58-67.)
Keywords	peer support; ovarian cancer; breast cancer; online health communities; social media; health information sharing; Facebook group; moderation; privacy risks; misinformation

Peer information exchange and support is a significant part of the continuum of care for many people experiencing health challenges.¹⁻⁵ Increasingly, patients are connecting with others who share the same health challenges in communities on social media.⁶⁻¹⁰ Patients participate in online peer groups for a host of reasons, including an urgent need for information and support.^{11,12} Most research on peer support to date has focused on narrow research questions framed within a single patient community and been conducted by researchers outside of these communities. This patient-conducted, cancer-specific needs assessment study was intended to broadly capture patient experiences and perspectives on the role that online peer support groups

play in navigating cancer or cancer risk as well as how these groups can be improved.

The potential benefits of participating in health communities on social media are many, including an increase in self-efficacy/empowerment,^{11,13-16} greater patient engagement,¹³ increased health literacy,^{17,18} increased patient knowledge,^{11,19,20} democratization of access to knowledge,²¹⁻²³ and the ability to collectively organize.¹⁹ Moreover, many of these benefits may contribute to both lower health care costs^{24,25} and better health outcomes.^{26,27} There are also risks associated with participation in online groups. Most platforms are not equipped, governed, or regulated to ensure the safety and privacy of participants. Participation comes with risks of privacy violations²⁸⁻³² and exposure to medical misinformation and/or disinformation campaigns.^{33,34} Further, group moderators and administrators (themselves cancer patients) on most platforms do not receive the training, resources, or support necessary to ensure the quality of their forums, nor do they receive remuneration.

Corresponding author: Jill Holdren,
The Light Collective, 1430 Willamette St., Eugene, OR
97401 (jill.holdren@gmail.com)

Consequently, the scope and quality of moderation varies widely across different groups and platforms.

In 2018, in the wake of Cambridge Analytica, one of the authors of the work presented herein discovered a major vulnerability (SICGRL) in so-called “closed” Facebook groups, which put the privacy of group members at risk.³⁵ The authors, each a member of several ostensibly private cancer-related Facebook groups in which a tremendous amount of personal health information was shared every day, became concerned about the safety of participation in these groups and began thinking about new models for rights and governance for online patient communities. In collaboration with Dr. Robert Cook-Deegan at Arizona State University, the authors received a grant from the Robert Wood Johnson Foundation (RWJF) to explore issues of digital rights, privacy, and collective governance in online patient communities, an initiative that eventually grew into the nonprofit The Light Collective.

As part of that grant and in order to better understand participant perspectives on the use and value of online support groups, how groups can be improved, and perceptions of privacy and security, the project team conducted a community needs assessment consisting of the surveys and interviews discussed hereinafter.

METHODS

In this mixed-methods needs assessment study, we developed an anonymous survey including both multiple choice and free-text data (Online Appendix A), in collaboration with a biostatistician, a bioethics expert, and several patient advocates. The survey instrument was

piloted with a group of patient advocates in the hereditary cancer community and approved by the Arizona State University institutional review board. The survey was administered via Survey Monkey with IP address tracking disabled and could only be completed once by each unique IP address. Eligible participants were adults 18 years or older who were members in 1 or more of 6 closed (ie, content only visible to members) Facebook peer groups focused on hereditary cancer, ovarian cancer, and/or breast cancer. The survey invitation and link were posted periodically to these groups over a period of 6 months, beginning in January 2018.

The 6 group sizes range from a few hundred to several thousand (Table 1). We received 291 survey responses. We also conducted a total of 20 semi-structured interviews, 14 with group members and 6 with group moderators (all of whom were patients themselves). Member interview respondents were selected through additional posts on the Facebook groups asking for volunteer interviewees among people who had not taken the survey. Member-moderator interview respondents were selected through direct outreach to moderators of participating groups and through snowball sampling of these moderators. Interviews were conducted over Zoom and recorded. Responses from interviews were analyzed and are included, where relevant, in the discussion and labeled accordingly. Quotes from interviews and free text survey responses should not be viewed as generalizable; instead, they serve to provide anecdotal insights.

