FRAMEWORK OF COMMUNITY REPRESENTATION ON HEALTH RESEARCH COMMITTEES: A PRACTICAL TOOL TO ASSIST ORGANIZATIONS WANTING TO INCORPORATE THE VOICE OF THE PUBLIC

INTRODUCTION

There is a groundswell of support for involving the public in meaningful ways in health research. Acting as a research participant is not the only way for a *civilian* or *lay person* (i.e. someone not usually directly involved in the conduct of research) to be part of the scientific investigations that are designed to lead to improved, or at least better understood, medical treatments. In Canada, and around the world, there is a call for community representation on advisory boards, ethics review panels, groups that review funding applications, hypothesis/research-question generating committees, community-based participatory research projects, research steering committees and knowledge translation groups, to name only a few examples. The question then becomes, how does an organization go about successfully including community representation on a health research committee or – in the case of committees that already have community representation – maintain and enhance the quality of the community representative experience for both the members of the public who are involved as well as the organizations which need their input? The purpose of this article is to describe a tool that has been developed – called a "Framework of Community Representation on Health Research Committees" [hereafter referred to as the Framework] that can act as a roadmap to the most the important elements of incorporating the voice of the public into health research committees. The Framework was created for the purpose of aiding organizations that are looking to either develop or boost the input of community representatives on their committees.

BACKGROUND

In 2013, the Canadian Cancer Clinical Trials Network (3CTN) – a pan-Canadian initiative to improve the efficiency and quality of clinical cancer trials in Canada – established a "Lay Representative Working Group" (LRWG) to explore and identify means by which to develop and enhance meaningful participation of community representatives in its structures and research activities. This led to the authors developing the first draft of the Framework that is the focus of this paper. To provide a foundation for this activity, the LRWG commissioned a literature search on the topic which addressed questions around how community representatives are identified, recruited, utilized and even rewarded for their contributions [1].

In 2014, the Canadian Cancer Action Network (CCAN) – which has, as part of its mission statement, the desire to engage a patient/caregiver perspective in the health-care system – joined the 3CTN effort and provided support for the LWRG until the end of March 2015.

It should be pointed out that although the term "lay" was initially selected to describe what we now refer to as a "community" representative, subsequent research suggested that the former term was neither as popular nor as descriptive as the one eventually adopted [1]. Other possible terms included:

- public member
- associate
- non or unaffiliated member
- consultant
- outsider
- non-scientist
- patient representative or advocate
- volunteer

Although the term "committee" is being used here to describe the entities where community representation takes place, it is not meant to restrict the nature of the groups which might adopt this framework such as boards of directors, working groups, clubs and panels.

SURVEY

The LRWG commissioned an online survey entitled, ‘An Examination of the Roles of Lay Representatives on Health Research Committees’ to obtain and contrast the informed opinions of two groups involved in health research committees: community representatives and non-community representatives. The questions were developed as a result of the literature review described above [1] as well as extensive discussions with the LRWG which was composed of experts on this topic. The full report on this survey is available online [2].

FRAMEWORK OF COMMUNITY REPRESENTATION ON HEALTH RESEARCH COMMITTEES

The draft Framework that was developed as a roadmap to the most the important elements of incorporating the voice of the public into health research committees was included in the survey; respondents were challenged to evaluate each component of the flowchart as well as provide opinions about the roles played by community representatives. Based on this feedback we are now able to present a completed version of the Framework (see Figure 1) which can be used as a tool by committees that are currently in existence or those being created. It can also be used by committees that are completely composed of community representatives, have only one or a small number of community representatives, or no community representatives but have an eagerness to incorporate the voice of the public.

The components of the Framework are explained here:

1. **Need for Involvement of Community Representatives Identified:** There are many reasons for believing that involving the public in research is both appropriate and beneficial. However, the motivation to include representatives from the community in some aspect of health research can be unique to every organization where this occurs. Generally speaking it starts from the premise that research has the potential to benefit society [3] and that health research offers the possibility of improving both the quality and longevity of human life.

