

# Results of a Survey on the Roles of Lay Representatives on Health Research Committees



***Referencing of the report should be as follows:***

O'Hara, P., Schmaltz, R., Arts, K., Morrison, M., Bishop C., Ermel, D., Ghent, H., Needham, J., Eugene Vayda, E., Results of a Survey on the Roles of Lay Representatives on Health Research Committees, Toronto: Canadian Cancer Action Network (Lay Representation Working Group) March 2015.

Access to the March 2015 report is available on the Canadian Cancer Action Network website:  
(<http://www.ccanceraction.ca/>)

***Copyright***

This report is copyrighted by the Canadian Cancer Action Network (CCAN). The report herein may not be reproduced without the express written permission of CCAN. CCAN reserves the right at any time, and at its sole discretion, to change or revoke this authorization.



## ACKNOWLEDGEMENTS

The report, **Results of a Survey on the Roles of Lay Representatives on Health Research Committees** is an initiative of the Canadian Cancer Action Network.

Production of this report has been made possible through financial support from the Canadian Partnership Against Cancer and Health Canada. The views expressed herein represent the views of the Canadian Cancer Action Network and do not necessarily represent the views of Health Canada.

The survey was conducted by Dr. Paddi O'Hara and Dr. Rodney M. Schmaltz of O'Hara Consulting, working in close collaboration with the Canadian Cancer Action Network Lay Representative Working Group. The report was prepared by O'Hara Consulting. The cover was designed by the Canadian Cancer Action Network Secretariat.

The Working Group was chaired by Marjorie Morrison, Chief Executive Officer, Canadian Cancer Action Network. Administrative support was provided by Fay Bennie.

The Canadian Cancer Action Network wishes to gratefully acknowledge the contribution of the Lay Representation Working Group members: *Karen Arts; Carol Bishop; Diana Ermel; Helen Ghent; Dr Paddi O'Hara; Judy Needham; Dr. Rodney M. Schmaltz; Eugene Vayda.*

Further, the Canadian Cancer Action Network wishes to gratefully thank all those who informed the survey and report outcomes through their respective participation in the initiative.

For more information about this funded initiative of the Canadian Cancer Action Network (Stakeholder and Membership Engagement portfolio), or the work of the Canadian Cancer Action Network, please call 416.619.5784 or visit [www.ccanceraction.ca](http://www.ccanceraction.ca)

## **WE ARE INTERESTED IN YOUR FEEDBACK!**

An initiative of the Canadian Cancer Action Network, this report is the result of the dedication and work of a small group of people, many of whom are lay representatives on health research committees. We believe that it offers important information about the role of the lay representative in Canada and will help to encourage and support the voice of the public in research.

If you would like to comment on the report, share your experiences and observations about lay representation, provide policies, guidelines or best practices having to do with lay representation on research committees, or suggest ways in which the Canadian Cancer Action Network (working collaboratively with other key stakeholders in Canada) may continue to encourage and support the role of lay representative in research, please contact the lead author:

**Paddi O'Hara**

*O'Hara Consulting*

**942 Kingsmere Avenue**

**Ottawa, Canada K2A 3K4**

**Email: [PaddiOHara@rogers.com](mailto:PaddiOHara@rogers.com)**



*O'Hara Consulting*

## **Table of Contents**

<b>Table of Contents</b>	<b>1</b>
<b>Acronyms</b>	<b>2</b>
<b>Executive Summary</b>	<b>3</b>
<b>Introduction</b>	<b>5</b>
<b>Methodology</b>	<b>6</b>
<b>Results</b>	<b>9</b>
<b>Discussion</b>	<b>17</b>
<b>Conclusion</b>	<b>22</b>
<b>References &amp; Resources</b>	<b>25</b>

## Acronyms

3CTN	Canadian Cancer Clinical Trials Network
CCAN	Canadian Cancer Action Network
CCS	Canadian Cancer Society
CCSRI	Canadian Cancer Society Research Institute
CIHR	Canadian Institutes of Health Research
CPAC	Canadian Partnership Against Cancer
CSPA	Canadian Skin Patient Alliance
LR	Lay Representative
N2	Network of Networks
NA	Non-affiliated
NLR	Non-Lay Representative
NS	Non-scientist
REB	Research Ethics Board
SD	Standard Deviation
SPOR	Strategy for Patient-Oriented Research
TCPS	<i>Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans</i>

## Executive Summary

There is a growing realization that being a research participant is not the only way for a *civilian* (i.e. someone not directly involved in the conduct of research) to be part of such investigative endeavours. This report describes a project to create, conduct and analyse a survey of both lay and non-lay representatives on various types of health research committees for CCAN in support of the activities of their Lay Representative Working Group.

The online survey was hosted on the Qualtrics platform through MacEwan University and the questions were developed as a result of an earlier literature review on the topic by the authors as well as extensive discussions with the CCAN Lay Representative Working Group composed of experts on this topic. A convenience sample was identified and contacted with the help of three organizations, that is, CCAN, 3CTN and N2. Although this did not allow for the calculation of a response rate it was felt that the number of participants (n=107) which was almost evenly split between the lay and non-lay groups was sufficient for the purposes of this quality improvement project.

Although there was a striking similarity between the answers provided by the groups when responding to *forced choice* items, the language used for the open-ended items tended to be less scientific and more patient-centred for the lay representatives than the non-lay representatives.

Slightly different profiles emerged for the groups, with lay respondents being older and more likely to be retired than non-lay respondents. More than twice as many of the non-lay respondents were health care providers as the lay respondents. However, it is interesting to note that almost one-fifth of the lay respondents *did* identify themselves as health care providers.

Importantly, there was a high degree of agreement between the way non-lay representatives saw their lay colleagues and the way lay representatives see themselves. It would appear that there is almost universal agreement in the value of having lay representatives on health research committees.