Survey data were analyzed using univariate statistical methods, most notably frequency tabulation for

Table 1. Online (Facebook) Peer Support Groups Surveyed

Facebook group	Focus	Approximate group size	No. of study participants
Beyond the Pink Moon	Breast (and ovarian) cancer	6500	45
BRCA Advanced Journal Club	Research relevant to hereditary cancer	3000	38
BRCA Commons	Data rights/issues in hereditary cancer	1000	12
BRCA Sisterhood	Living with a <i>BRCA</i> or other hereditary cancer gene mutation and associated cancers	10,000	182
My Breast Years Ahead	People living with cancer (primarily breast cancer) in Georgia area (Black-founded and run, largely Black membership)	350	11
Sisterhood of Ovarian Cancer Survivors	Living with ovarian cancer	6500	21

Notes: There is considerable overlap in group membership among BRCA and cancer groups. People were asked to indicate all groups in which they saw the survey, hence the total is greater than the 291 people who participated.

descriptive statistics of counts and proportions. All analysis was completed using R version 4.1.1 statistical package.³⁶ The free text and interview data were hand-coded by the project team, resulting in a code book divided into the following subject matter categories: Reasons for and benefits to participation; Needs/gaps/room for improvement; Privacy and security; Moderation; and Satisfaction with platform and engagement.

RESULTS

Demographics: Age, Health Status, Online Group Membership

Demographic and participation results are presented in Table 2. The majority (77%) of respondents were ≥40 years old, with nearly half of respondents (45%) between 40 and 54; 21% were in the 25–39 age bracket, and fewer than 2% were 18–24. More than half (56%) of respondents identified as survivors or people living with cancer. Another 47% identified as previvors (people who are at increased risk of cancer due to a hereditary cancer mutation but who have not yet developed it). Nearly 8% identified as family members or friends and about 3% as caregivers. Respondents could choose up to 2 primary reasons for being in the online group — for example, some people may have chosen “survivor/living with cancer” because they have one type of cancer but also “previvor” because they are at high risk for, but have not yet developed, breast cancer. Nearly 77% of respondents were active in their group(s) at least a few times a week, with almost 40% active every day. The majority (81%) had been a member of their respective group for at least 1 year, and 36% had been a member for more than 3 years.

Reasons for Participation

A primary question of this needs assessment was why people with cancer or at high risk of cancer participate in online support groups (Table 3); 79% of participants indicated they participated in online peer groups to receive and share information (also a common statement in free-text responses), including as a solution to limited time for questions during in-person medical appointments. Comments emphasized the importance of the information gathered on groups and their role in encouraging self-advocacy as well as the advantage of asking questions virtually to the global membership of the group, which facilitates real-time dialogue and information-sharing within a global community. Moreover, 64% of respondents stated they participated in part to provide support. Connecting with others with similar conditions (76%) also was deemed important. In free-text responses (and transcribed participant interviews), many expounded on the importance of the support they receive in groups in making them feel less alone, empowered to take action, or feel hope.

Almost 40% of respondents indicated they did not get information or support from any other online or offline organizations and used their support groups as a primary source, if not the primary source, of information about their condition (other than, presumably, their providers). Comments indicated some respondents participated in their group to follow the latest research on their condition.

Room for Improvement

Participants were asked to indicate the importance in online groups (or lack thereof) regarding factors, including more professional input, better privacy and

Table 2. Demographics, Membership, Participation

Age (n=288 responses)				
<25 years	25–39 years	40–55 years	>55 years	
1.7% (n=5)	21.2% (n=61)	45.1% (n=130)	31.9% (n=92)	
Identify as [choose up to two primary identities for participation in the group] (n=288 responses)				
<u>Survivor/Person with cancer</u>	<u>Previvor (never had cancer but at high risk)</u>	<u>Caregiver</u>	<u>Family member/friend</u>	<u>Other</u>
55.9% (n=161)	47.2% (n=136)	2.8% (n=8)	7.6% (n=22)	2% (n=6)
How long have you been a member of the group? (n=287 responses)				
<6 months	6–12 months	1–3 years	>3 years	Other
3.6% (n=11)	14.6% (n=44)	45.4% (n=137)	36.1% (n=109)	0.3% (n=1)
How often do you participate (read, like, post)? (n=283 responses)				
<u>Every day</u>	<u>A few times/week</u>	<u>A few times/month</u>	<u>Very rarely*</u>	<u>Other</u>
39.6% (n=112)	36.8% (n=104)	16.3% (n=46)	6.4% (n=18)	1.1% (n=3)