Given the importance of health research, therefore, we have suggested several categories of reasons to **CAPTURE** the voice of the public:

a) **Calibre**: It is clear that the involvement of the public is very important to ensuring health research of high calibre. The Canadian Institutes of Health Research Act [4] states that Parliament recognizes that "excellence in health research is fundamental to improving the health of Canadians and of the wider global community." To that end, CIHR has developed a Strategy for Patient-Oriented Research (SPOR) in which the goal is to have the public "meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge (i.e., the process referred to as "knowledge translation")." Only by including the voice of the public in all aspects of research will we be assured of having high-quality investigations that meet the highest international standards of excellence and address the topics deemed to be the highest priority by the public. Furthermore, the need to assure the public that the "rights, safety and well-being of trial subjects are protected, consistent with the principles that have their origin in the Declaration of Helsinki, and that the clinical trial data are credible" are enshrined in the International Conference on Harmonisation (ICH) Good Clinical Practice (GCP) guidance [5] which has been adopted by Health Canada.

b) **Accountability**: According to the Canadian Policy Research Networks [6] Canadians are the shareholders of the public health care system. CIHR is Canada's federal funding agency for health research and, as such, it is supported by Canadian taxpayers thus making Canadian citizens the shareholders of most of the health research that takes place in Canada. Investigators are held accountable to their shareholders for all aspects of research integrity and reliability including the open sharing of information and policies to address research methodology and conduct. This means that including the public in all relevant aspects of the research process is one tangible way to assure appropriate accountability to those who are supporting clinical and other investigations.

Transparency of the research record (i.e. information about what research is taking place and the findings of such research) is also part of what investigators need to share with the public as part of their duty to be held accountable. The importance of ensuring that information about clinical trials is publically accessible and free to access has been stressed by the World Health Organization in their recent Statement on Public Disclosure of Clinical Trial Results [7].

c) **Partnership**: Although it can be argued that the power dynamics in the relationship between researchers and research participants leans heavily toward the researcher (particularly when that relationship is further clouded by the therapeutic association that may exist between health care providers and patients), it should still be acknowledged that there is a partnership between researcher and participant which is the foundation of all research. In fact, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* [3] which serves as a guideline for investigators, members of Research Ethics Boards (REBs), research administrators and sponsors for much of the funded research that takes place in Canada now describes human volunteers as *participants* rather than *subjects*, thus acknowledging that they are important players in the endeavour of research and not merely guinea pigs. Therefore, for this to be a meaningful concept this partnership deserves more than lip service. According to the Multiple Sclerosis Society of Canada [8], “Community representatives read and comment on the lay summaries of the projects [in funding applications] and provide feedback on ways that researchers can communicate their work in an understandable way for the public, which is equally as important as their ability to communicate their work scientifically.” Having a public voice on committees can ultimately increase the public understanding of the value of health research and strengthen the partnership between researchers and research participants that is so highly valued.

d) **Trust**: Research misconduct reported in the press has had a negative impact on both recruitment in research, as well as the trust that the public places in the enterprise of research [9]. Incorporating the voice of the public on health research committees has the potential to strengthen trust in the research process. It is clear that investigators are indebted to the community providing human participants for research as the participants are the ones taking the most immediate risks. Moreover, with health research there is the very real possibility that studies may be interwoven with patients' standard medical care thus creating confusion in the minds of the people who are donating their time and personal resources for the possibility of helping to advance scientific knowledge. To be able to place trust in this process, the public must play important roles in the enterprise of research.

Another facet of trust has to do with the people targeted by research. In the past there have been concerns around the inappropriate inclusion or exclusion of participants possibly limiting the generalization of the research results. Rochon, Berger and Gordon [10] point out that the "underrepresentation of women, elderly people, the poor and other marginalized groups in clinical trials limits the benefit of drug therapy in these populations. People who differ because of sex, biologic factors, and ethnic and cultural factors may well have different clinical outcomes." Ultimately, the exclusion of these groups limits the trust that the public can place in the results of research. Until community representation on recruitment committees is realized, for example, we may not be able to have complete faith in the conclusions drawn by researchers. The TCPS 2 [3] outlines considerations around the appropriate inclusion and exclusion of human participants with particular care taken to describe the pitfalls associated with either over-protecting or over-burdening certain groups in research.

e) **Understanding**: What investigators understand about the results of their research may not be complete or even accurate to the people who live with the disease or condition (this includes not only the patients themselves but their caregivers and friends). There is a need to understand what research results mean to the public or the people affected by the research. The need to understand what is important on a very practical level requires the input of the public who are most affected by the condition in question.