The term “community representative” or “community member” was not only the most commonly used name to identify lay representatives by both groups but it was also preferred

amongst lay and non-lay representatives. Inevitably the question of what “community” does the lay representative serve is considered more important than the label assigned to this role.

It was suggested that the term “Community Representative” could be augmented with the phrase “and Lay Voice” in order not to lose the importance of bringing a different perspective to the research process.

Almost every respondent indicated that education is a huge part of the solution to having a well-informed and productive lay representative. Not only do lay – as well as non-lay – committee members need *ongoing* education but training needs to come from multiple sources including online, face-to-face mentoring, workshops and other forms of instruction.

One of the themes often brought up by lay representatives was the tremendous time commitment involved in their role (including the need to read and understand a lot of scientific material). Many respondents suggested that it could be beneficial to have at least two lay representatives on any given committee so that the burden would not always fall on one pair of shoulders. The report also includes other suggestions to address this issue.

Finally, all of the elements described by our survey respondents - both lay and non-lay representatives - have been captured in the draft “Framework for Lay Representation”<sup>1</sup> that was included in the survey and originally developed by 3CTN. As one of the lay respondents stated succinctly, “It looks good. I want in.” Now that the conceptual structure of the Framework has been validated it is time to expand on what it means and how it can be used. Once this lay representation “road-map” is completed it is hoped that it can be of tremendous use to health research committees that would like to optimize the use of lay representation in their ranks.

---

<sup>1</sup> Please note that the actual Lay Representation Framework (a flowchart which illustrates what we think are the most the important elements of incorporating lay representation into committees) is not included in this document as it is still under development. It is hoped that when this “Framework” is completed and published it will be a practical aid to organizations that are looking to either develop or boost the input of lay people on their committees.

## Introduction

### Purpose of Report

In 2014 the Canadian Cancer Action Network (CCAN) contracted with O'Hara Consulting to conduct a quality improvement project entitled, 'An Examination of the Roles of Lay Representatives on Health Research Committees.' This online survey was carried out on behalf of the CCAN Lay Representation Working Group by Dr. Paddi O'Hara and Dr. Rod Schmaltz.

### Background

In 2013, the Canadian Cancer Clinical Trials Network (3CTN) – a pan-Canadian initiative to improve the efficiency and quality of clinical trials in Canada – established a “Lay Representative Working Group” to explore and identify means by which to develop and enhance meaningful participation of lay representatives in research activities. In 2014, CCAN – which has as part of its mission statement the desire to support a patient/caregiver perspective in the health-care system – took over the leadership of the Lay Representative Working Group.

There is a growing realization that being a research participant is not the only way for a *civilian* (i.e. someone not directly involved in the conduct of research) to be part of such investigative endeavours. Of course even the term “lay representative” is not sufficient to encompass the wide variety of roles used to describe the roles of civilians on research committees. This list of terms includes:

- public member
- associate
- community representative or member
- a non affiliated person from outside the organization but who still uses the services of the organization
- unaffiliated member
- outside consultant
- outsider
- lay person
- non-affiliated
- non-scientist
- patient representative
- patient advocate

While not exhaustive, the list is based on previous research (Schmaltz & O’Hara, 2013) and serves as a guide to how different organizations throughout the world define lay representation.

There are also a growing number of health research advisory boards, ethics review panels, hypothesis/research-question generating committees and knowledge translation groups – just to name a few examples – that are seeking the input of lay representatives. The question then becomes, how are such representatives identified, recruited, utilized and even rewarded for their contribution? While it is apparent that the idea of finding new and useful ways of incorporating the input of the public in research is still in its formative stages (as evidenced by the limited availability of data, particularly in a Canadian context) it is clear that in more and more research settings thought is being given to how best to encourage the participation of lay representatives. There is also concern about how lay representatives understand and view their roles (e.g., in terms of feeling that they are making a useful contribution) as well as how their colleagues understand and view the roles of lay representatives.

As a first step towards addressing the paucity of Canadian data on lay representation, a survey was administered to individuals currently serving as lay representatives and their “non-lay” representative counterparts. Respondents represented a range of various types of health research committees with a particular emphasis on cancer research groups. This report describes the project to create, conduct and analyse such a survey for CCAN in support of the activities of the Lay Representative Working Group.

## **Methodology**

### **Participants**

There were two types of participants needed for this survey: lay representatives on health research committees and non-lay representatives on health research committees. It should be noted that although the term “committee” is used throughout this report, it is meant to refer to any health research entity and could, therefore, include boards, clubs, organizations, steering groups, working groups etc. The focus of these committees could be advisory, capacity building, collaboration, ethics, interpretation of results, peer review, hypothesis/question-generating, recruitment, scientific review or any other aspect of health research. The type of health research that was the focus of the committee could be cancer (given the sponsorship of this

project by CCAN) or any other type of disease or health condition. In summary, the inclusion criteria for participants were that:

- The participants must be lay or non-lay members of a health research committee and able to identify themselves as such.
- The committee must have (or had) at least one lay representative.
- The committee had to be involved in some stage of the *research* process (in other words, simply being a patient advocacy group would not meet the criterion for participation in this project).
- The committee had to have a focus on some type of *health* research, that is, involving a disease, condition, injury etc.

In order to identify health research committees where potential participants met the above requirements, email lists of member organizations under the auspices of CCAN, 3CTN and N2 (Network of Networks) were collected. While there was some overlap in these lists, it allowed a large number of organizations to be contacted in a brief period of time (i.e. October and November 2014):

- CCAN: 97 organizations
- 3CTN: 50 organizations
- N2: 75 organizations

### **Consideration of Sample Size**

With an online survey of this type it is impossible to gauge the response rate which is defined as the number of respondents who completed a questionnaire divided by the total number of respondents who were asked to participate. It is also true of this particular project that while we know the number of umbrella organizations ( $n=3$ ) which sent a request to participate to an approximate number of member organizations ( $n \approx 200$ ), there is no way of knowing how many health research committees are in some way attached to these member organizations (and would have lay representatives) or how many health research committees were actually contacted by these member organizations. In the end, however, the authors suggest that the convenience sample reflected in the results of this survey is suitable for the purposes of this quality improvement project because:

- The two sub-groups (lay representatives  $n=56$  and non-lay representatives  $n=51$ ) are almost equally reflected in the sample;
- The data are being used to describe the issues and provide insight into the topic of lay representation rather than for statistical inference; and

- Inspection of the data support the claim that there is sufficient “information richness” to satisfy the objectives of the project.