*Combination of two answer categories: “almost never” and “a few times a year.”

Table 3. Results From Needs Assessment Survey (n=291) and Semi-Structured Interviews (n=20)

Why do you participate in the group? Check all that apply. (n=287 responses)					
<u>Receive emotional support</u>	<u>Exchange/ receive information</u>	<u>Connect with others with my condition</u>	<u>Get/share recs</u>	<u>Provide support</u>	<u>Other</u>
60.6% (n=174)	79.4% (n=228)	76.3% (n=219)	65.2% (n=187)	64.1 (n=184)	5.6% (n=16)
How important are each of the following to improve online support group experience?					
	<u>Very important</u>	<u>Somewhat important</u>	<u>Don't know</u>	<u>A little important</u>	<u>Not at all important</u>
More moderation, n=283	15.6% (n=44)	24.4% (n=69)	24.7% (n=70)	14.5% (n=41)	20.9% (n=59)
Ability to use pseudonym, n=282	3.6% (n=10)	18.8% (n=53)	32.6% (n=92)	12.4% (n=35)	32.6% (n=92)
More expert input, n=286	33.9% (n=97)	40.6% (n=116)	8.0% (n=23)	10.5% (n=30)	7.0% (n=20)
Better privacy, n=286	31.8% (n=91)	25.9% (n=74)	15.7% (n=45)	11.5% (n=33)	15.0% (n=43)
More engagement, n=282	19.5% (n=55)	27.3% (n=77)	21.6% (n=61)	12.8% (n=36)	18.8% (n=53)
Do you have concerns or frustrations with Facebook online support groups? (n=283 responses)					
No	61.5% (n=174)				
Yes	38.5% (n=109)				
If Yes to above, how concerned are you about the following?					
	<u>Not enough moderation or moderators. n=176</u>	<u>People outside learning about condition. n=193</u>	<u>Info about me might be shared by Facebook. n=193</u>	<u>Hackers might get access to my info. n=193</u>	<u>Behavior of other people in group. n=190</u>
Very concerned	2.3% (n=4)	18.7% (n=36)	46.1% (n=89)	34.2% (n=66)	9.5% (n=18)
Somewhat concerned	27.2% (n=48)	23.8% (n=46)	26.9% (n=52)	29.5% (n=57)	28.9% (n=55)
Not very concerned	40.3% (n=71)	29.0% (n=56)	17.6% (n=34)	23.8% (n=46)	40.5% (n=77)
Not concerned at all	30.1% (n=53)	28.5% (n=55)	9.3% (n=18)	12.4% (n=24)	21.1% (n=40)
Have you considered not participating in online groups because of privacy concerns? (n=286 responses)					
No	62.9% (n=180)				
Yes	37.1% (n=106)				
If you have considered not participating in online groups due to privacy reasons, what are the primary reasons you remain? Check all that apply. (n=144 responses)					
Don't know of other option	45.8% (n=66)				
Don't want to lose peers and relationships	44.4% (n=64)				
Don't believe any other platform will be better than Facebook	39.6% (n=57)				
Don't want to lose the history contained in the group	25.7% (n=37)				
Do you participate in other online support groups outside of Facebook? (n=287 responses)					
No	77.4% (n=222)				
Yes	22.6% (n=65)				
Do you regularly use any other cancer or other specific health issue-oriented organizations for information or support online or offline? (n=285 responses)					
Yes	61.7% (n=174)				
No	39.5% (n=111)				

security, more/better moderation, and ability to use a pseudonym, for improving their online support group experience. Most participants (75%) indicated having more professional input in the groups was somewhat to very important, with 85% saying this improvement was at least a little important. Free-text response survey comments emphasized the importance of scientifically based information. A few participants expressed concern that researchers permitted to partake in groups could be focused on recruiting patients for studies rather than contributing to greater health literacy.