f) **Respect**: Every major code of ethics regarding human research describes the underlying principle of respect for persons. For example, the TCPS 2 [3] states that research should be "conducted in a manner that is sensitive to the inherent worth of all human beings and the respect and consideration that they are due." While this principle has traditionally been applied to the way in which human *participants* are utilized, as the role of the public increases in research so should the understanding of what it means to show "respect." One can therefore argue that the opinions, knowledge, experience and desires of the public must be respected in all aspects of the research process from the earliest identification of the research question to the way in which the results are interpreted and understood.

g) **Empathy**: Anecdotal evidence suggests that there is sometimes a perception that community representatives may feel too passionate about the work of the committee (e.g., they may be too connected to the disease or condition that is the focus of the research) which creates a lack of objectivity in their thinking and perhaps even impairs productivity as a result of this state of empathy. However, it should be noted that objectivity (defined as impartiality) is not the opposite of empathy (defined as understanding). Subjectivity (defined as bias or prejudice) *is* contrary to the concept of objectivity and it should not be assumed that it is synonymous with, or necessarily tied to, the concept of empathy. It is precisely this empathy towards the topic of the research and the people whose lives are affected by the research that serves as the foundation for all the categories of reasons to include the voice of the public that have been listed here. For example, the **Understanding** that community representatives bring to assigning research priorities or interpreting research results is likely a direct consequence of their personal understanding of the disease or condition in question. In addition to the technical and behavioural characteristics one wants to optimize in order to have a well functioning committee it may, therefore, be useful to increase the emotional intelligence of the group by valuing the empathetic contribution of the community members.

2. **Develop Philosophy, Vision, Mission, Goals of Committee and Identify Area of Focus:** Whether or not the committee in question is completely composed of community representatives, already has community representatives or is considering integrating community representatives into the fabric of the group, it is extremely important to ensure that the purpose of the committee as a whole is well understood before articulating the functions of the individual members. The mission of the committee may encompass multiple foci such as:

- Identification of research questions
- Hypothesis building
- Protocol/scientific review
- Ethics review
- Funding decisions
- Recruitment of participants
- Community/research liaison
- Advocacy
- Trial participation
- Assessment of cultural impact

Much has been written about the best way to create a committee, often starting with a matrix that details the skills and competencies of members who are presumed to be the desired composition of the group. The potential problem with this approach is that it may overly focus attention on what individuals bring to the table as opposed to what the organization needs the group to accomplish. Whether one starts with a task force or governance group which sets out the philosophy, vision, mission and goals of the committee as well as its specific foci, or one has regular opportunities to revisit the mandate of the committee (e.g., through annual retreats), it is extremely important to be clear about the function of the committee as a whole *first* and its individual membership *second*.

3. **Role Creation:** Having established or clarified a clear mandate and raison d’être for the committee, the next step is to ensure that there are appropriate role descriptions for all members. It may be helpful to think in terms of job descriptions for community members (identify ideal qualifications, interests, abilities etc.) that will best serve the committee mandate. It is at this point that it is necessary to describe the structure of the committee and how the community representatives will interact with other members/roles (e.g., health care providers) or committees. It is also important to consider the optimal size of the whole committee; many experts suggest that groups larger than 13-17 individuals may present problems with keeping members interested and involved; this can be particularly important when dealing with community representatives who can feel intimidated by larger groups or unable to have their opinions heard. It can also be more difficult to attain quorum with larger committees. On the other hand, it can be difficult to represent a variety of perspectives with small committees.

4. **Recruitment Plan:** There are many potential sources of community representatives which need to be identified and explored. For example, it may be appropriate to target “known” candidates such as patients and/or their caregivers, retired health care professionals, members of associated health care organizations, advocates for the condition in question and possibly even associates of current members of the health research committee. There are also the “unknown” candidates who may have an interest in the research topic but who are unfamiliar to the existing committee. While either approach to recruitment can be effective, it is important to note that recruitment of “known” candidates may result in a committee that does not deviate from the established status quo [11]. A good recruitment plan starts with a description of the community to be represented as well as the roles to be played (as mentioned in component #3). It is also essential to identify sources of potential conflict of interest between community representatives and committee/board roles. The recruitment strategy should include information about who approaches the candidates, what information is provided and what interview questions are used. Even if committee members are able to identify potential community representatives it is often best if the actual recruitment process and ultimately the invitation to participate is assigned to a governance group or at least to someone on the committee who is specifically designated

to take care of this task. There were five recommendations regarding recruitment offered as a result of the literature review conducted by Schmaltz and O'Hara [1] and subsequently confirmed by the survey conducted by O'Hara and Schmaltz [2]:

I. Promote volunteer opportunities through websites (e.g. http://www.invo.org.uk) which allow potential candidates to learn more about the organization and the role that community members can play.

II. Volunteer opportunities should be posted in hospitals and research centres to inform patients and/or friends and family members of patients. As well, organizations could consider open public forums or radio/television programs to explain the need for community members.

III. Involve organizations which may reflect the voice of the patient, such as the Canadian Cancer Society, Cancer Advocacy Coalition of Canada, Canadian Cancer Action Network and the Canadian Partnership Against Cancer, to advertise community board positions.

IV. Where feasible, information about roles for community representatives on committees could be provided to research participants in the debriefing process following their involvement in the study.

V. Recommendations from current board members are a potentially valuable resource in recruiting community members. The organization should be aware though, that recruiting through board member recommendations could limit the diversity of perspectives on the board (i.e., it is unlikely that a current board member would recommend a community member with strongly differing opinions or perspectives). As well, the organization wants to avoid the perception that the opportunity to participate as a community member is based on knowing the right person.

5. **Recruit and Interview Potential Candidates:** A committee with a clear philosophy, vision, mission, goals and area of focus (Component #2) that are reflected in well defined "job descriptions" for the roles that will be played on the committee (Component #3) can now recruit and interview candidates who have the potential to fill these roles. The qualifications of potential candidates need to be assessed in terms of their skills "on paper" as well as in person; after all, every member must function as an independent contributor as well as a cog in the larger entity that is the committee. It is always possible to be impressed by personal experience, education and other noteworthy qualifications but if the individual is incapable of effective communication or lacks the passion to put the needed time and effort into the role assigned, those qualities will never be utilized. It should be noted that this process of recruiting and interviewing candidates could end up impacting and even broadening the understanding of what is needed in the role of community representative (or any role on the committee). As such, a feedback loop to Role Creation has been included in the Framework. It is important to make sure that people are being "mapped to the right partnerships," both to maximize the functioning of the committee and also to provide what will ultimately be a fulfilling experience for the committee member. Potential candidates should be questioned about what they think their role on the committee will be as well as how they perceive the function of the committee to ensure that this "mapping" process is a good fit. If all goes well, the candidates should be invited to join the committee. It may be beneficial to suggest a trial period (e.g., six months) to allow both the new members and the committee to evaluate the relationship before it is made permanent. [Note: many committees have a term limit policy which identifies the maximum number of consecutive terms a member can serve as well as the length of these terms. While it can invigorate a committee to have new members with fresh ideas it can also be a detriment in the potential loss of institutional memory. Such policies, therefore, need to have some flexibility so that the best composition of the group is always the top priority.]

6. **Identify Educational Needs and Sources of Education and Support:** The types of education, training or support needed for any given committee depend primarily on the function of that committee. For example, if the committee vets research protocols, members should be trained generally in what to look for in terms of complete, appropriate and well-crafted

submissions (although not every member can be expected to have the skills necessary to evaluate every component of the proposal; for example, some members may have expertise in science while others are familiar with laws and regulations). While education for community members may have to take into account that they are less familiar with research operations than their non-community counterparts, education aimed at non-community members may have to include an understanding of what community members can bring to the committee (in other words, encouragement for the value of the community perspective). It is also extremely important to ensure that all members are provided with information about how the committee functions. For some this could include training in how to be an effective communicator *and* listener.

An educational needs assessment should be conducted on an annual basis in order to keep up with changing membership and the possible evolution of committee function. It is critical to include community members in the design and execution of the assessment. This will encourage trust in the process and it will also provide them with an opportunity to ask for educational resources without embarrassment. The committee also needs to keep a current list of possible educational resources as well as having a training "plan" that ensures regular education for all members. It should be noted that some community members believe that they have sufficient expertise (e.g., patient experience, graduate training, previous committee experience) when joining a committee and, therefore, they do not need to receive additional training while others think that it is sufficient to be self-taught [2]. The problem is that without training, members may not know what they are missing as they have never been exposed to this information in the first place.