### **Procedure**

Two versions of an online survey entitled, ‘An Examination of the Roles of Lay Representatives on Health Research Committees’ were created using the Qualtrics online survey platform through MacEwan University, Edmonton, Alberta. The versions of the survey were almost identical, differing only in that they addressed the issues from either the perspective of the lay or the non-lay representative. The questions were developed as a result of an earlier literature review on the topic (Schmaltz & O’Hara, 2013) as well as extensive discussions with the CCAN Lay Representative Working Group composed of experts on this topic. The survey was a combination of quantitative and qualitative items with most of the questions being multiple choice (some allowing more than one response) and a few items requiring a text response. After pilot-testing the surveys on a small group of lay and non-lay health research committee members, some items were simplified and/or shortened.<sup>2</sup>

The data collected through the online surveys were completely anonymous, that is, there was no gathering of directly identifying information (e.g., personal identifiers such as name or social insurance number, or electronic data such as IP or email addresses), indirectly identifying information (e.g., date of birth, place of residence or unique personal characteristics) and no coded information that would allow re-identification of individuals. Results are presented on amalgamated data only.

The umbrella organizations (CCAN, 3CTN & N2) were sent an email letter of introduction concerning this project with an attached letter of explanation and invitation to participate in the online survey concerning lay representation. It was then up to these organizations to identify appropriate health research committees within or connected to them in order to target lay and non-lay representatives of health research committees.<sup>3</sup> The initial email introducing

---

<sup>2</sup> Consultation with ethics experts confirmed that it would not be necessary to acquire clearance from Research Ethics Boards before collecting any data for this quality improvement project. According to Article 2.5 of the TCPS2, “Quality assurance and quality improvement studies, program evaluation activities, and performance reviews, or testing within normal educational requirements when used exclusively for assessment, management or improvement purposes, do not constitute research for the purposes of this Policy, and do not fall within the scope of REB review.”

<sup>3</sup> The consultants were cognizant of Canada’s recently enacted anti-spam legislation which could limit bulk commercial electronic messages (CEMs); however, it was felt that this request to participate in an online survey did not qualify as a CEM which is a “message that encourages participation in a commercial activity, including, but not limited to: offering, advertising or promoting a product, a service or a person.”

this project was followed by weekly reminders to continue to identify health research committees and distribute the information about this project. Most importantly, this information contained two links to the two versions of this online survey: one for lay representatives and one for non-lay representatives of health research committees.

## **Results**

### **Participants**

One hundred and seven participants completed the survey. Of these, 56 (52.3%) were lay representatives (37 female, 19 male) and 51 (47.7%) were non-lay representatives (36 female, 14 male, with one respondent who chose not to specify). The majority of lay representative participants were between the ages of 65-74 (33.9%), while the majority of non-lay representative participants were between the ages of 55 and 64 (33.3%).

### **Description of Membership and Committees**

Twenty-two (43.1%) of the non-lay representative participants and 11 (19.6%) of the lay representative participants were health care providers. Only two (3.9%) of the non-lay representative participants who completed the survey were retired, while 21 (37.5%) of the lay representatives were retired.

When asked how to “best describe” their committee, respondents gave a wide variety of answers. Many non-lay representatives identified something to do with grant review/competition as well as advisory panels. In addition to those functions, lay representatives also described their committees in terms of bringing a patient voice to the research process. There were 18 (35.3%) non-lay representatives and 31 (55.4%) lay representatives on committees with a cancer focus.

The average number of members in the committees described by non-lay respondents was 12 (ranging from 8 to 17, SD=2.6) and the average number of lay representatives on these committees was 1.8 (ranging from 1 to 3, SD=0.7). The average number of members in the committees described by lay respondents was 13 (ranging from 4 to 24, SD=4.9) and the average number of lay representatives on these committees was 4.1 (ranging from 1 to 15, SD=3.6).

### **Committee Roles**

There was a wide range of roles that respondents identified in order to describe their committees in greater detail. Both lay and non-lay respondents tended to identify scientific review, ethics review and peer review as part of their committee mandate.

On the other hand, there was a difference in the terms self-selected by respondents to describe “other” roles played by their committees. While non-lay representatives seemed to interpret their committee in a more technical or scientific light (e.g., liaison between research staff and research upper management, quality assurance services and clinical trial operations) the lay representatives saw their committees in terms of bringing a patient perspective to the research process and identifying with the values of the research participants.

### **Terms Used to Describe Lay-Representatives**

Both lay representatives and non-lay representatives reported that the terms “community representative” or “community member” are the most commonly used to identify lay representatives.