Moderator interview responses on participation of medical experts varied. While most moderators invited and encouraged participation of experts in their groups, negative experiences from including outside experts also were reported. One moderator of an invitation-based breast cancer group stated that only medical professionals who also have breast cancer are permitted to join.

Privacy and Security

The second most commonly identified need for improvement was better privacy and security; 58% of respondents indicated better privacy was at least somewhat important to them. While 62% of respondents said they did not have concerns or frustrations (not limited to privacy and security) with Facebook groups, 67% of all respondents still answered the question, “If you have concerns about Facebook groups, how concerned are you, if at all, about the following?” Of this subset, 73% were at least somewhat concerned that their personal health information might be shared by Facebook without their consent, 64% were at least somewhat concerned that hackers might access their information and use it against them, and 43% were concerned that people outside of the group might learn of their health issues. When survey participants were asked how concerned they were about keeping their health information and posts private, only 16% were “not concerned at all,” 40% of respondents were “very concerned,” and 37% of respondents had considered not participating in online groups due to privacy concerns.

In free-text responses, several participants highlighted that their concern about privacy and security arose from worries about losing access to certain types of insurance or care if their health information were to be exposed, a view echoed in several of the moderator interviews. When asked what are the primary reasons for remaining in online groups despite concerns about privacy, 46% of people said they did not know of another option for online peer support, 44% reported they did not want to lose the peers and relationships they had developed in their groups, 40% did not believe any other platform

would be safer than Facebook, and 26% were concerned about losing the history contained in their group.

All moderators interviewed were concerned about the risks to privacy and stated that they work to identify ways their communities can exist without being vulnerable to harm and exploitation. While all moderators and most member interviewees were aware of Facebook data breaches and the real possibility of other privacy violations, most also believed that the benefits of participation outweighed the risks.

Moderation of Online Groups

Just 30% (n=52) of the 192 respondents who indicated they had some concerns or frustrations with a Facebook group indicated they were at least “somewhat concerned” about moderation. However, in a subsequent question asking how important more moderation or moderators was to improving their experience, 55% (n=157) of 286 respondents stated that more moderators or moderation was at least a little bit important. Some respondents shared via free text that more diversity among moderators would be beneficial. One interviewed moderator, a woman in the 40–54 age bracket, recounted that she founded her group precisely because she did not see group leaders of existing groups who looked like her.

Moderators interviewed indicated that they need help in the form of training, more co-moderators, and ongoing support, including the need for training in grief counseling. All moderators brought up working long, uncompensated hours, the weight of responsibility they felt for their communities, and the need for more support.

Satisfaction With Platform and Engagement

Nearly 60% of survey respondents indicated that more engagement from other group members was at least a little bit important to improving their group experience. About 35% of survey respondents believed that it was at least a little bit important that people are able to use pseudonyms when participating in online peer support groups in order to protect their identities, a feature not supported on Facebook. Finally, numerous respondents identified Facebook’s frequent censorship of mastectomy, reconstruction, and other similar types of photos as a major concern and frustration.

DISCUSSION

Benefits of Online Peer Support

The formal health care system plays a necessary role in providing care to people with a range of health conditions. It does not provide the level of information and support that many people with serious health conditions like cancer require to make decisions, cope with pain and

treatment side effects, manage psychosocial impacts of their disease, and more.⁵ As a result, people experiencing health challenges frequently gather in online peer groups to seek the information and support they need.^{11,12}