7. **Provide Education and Support (This also applies to Component #12)**: There are several possible categories of education that may be utilized by committees:
    I. Initial orientation/training session prior to first meeting: Regardless of the roles to be played by new members, it is essential to provide them with standardized information about the purpose of the committee, the way in which it functions and the **expectations** regarding the roles to be played.

II. Targeted training provided by researchers/clinicians/peers: It is often very helpful to have people conducting the research that is the focus of the committee actually provide training in their methods, treatments, hypotheses etc. (all of these factors can change/evolve over time and keeping up-to-date can be an important responsibility for committee members). In the case of community members, it can also be helpful to have educational sessions run by their peers (either current or former community members from their group or other organizations) to share ideas, tips and suggestions for being a productive and fulfilled committee member.

III. Reading materials/online tutorials: Every committee should have terms of reference or bylaws which detail the way in which the committee functions (e.g., role expectations, training manuals) as the basis for the way in which members conduct themselves. Furthermore, tutorials can be an excellent source of education on a variety of topics that may be of interest to committee members, particularly community members who do not have a background in research. For example, the Network of Networks (N2) has partnered with the Collaborative Institutional Training Initiative (CITI) to provide a source of high quality, web-based, Canadian instruction on a variety of topics that encourage research with human participants to be conducted in a manner that is appropriate, safe, responsible, ethical and meets the criteria offered by guidelines, regulations and legislation in this country. This online curriculum is available to all individuals and organizations with a membership in N2 and the topics covered include Good Clinical Practice (GCP), the Responsible Conduct of Research (RCR) and Biomedical Research Ethics. Committees involved in various aspects of health research could find this sort of training invaluable for their members.

IV. Assign mentors: While training in the technical and procedural facets of research is usually best accomplished with group sessions or via reading materials and online education, the more interpersonal side of learning to be a good and effective committee member can be facilitated by an individual mentor. This person could be someone currently on the committee (although one would have to be aware of the possibility of undue influence over a novice) or, even better, someone who is no longer on the committee or who volunteers for another similar group.

V. Think of education as an ongoing mission: No matter how extensive initial training may be, there will always be a need for additional and ongoing education. Many committees find an annual retreat to be an excellent way to reboot the interest and passion of their members, as well as an opportunity to refresh general knowledge about research and committee function. This sort of activity is also a way to encourage the cohesiveness of the committee and, in the case of community members, help them to feel that they are a legitimate and important part of the group.

8. **Functioning Committee**: Having created a place for community representatives on health research committees, it is now time to activate their membership or revise the committees as needed. Another consideration is the number of communities that need to be represented in a given committee; for example, is it as simple as having someone with first-hand knowledge of the disease being researched or is it important to represent different age groups, genders or other characteristics?

9. **Evaluate Progress and Further Needs:** From the creation or revision of the committee to the ongoing need for training and education, there are a number of loops built into this framework based on suggested evaluation points. It is up to each committee to decide how progress is measured (e.g., number of protocols evaluated, amount of funding dispensed, satisfaction of members etc.) and define the benchmarks for their success. It can be helpful to think in terms of a gap analysis when comparing the actual performance of the committee with potential or desired performance. The gaps may occur at the level of the committee itself (i.e. poorly defined mandate) or the members (skills do not match roles) or the resources provided (e.g., missing or incomplete education).

10. **Formal Evaluation:** While it is beyond the scope of this article to describe formal methods of evaluating committees, it is a task that should occur on a regular basis. This process should not be looked at as an attempt to argue the *value* of the committee but rather an opportunity to improve the way in which it functions. Whether the evaluation is conducted by outsiders or it is an exercise in self-evaluation, it should be based on clearly established

criteria that have been pre-determined to represent optimal committee function or, if available, best practice guidelines. In addition to highlighting areas where the committee can improve, a formal evaluation provides validation for the way in which it operates and credibility for the work accomplished.