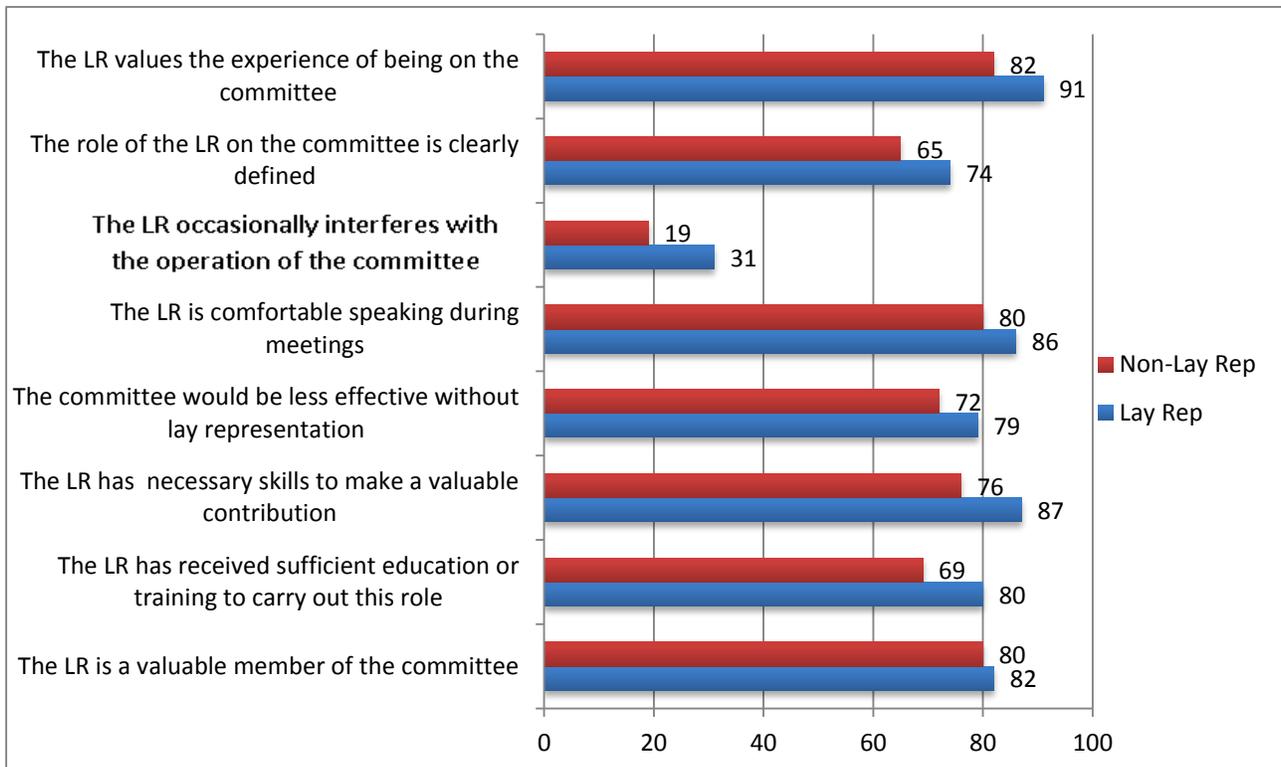
When asked which term *should* be used, the majority of both lay representatives and non-lay representatives again chose the term community member/representative.

### **Recruitment**

The majority of non-lay representatives reported that they were either unsure of how lay representatives were recruited, or reported that lay representatives were recruited through current members. Lay representatives overwhelmingly reported that they were either recruited from health related organizations or from recommendations of committee members.

### **Perspective on Lay Representation from Non-Lay Representatives and Lay Representatives**

Participants were asked to indicate how much they agreed or disagreed with statements regarding the value of lay representatives, using a scale of 0 (Strongly Disagree) to 100 (Strongly Agree). For the most part, both non-lay representatives and lay representatives appeared to have positive opinions of lay representation (see Figure 1).



**Figure 1: Value of Lay Representation**

**Non-Lay Representative Perspective on Education and Training Provided to Lay Representatives**

Twelve respondents were not sure how training was handled and two stated that there was no formal training for lay representatives. Other non-lay respondents suggested that training was provided by the following:

- Chair and/or the coordinator of the committee
- One-on-one, or group workshops
- Provided with a handbook
- Provincial and national workshops, as well as in-house training
- On-line tutorial
- 2 hour presentation prior to reviewing first protocol
- TCPS II tutorial
- Initial orientation sessions, followed by articles provided to board members throughout the lay representatives term

### **Lay Representative Perspective on Education and Training Provided**

Some respondents reported that they had sufficient expertise (e.g., patient experience, graduate training, previous committee experience) when joining the committee and, as such, did not receive additional training. Several respondents reported that they received little/no training, or that they were self-taught.

Training generally fell into the following categories:

- Orientation/training session prior to first meeting
- Training provided by researchers/clinicians/board of directors/peers
- Provided with reading materials/online tutorials (e.g., role expectations, training manuals)

### **Lay Representative Perspective on the Need for Further Education/Training**

Forty-four participants responded to this question. Twelve participants indicated that they did not need further education or training; however, many respondents reported the need for continued education. Of note, one respondent stated, “Canada needs cross-ministerial training (probably by province) to empower family members/public to understand their role as participants in policy-making and research priority setting. Something like Partners in Policymaking. Let's get this going!”

The rest of the responses generally fell into the following categories:

- Stated need for further training, but not sure exactly what this would entail
- Ongoing training
- Science education/clarification of medical terminology
- Act as an observer prior to joining the committee
- Clarification on committee’s process, mission, values, strategic priority
- Role clarification

### **Perceived Benefits of Lay Representatives Representation by Non-Lay Representative Members**

For the most part, non-lay representatives were very positive regarding the benefits of lay representation on their committee. For example, one respondent reported, “If it were not for the lay members, excellent grants with novel and innovative approaches toward understanding

and treating cancer would not have been funded.” Respondents often focused on the role of lay representatives to keep the committee focused on real world issues, and to add the patient/participant perspective.