There are many reasons why people seek to connect with peers when confronting a health challenge. In the case of rare diseases, patients or their caregivers desperate to understand their conditions often can learn more from crowdsourcing information in groups of others who share their experience than they can from providers or published research.³⁷⁻³⁹ Many of these patients have fallen through the cracks of the medical system with misdiagnoses, uninformed providers, and a dearth of even basic information about their condition.⁴⁰⁻⁴⁶ Even in cases of more well-studied conditions, a single provider is unlikely to have witnessed the full spectrum of the condition or be abreast of all current research. In a peer support group numbering thousands or more, there are likely to be both people who have experienced something similar *and* people who are aware of the latest research and are willing to share it. Moreover, there are important differences between the lived experience of a condition and the experience of being even the most knowledgeable health care provider for people with that condition. Those differences matter, and participants in this needs assessment study expressed clearly their need to engage with others who had shared experiences.

Further, when people are diagnosed with a life-changing condition, their need for information and social support is intensive for a period of time. They may see their provider periodically, but as they navigate questions of surveillance, surgeries, treatments, and side effects, they may wish to engage daily with a community that can provide both answers and support. Disease-specific communities on social media can fulfill these needs.⁴⁷ Many respondents talked about their urgent need for information and support as they managed their cancer or hereditary cancer risk. One interviewed cancer survivor [woman, age 25–39] stated:

“There are so many instances where I had lots of questions, and my doctors did not have time to answer. All of my questions were answered within the group.”

A previvor [woman, age 40–54] stated in an online survey open-ended response:

“Being part of this support group gave me the courage to follow through with surgeries. I didn’t feel alone.”

Another previvor [woman, age 25–39] noted in an online survey open-ended comment:

“[Group X] was the best, most valuable resource I had to navigate through one of the toughest times of my life.”

I would be lost without being able to search for certain surgery topics and ask people for input and opinions.”

Online patient communities with membership in the thousands or tens of thousands offer other benefits as well; they are places where a democratization of information can happen²¹⁻²³ and where patient engagement can increase.⁴⁷ One survivor [woman, age 25–39] commented in an online survey open-ended response:

“The exchange of information in this way is invaluable. There’s no embarrassment associated with having to ask tough questions in person, and I’m able to get information from all over the world.”

People seeing providers at the best hospitals in the world share treatment protocols, research, and resources with people who may be in rural or otherwise underserved areas. People who understand genetic risk, or the details of a surgery procedure, share that information with people who do not. Even patients at the best facilities in the world can benefit from the collective knowledge and experience of many. One previvor [woman, age 25–39] stated during her interview:

“I was at one of the premier hospitals for BRCA care in the world, but had I not been in online BRCA support groups I wouldn’t have learned a few years ago that it was possible to get direct-to-implant surgery. And, I wouldn’t have known that salpingectomy was a thing. My physicians at my top hospital were not bringing those options up. Participation in these groups teaches you to advocate for yourself.”

Risks of Online Peer Support

Participation in online groups also poses risks of harm, including risk to privacy and of exposure to misinformation and disinformation. While most participants were either not aware of or not concerned about privacy, risks to privacy and security posed by sharing information on social media are substantial.⁴⁸⁻⁵⁰ Notably, many who were aware of privacy issues shared that their need for information and support was so acute that it outweighed worries about possible risks to participation, a phenomenon that has been noted in the literature.⁵¹ One interviewed previvor [woman, age 40–54] noted:

“If I had any choice I wouldn’t be on Facebook. What has become clear is that almost all fora have moved to Facebook and if you want access to that information you have to be there too.”

Events in recent years have demonstrated unequivocally that social media can be rife with misinformation and disinformation.⁵²⁻⁵⁵ While the groups in this needs assessment did not have significant problems with

misinformation or disinformation due to dedicated moderators, some participants did express concerns about misinformation in their groups. The vast majority of study participants expressed interest in greater expert participation and sharing of research, as well as high-quality moderation in their online groups, both of which would serve to increase the quality of information shared and likely improve health literacy among members. One online survey respondent [survivor, woman, age 40–54] noted:

“I really appreciate being able to connect and read about what concerns me [and] about the newest research status on breast cancer — great job from the moderator! It also lets me get the latest news on the new research.”