11. **Feedback:** Everything learned from gap analyses, progress checks and formal evaluations should be channelled into feedback that is of practical use to the committee. For example, learning the type of education that is most useful to community members could influence the training provided by the committee. The committee should also ensure that there is continuing interaction between the community member and the community which they represent. For community members who have served multiple (or lengthy) terms, it may be necessary to ensure that the member still adequately represents and reflects the community.

12. **Provide Ongoing Support and Education:** See Component #7.

13. **Guiding National Community Representative Committee:** In light of the timeliness of the concept of encouraging community membership on health research committees [12], the authors believe that a pan-Canadian approach to connecting and supporting community members would be advantageous. This group could be under the umbrella of a national organization or partnership of organizations (as this Framework was developed in the context of cancer research and under the auspices of 3CTN, it is suggested that 3CTN would be an example of such an organization). There could also be an important role here for CIHR as part of their Strategy for Patient-Oriented Research (SPOR). SPOR is a coalition of federal, provincial and territorial partners (including patients, caregivers and researchers) who are dedicated to the integration of research into care. A national community representative committee would benefit from sponsorship by SPOR which would be in keeping with its goal to “actively collaborate to build a sustainable, accessible and equitable health care system and bring about positive changes in the health of people living in Canada” [13]. The guiding committee could contribute to many aspects of being a successful community representative by helping to establish a variety of “job” descriptions for lay members,

creating best practices for the inclusion of community representatives on health research committees and coordinating educational initiatives that will support the work of these lay volunteers.

CONCLUSION

Regardless of the nomenclature used to describe the role of community representatives, it is clear that the time has come to incorporate the voice of the public on health research committees in a meaningful and respectful way. The slogan “Nothing about us without us” – popularized by Charlton [14] – underscores the importance of including community members in all aspects of research that could eventually influence the way that the public is diagnosed and treated. Only by being part of the process can the public be truly empowered as players in the research process.

In case there is any doubt about why the role of the lay representative in research is crucial, we have suggested several categories of reasons to **CAPTURE** the voice of the public. Community membership has the potential to increase the **Calibre** of the research and it offers increased **Accountability** to the public. It provides an opportunity for **Partnership** between investigators and the community that goes beyond simple lip service, as well as engendering **Trust**, **Understanding** and **Respect** between those who provide the research and those who may eventually benefit from the research. Finally, including community membership on health research committees invites the possibility that, in addition to all the technical expertise that a committee may require, it also has room for the **Empathy** that can only be supplied by people with a direct stake in the disease or condition under study.

It is hoped that the “Framework of Community Representation on Health Research Committees” that is presented here can be a practical aid to organizations that are looking to either develop or boost the input of community representatives on their committees. This Framework - which grew out of an extensive literature review, a survey of health committees across Canada and the expertise of the “Lay Representative Working Group” – offers step-by-step advice to encourage, incorporate and support community members in a wide variety of health research groups.

The Framework starts with an examination of why community representatives are needed and finishes with the recommendation to set up a Guiding National Community Representative Committee. This group could be under the umbrella of a national organization such as 3CTN or a partnership of organizations. There is much that this sort of Pan-Canadian group could accomplish that would be too much to expect from any one committee, for example: establish a variety of "job" descriptions for lay members; create best practices for the inclusion of community representatives on health research committees; coordinate educational initiatives that will support the work of these lay volunteers; provide education for the public; and host workshops and national conferences in order to bring together volunteers and interested members of the public representing a wide variety of research themes.

It could also be beneficial to create a Council of Community Representatives that would provide ongoing support to lay members of health research committees. The Network of Networks (N2) would make an ideal home for such a Council as this organization acts as a national voice and advocate on behalf of a broad range of stakeholders that have an impact on the efficiency and quality of clinical trials conducted in Canada. N2 is a not-for-profit incorporated organization which brings together Canadian research networks, institutions and organizations working to enhance national clinical research capability and capacity. Through this alliance of clinical research professionals, N2 provides a common platform for sharing best practices, resources and research-related content to ensure efficient and high-quality research as well as integrity of clinical practices and accountability. Including a vehicle for the voice of the public would round out N2's commitment to represent all stakeholders in the enterprise of health research.

We look forward to seeing what the future may hold for community members of health research committees, recognizing that the ultimate result of this effort should be an increased meaningful involvement of community representatives in research and, ultimately, an even higher quality of research in Canada.