Responses generally fell into the following categories:

- Valuable to have patient/participant perspective (e.g., perspective of a “normal” person, objective assessment of value of research)
- Enhances research (e.g., richer survey tools, community oriented research questions, grounds discussion in the context of real world issues)
- Public relations

### **Perceived Benefits of Being a Lay Representative**

Lay representatives reported many benefits of being on a committee. For the most part, the lay representatives value the input they are bringing to the committee and are passionate about their role. For example, one respondent reported, “This project would never have happened if the lay representative (i.e. patient partner) had not brought it forward to the right people. We are now studying a question that very strongly reflects the needs, values and preferences of patients. The clinician and researchers are learning a lot about what matters to patients. As lay reps/patients, we bring forward ideas the others would never come up with.” The responses generally fell into the following categories:

- Bringing a patient/participant perspective
- Value the contributions and experience of serving on the committee (e.g., learning about cutting edge research, interacting with researchers/physicians/experts in field, resume building, understanding funding)
- Advocacy opportunities/opportunity to share information

### **Perceived Difficulties of Lay Representation from Non-Lay Representatives**

Twenty-one participants responded to this question. Eleven respondents reported that there were few or no difficulties. The perceived difficulties generally fell under the banner of a lack of expertise to meet the demands the committee. One respondent noted that this was not the fault of the lay representative, as many of the “lay” abstracts were not written in such a way for the lay representative to fully understand the project and questions being asked.

### **Perceived Difficulties of Lay Representation from Lay Representatives**

Of 44 respondents, six reported that they had no difficulties as lay representatives. For those who did report difficulties, the responses generally fell under the following categories:

- Time commitment, heavy workload
- Uncomfortable/nervous speaking at meetings/perceived lack of opportunity to speak at meetings
- Lack of role clarity
- Lack of scientific knowledge/training

### **Recommendations Regarding Lay Representation from Non-Lay Representatives**

Of 21 respondents, one was unsure of making any recommendations and six stated that they had no recommendations. Only one respondent had a negative view of lay representatives. Most non-lay representatives felt that further training and education was important. Responses generally fell into the following categories:

- Emphasize the importance of lay members, and the impact they can have on protocols. Encourage comments during meetings.
- Recruit lay representatives with an interest/knowledge in relevant science
- Additional training/education
- Pre-meeting engagement and portions of meetings dedicated to lay representative concerns

### **Recommendations Regarding Lay Representation from Lay Representatives**

Of 40 respondents, eight stated that they had no recommendations. The responses were generally positive although one individual reported thinking that lay representation was not always an asset on every committee. One theme that emerged from the responses was that lay representatives feel they would benefit from increased training and education and that the role and expectations of the lay representative need to be clearly defined. Responses generally fell into the following categories:

- Enhanced communication with committee. Ensure that members are comfortable/confident to contribute.
- Role clarification
- Education/Training
- Have at least two lay representative members on the committee

- Ensure geographic areas/diversity represented
- Honorarium

### **Reimbursement for Lay Representatives**

Twenty lay representatives reported being reimbursed, 27 reported that they were not reimbursed and four were not sure. Five of the non-lay representative participants reported that lay representatives on their committee were reimbursed, seven reported that the lay representatives were not reimbursed and 15 were unsure. The reimbursement types fell under the following categories:

- Honorarium (e.g., \$25 per meeting, \$50 per meeting, \$100 optional, or based on number of protocols)
- Meal
- Travel
- Conference attendance
- General expenses

### **Evaluation of the Lay Representation Framework<sup>4</sup>**

#### ***Non-Lay Representative Perspective:***

Thirteen non-lay representatives out of 26 respondents (50%) reported that the Lay Representation Framework made sense while two reported that it did not and 11 reported being unsure. In response to the question, “Do you think that this type of framework has the potential to help health research committees wishing to create or enhance the role of lay representation?” only 11 out of 26 (42.3%) responded affirmatively. Eight respondents reported that they were unsure about the Framework.

#### ***Lay Representative Perspective:***

Lay representatives had a mixed review of the Lay Representation Framework. Thirty-five participants reported that the Framework made sense to them, eight said it did not and nine were unsure. In response to the question, “Do you think that this type of framework has the potential to help health research committees wishing to create or enhance the role of lay

---

<sup>4</sup> Please note that the actual Lay Representation Framework (a flowchart which illustrates what we think are the most the important elements of incorporating lay representation into committees) is not included in this document as it is still under development. It is hoped that when this “Framework” is completed and published it will be a practical aid to organizations that are looking to either develop or boost the input of lay people on their committees.

representation?” only 26 out of 52 (50%) responded affirmatively. See Figure 2 for a comparison of group responses.