Opportunities for Researchers, Providers

Future research into understanding better whether and how participation in online peer support communities improves, worsens, or does not impact specific outcomes of interest and what elements/structures/organization of peer support groups facilitate or hinder positive outcomes would be beneficial given the enormous role these communities play in the lives of many people experiencing health challenges like cancer. Further, supporting the development of systems and partnerships that ensure that patients’ information and support needs are met without risk of exploitation or harm should be a priority. Innovative approaches that establish partnerships between health care and research institutions and online patient communities should be explored.⁵⁶ Agreements might include moderator training in such areas as disease-specific science, grief and loss, and facilitation; co-production of research; moderator compensation; participation of clinicians and researchers on an “on-call” basis; and safe, nonexploitative platforms on which to convene.

One solution of particular interest to the authors is the establishment of patient-governed civic data trusts.^{57,58} By establishing community- and data asset-specific civic data trusts, communities can position themselves to negotiate mutually beneficial collaborations with other entities, including clinical and research institutions and, importantly, technology companies. The benefits to articulating and formalizing partnerships with health care and research institutions could be substantial for patient-driven research, scientific progress, improved health outcomes, improved access to peer support for people from historically excluded groups, and increased patient literacy and engagement. Benefits to successful negotiations with technology companies could include greater protections of health information with fewer risks of exploitation and harm.

Limitations

There are a number of limitations to these study findings. Survey respondents and member interview participants may not be representative of the user population in each group, and their views on peer group use may differ from nonparticipants. In addition, the response rate was low, which may in part reflect the structure of Facebook feeds in which messages disappear from view very quickly. Respondents were potentially persons most concerned about the issues discussed. Some populations may have been underrepresented in the groups we surveyed, a common problem in many social media groups.³⁷ Similarly, selection bias may have occurred in identifying moderator interview participants. Finally, not all people with cancer or other health conditions have access to the internet or the time or resources to participate in online groups (or in surveys and interviews, in particular). Understanding the information and support needs of all individuals experiencing health challenges and how to address them is an important area for research and policy.

CONCLUSIONS

In the past decade, online peer support has become an important component of care for many people with cancer or hereditary cancer risk to share their experiences, their knowledge, and their support. While our findings suggest the potential benefits of patient participation in online health communities is significant, there is also concern about the real risks of harm in the forms of privacy breaches, unethical data use, and exposure to misinformation or disinformation (with consequences for health care institutions and both individual and public health). Many participants in this study appear unaware of or unconcerned about the risks posed, while those who are concerned believe their information and support needs are so important that fulfilling them via online groups outweighs the risks. The vast majority of study participants expressed a clear interest in the inclusion of more medical experts in their peer support groups and a strong desire for vetted scientific information. Many participants also recognized the value of good moderators and moderation in curbing bad behavior, correcting misinformation/disinformation, facilitating conversations and engagement, and providing credible information.

Much work needs to be done to better quantify the benefits or harms people experience from participating in online patient communities and how variations in platform, leadership, moderation, professional expertise, facilitation strategies, and other factors contribute to patient outcomes. In the meantime, every day millions of patients flock to online communities seeking information and support. Solutions that simultaneously

explore important research questions while supporting the development of safer, accessible, nonexploitative, community-governed, evidence-based environments in which patient communities can convene (eg, the establishment of patient-governed civic data trusts) are urgently needed.

Patient-Friendly Recap

- People with cancer routinely seek disease-related information and support in peer groups on social media despite the potential for data breaches, misinformation, and disinformation.
- To better understand patient perspectives on the value of online peer groups, how groups might be improved, and concerns surrounding privacy, data security, and accuracy, researchers qualitatively analyzed feedback from members of six cancer peer support communities.
- Survey respondents (n=291) and interviewees (n=20) stressed that online peer support was important enough to outweigh their concerns about participating. They expressed a clear interest in having more participation by medical experts and greater privacy and security.

Author Contributions

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Author Contributions

Study design: Holdren, Downing. Data acquisition or analysis: Holdren. Manuscript drafting: all authors. Critical revision: Holdren, Surkan.

Conflicts of Interest

None.

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