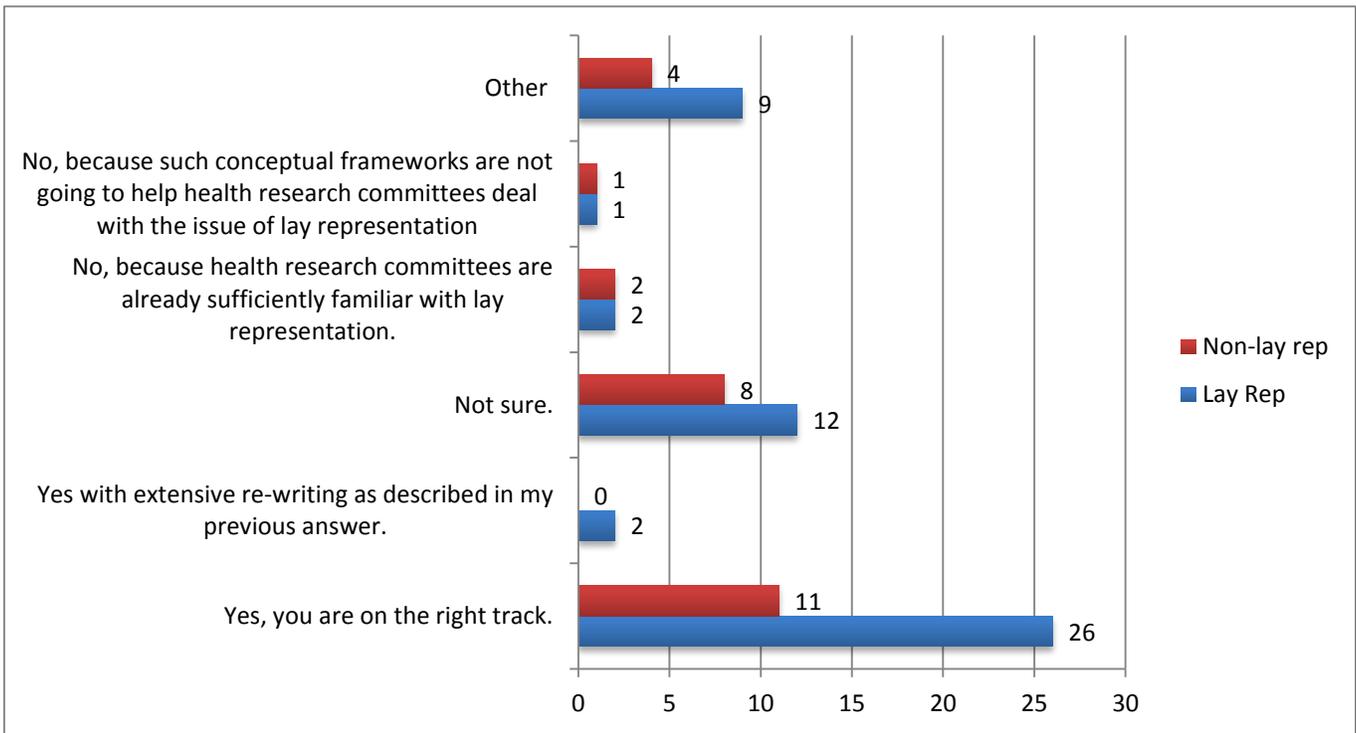


Figure 2: Opinions Regarding Framework

**Description of What Respondents Liked/Did Not Like Regarding the Framework**

*The following themes emerged from the comments of non-lay representatives:*

- Questions on specifics of framework (e.g., how will participants be screened)
- Lay representatives should be involved at each stage
- Further detail needed (e.g., guidelines to recruit and identify lay representatives, number of members required)
- Overly complicated

*The following themes emerged from the comments of lay representatives:*

- Overly complex/complicated
- Logical, clear structure, role description is good, comprehensive
- Communication processes not addressed

- Further detail needed (e.g., guidelines to recruit and identify lay representatives, number of members required, ongoing education, details of formal evaluation)

For the most part, participants did not have issues with the content of the framework. One of the most frequent criticisms of the frameworks was that it is overly complex or complicated. Conversely, some participants felt that there was not sufficient detail in some aspects of the framework. While the latter comments are fair, it appears that some participants did not realize the scope of the framework and how it is meant ultimately to apply to a wide range of committees.

## Discussion

The first observation that can be made about the results of this survey is that there is a striking similarity between the answers provided by the lay representatives and the non-lay representatives when responding to *forced choice* items. This is somewhat unexpected and not necessarily consistent with other research, for example, Katz et al. (2012) found that patient advocates perceived their input and the value of their role in the clinical trials process as more beneficial than investigators. It should be noted, however, that there are major differences between the work conducted by Katz et al. (2012) and this project. Our survey targeted lay and non-lay individuals who sat on committees with each other whereas Katz et al. (2012) surveyed lay individuals on committees and *investigators*, many of whom had limited knowledge of the activities of the advocates. It should also be noted that our project took a broad view of the many roles that could be part of the “lay representative” category whereas Katz et al. (2012) concentrated on a subset of the lay category, that is, patient advocates.

Despite our findings of apparent similarities in the opinions of the groups targeted in this project, the lay representative respondents and non-lay representative respondents used language that differed in tone and content when answering the *open-ended* items. This will be addressed in several of the discussion points below and it will offer greater insight into the perceptions of the respondents. Generally speaking, the responses generated by the lay representatives tended to be less scientific and more patient-centred than those of the non-lay representatives.

Slightly different profiles emerged for the groups, with lay respondents being older and more likely to be retired than non-lay respondents. More than twice as many of the non-lay

respondents were health care providers as the lay respondents. However, it is interesting to note that almost one-fifth of the lay respondents *did* identify themselves as health care providers; therefore, it is clear that the role of “lay” representative is not seen as conflicting with having a professional medical background. Almost half of all respondents represented cancer research committees.

The lay and non-lay groups reported that they came from similarly sized committees (12 to 13 members, on average); however, lay respondents came from committees with more than twice as many lay representatives as non-lay respondents. This is probably due to the fact that in at least five cases, lay respondents came from all-lay committees.

It was clear that there are differences in the way that members see their committees. Even though both groups chose similar terms amongst those offered in a multiple choice question, when prompted to provide their own descriptors the non-lay representatives tended to use more scientific terms while lay representatives saw a more personal – even human – role for their committees.

There was a high degree of agreement between the way non-lay representatives saw their lay colleagues and the way lay representatives see themselves. It would appear that there is almost universal agreement in the value of having lay representatives on health research committees. As one respondent put it, lay representatives offer a unique perspective and valuable insights that have “relevance beyond [the] narrow band of science.”

The term “community representative” or “community member” was not only the most commonly used name to identify lay representatives by both groups it was also preferred amongst lay representatives and non-lay representatives. Of course the semantics of the label are less important than identifying the actual roles that are represented but, at the same time, this could be an important element in confirming the validity of the lay representative position. It also comes back to the question of what “community” does the lay representative serve? This question is key to understanding what is meant by a lay representative. In discussion of this point the LRWG suggested that the term “Community Representative” could be augmented with the phrase “and Lay Voice” in order not to lose the importance of bringing a different perspective to the research process. Given that the textbook definition of “lay” can seem

somewhat pejorative,<sup>5</sup> this combination of terms could be an elegant answer to the question of what to call “lay representatives.”

This survey provides overwhelming evidence that everyone – be they lay or non-lay representatives on health research committees – thinks that education is a huge part of the solution to having a well-informed and productive lay representative. However, it would appear that lay representatives do not necessarily know what they are missing if education is not provided (or only minimally provided). They often feel that their only or primary skill is understanding the experience of being a patient; this may not facilitate their participation in more scientific or research-specific discussions. Another potential area for training has to do with being able to present contradictory opinions, or argue, effectively. It was pointed out that someone who does not know how to “argue” within the context of their research committee may be seen as having a lack of respect for others or for the process. This skill also extends to discussing issues with government representatives, funders and others. Respondents mentioned that they need additional sources of online training but education must not stop there. There is no replacement for face-to-face mentoring, workshops and other forms of instruction.

Several respondents also mentioned that lay representatives on health research committees are not the only ones who need education or training. Not only could non-lay representatives benefit from guidance on how to perform their roles but it could also be extremely useful to provide education about the general functions associated with the lay role as well as the expectations of lay representatives. By better understanding lay representation, non-lay representatives will be able make the most effective use of this resource. This could be an opportunity for lay members to take charge of this aspect of committee training and offer, for example, annual workshops on the benefits of having lay representation on committees.

Regardless of the form education or training takes, respondents stressed that it is not enough to simply give information at the start of the lay representative’s involvement in the committee. Education needs to be ongoing and the requirement for additional training needs to be revisited as the committee evolves – and often grows – over time. As one individual asked a personal communication, “Did the other members of the committees take a one-day, on-line course to become a researcher/clinician?” This person went on to suggest that we may need to create a curriculum that helps lay representatives understand the basic underpinnings of

---

<sup>5</sup> According to the Oxford Dictionary, the term “lay” can be defined as “Not having professional qualifications or expert knowledge, especially in law or medicine.”

research which could include some first-person stories about why researchers/clinicians went into this field, what the state of the science is right now about "X" topic and how research is currently affecting policy.

One of the themes often brought up by lay representatives was the tremendous time commitment involved in their role (including the need to read and understand a lot of scientific material). This suggests that there might be benefits to a sort of work-sharing arrangement which would allow lay representatives to divide their duties instead of trying to carry the entire burden of being a community member alone. Perhaps there is need for a sub-group of lay representatives that could meet separately on occasion in order to learn from each other. This sub-group could then provide a pool of possible lay representatives to the main research committee. Alternatively – and again it depends on the size and needs of the individual group – it could be beneficial to have at least two lay representatives on any given committee. The message is clear that relief is needed for lay representatives who may feel that the demands of fulfilling their positions may exceed what they are able to offer, particularly as older and often retired members of the community.

The provision of additional resources may help lay representatives better cope with the significant workload. For example, there could be benefit in having a website where lay representatives can communicate with each other for the purposes of sharing best practices, tips and tricks, cautionary tales about dealing with other committee members as well as more practical information about how to conduct themselves as effective lay representatives.<sup>6</sup>

Criticism of lay representation was minimal. If there was any negativity expressed about lay representatives it was simply that they did not always understand the scientific or technical jargon used during meetings or within documents evaluated by the committees. In fact, it was pointed out that not all project descriptions supposedly written in “lay” language are actually understandable to lay persons. This has long been a problem with Research Ethics Boards (REB) where there is always supposed to be a description of the project (usually encompassed in consent materials) that is supposed to be understandable to potential participants and/or their substitute decisions makers. A recommendation often made by the authors is for REB members to start with the lay description of the project and if it is not understandable at the agreed level

---

<sup>6</sup> N2 will be launching a website early in 2015 which will be dedicated to providing information about clinical trials to current and potential research participants. This is the sort of space that might provide an area for lay representatives on health research committees to use for information exchange and communication.

(and this is where lay representatives can help the REB evaluate the language) then it should be returned to the investigators for revision.

Not surprisingly there were many differing opinions concerning the “Lay Representation Framework” when respondents were challenged to evaluate it in the survey, for example, some wanted more detail while others felt it was too complex. Overall, lay representatives seemed to value the Framework more than non-lay representatives; however, it may be fair to conclude that the former group has given these issues more thought than the latter group. Ultimately, it was clear that many respondents thought that it could be a helpful instrument to health research committees wishing to incorporate and/or support the role of lay representatives.

Digging into the responses provided by all participants in this survey, it was also clear that the individual elements included in the “Lay Representation Framework” have been validated by this sample, for example:

**Develop Philosophy, Vision, Mission, Goals of Committee and Identify Area of Focus:** Before understanding how lay representatives function within a committee, the committee itself must have a clear mandate and plan of action. This theme was echoed in the comments of many respondents.

**Role Creation:** Respondents mentioned the need to clarify both the requirements of the role of lay representative as well as the way in which a lay representative would be expected to function. Just as others in the research world have “job descriptions” to which they must adhere, lay representatives need this sort of clarity when embarking on their positions. For example, it may be clear that a “patient advocate” is there to safeguard the needs and dignity of a certain group of patients but there are many other lay representative categories for whom this clarity is not provided. If the term “community representative” is used, the nature of the community needs to be described in detail and the expectations associated with representing that community need to be clear.

**Recruitment Plan:** Many respondents did not seem to know how lay representatives were identified or recruited and when they did have insight into this question, all too often the answer was that names of potential lay representatives were simply suggested by other committee members. The gap in the plan to recruit lay members suggests that this aspect of the Framework is often under-developed in health research committees.

**Identify Education Needs, Support and Sources of Education and Support:** Time and time again respondents mentioned the need for education and they also reinforced the notion that training must be ongoing. This is consistent with the way in which the Framework sets out feedback loops that include the evaluation and provision of education (and other resources) for both lay and non-lay representatives.

**Guiding National Lay Representative Committee:** Ultimately the enthusiasm shown for all aspects of understanding and clarifying the many roles associated with lay representation that was generated by this project leads to the natural conclusion that it may be time to organize a guiding national lay representative committee. As proposed in the Framework, this group could be under the umbrella of a national organization or partnership of organizations.

In a personal communication from an individual who oversees a committee which is considering the need for a lay representative, many of the issues raised by our respondents are addressed, mainly that it is essential to consider the role that will be played by the lay representative:

There has been a tremendous shift within our organization to include the client voice at all levels and in a meaningful way.... For me the challenge is finding the 'right' client and what is the role? Do they function as a 'typical' committee member and review research applications for scientific merit and ethical considerations? Or would their voice be more appropriate in the planning and direction of the research program – but that is tied to the strategic plan. DO I need the 'right' client? – or should all the research we do be relevant and accessible to anyone and handpicking a 'research-sympathetic' person unnecessary and inappropriate. I suspect that a client voice will be represented in research in the very near future – I just need to continue thinking about the most appropriate role.

## Conclusion

There is no doubt that the desire and responsibility to include the voice of the public in research is being recognized and pursued by many different segments of society, from government to academia to grass-roots civic engagement movements. The people who ultimately benefit from health research want to be part of the process that decides what

warrants investigation, how research funds are allocated, what methodologies are considered ethical or appropriate, how to interpret findings from the perspective of the patient or their caregiver and a myriad of other factors that are important in the world of research. This aspiration to include the voice of the lay representative in research is reflected in documents such as the recently released “First Annual Patient Engagement Report” from Cancer Care Ontario (2014) or the Strategy for Patient-Oriented Research (SPOR) initiative at CIHR which is engaged in implementing CIHR’s Citizen and Patient Engagement Strategy.

The idea of incorporating lay membership in health research committees is not new, for example, REBs under the jurisdiction of the TCPS have been mandated to include at least one community member since the first version of the guidance was released in 1998. Many cancer organizations in Canada have led the way in terms of inviting patients and other members of the public to be part of their committees (e.g., 3CTN and CCAN). However, this does not mean that we are always clear on how to identify and recruit lay members, make use of their expertise or provide appropriate support so that they understand their roles and can operate in ways that are both effective and fulfilling.

This survey has provided strong evidence that the role of the lay representative is considered both valuable and necessary to the functioning of many health research committees. There are, however, ways in which we can improve the experience of lay representatives and increase the significance of their contribution as well as harmonize the way in which they function within their committees. It starts with knowing the mandate of the committee and quickly develops into setting the tone for public input by clarifying the process to identify and recruit lay members, setting out job descriptions of what is expected of lay members as well as the communities they serve, providing adequate and appropriate guidance for lay members *and non-lay members* throughout the course of their committee involvement and building in feedback loops and opportunities for evaluation that will ensure that lay representation roles continue to be needed, respected and appreciated.

Education was the single most important element identified in the quest to support and promote effective lay representation on health research committees. However, one lay representative expressed the need to go *beyond* education which although deemed necessary is not always sufficient to support the role of a community member. In this person’s view the ideal lay representative needs passion and time as well as fearlessness when it comes to asking the “stupid” – but often essential – questions.

We may be at the point where we should not necessarily assume that it is always about including *lay* representation on health research committees but rather it could be about including *non-lay* representation on *lay* health research committees. The bottom line is that the expertise needed to fuel health research must come from many different sources. These sources should include, but are not limited to, those with knowledge of science, psychology, policy, research administration, ethics and particularly the experience of being a patient or the caretaker of a patient.

Finally, all of the elements described by our survey respondents - both lay and non-lay representatives - have been captured in the draft “Framework for Lay Representation” included in this project and originally developed by 3CTN. As one of the lay respondents stated succinctly, “It looks good. I want in.” Now that the conceptual structure of the Framework has been validated it is time to expand on what it means and how it can be used. Once this lay representation “road-map” is completed it is hoped that it can be of tremendous use to health research committees that would like to optimize the use of lay representation in their ranks.

## References & Resources

Brandstetter S, McCool M, Wise M, Loss J. (2012). Australian health promotion practitioners' perceptions on evaluation of empowerment and participation. *Health Promotion International*, September 17.

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2010). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

Cancer Care Ontario (2014). Improving Ontario's Health System through Patient and Family Engagement. First Annual Patient Engagement Report.

Katz ML, Archer LE, Peppercorn JM et al. (2012). Patient Advocates' Role in Clinical Trials: Perspectives from Cancer and Leukemia Group B Investigators and Advocates. *Cancer*, 118(19).

London L. (2013). Health System Governance: Community Participation as a key strategy for realising the Right to Health. University of Cape Town Report.

McCoy DC, Hall JA, Ridge M. (2011). A systematic review of the literature for evidence on health facility committees in low- and middle-income countries. *Health Policy and Planning*, 1–18.

McMeeking L, von Kolpakow M. (2002). Community and Consumer Participation in Health. *NSW Public Health Bulletin*, 13(8).

Nathan S, Johnston L, Braithwaite J. (2010). The role of community representatives on health service committees: staff expectations vs. reality. *Health Expectations*, 14(3).

Nathan S, Braithwaite J, Stephenson N. (2013). Facilitating the action of community representatives in a health service: the role of a community participation coordinator. *BMC Health Services Research*, 13:154.

Oxford Dictionaries Online: <http://www.oxforddictionaries.com/>

PaCER (Patient and Community Engagement Research) Program in the Cumming School of Medicine - part of the Institute for Public Health (IPH) at the University of Calgary. [Partnered with Alberta Health Services through the Strategic Clinical Networks]:

<https://obrieniph.ucalgary.ca/pacer>

Schmaltz RM & O'Hara P. (2013). Results of a Literature Search on the Role of the Lay Representative in Research. Report Commissioned by the Canadian Cancer Clinical Trials Network (3CTN) Lay Representative Working Group.

SPOR (Strategy for Patient-Oriented Research): Coalition of federal, provincial and territorial partners led by CIHR: The objective of SPOR is to foster evidence-informed health care by bringing innovative diagnostic and therapeutic approaches to the point of care, so as to ensure greater quality, accountability, and accessibility of care: <http://www.cihr-irsc.gc.ca/e/41204.html>



Canadian Cancer Action Network  
1 University Avenue, Suite 300  
Toronto, ON M5J 2P1  
416.619.5784 / 1.866.378.1986  
[www.ccanceraction.ca](http://www.ccanceraction.ca)