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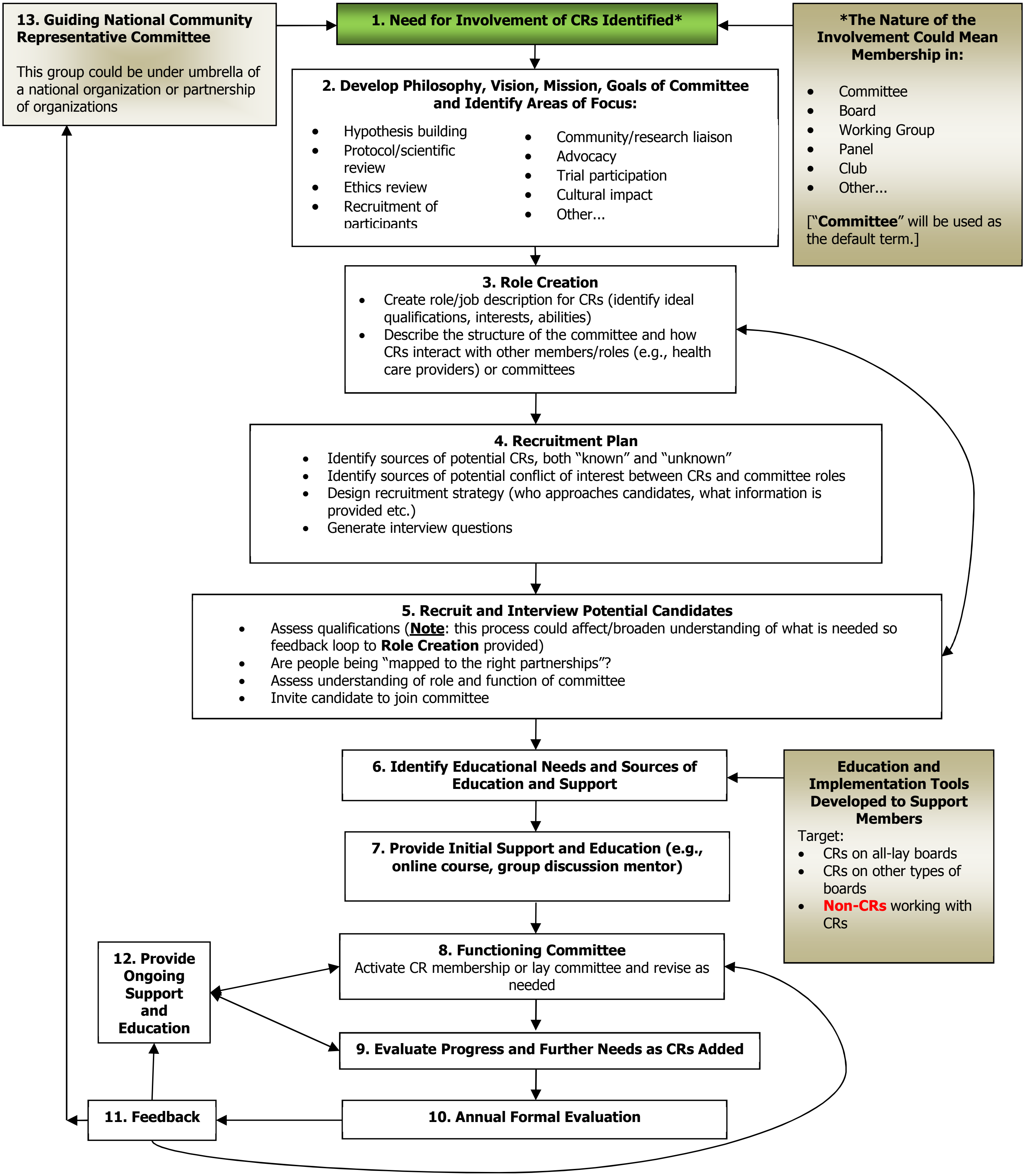
FIGURE 1: Framework of Community Representation on Health Research Committees



13. Guiding National Community Representative Committee

This group could be under umbrella of a national organization or partnership of organizations

1. Need for Involvement of CRs Identified*

***The Nature of the Involvement Could Mean Membership in:**

- Committee
- Board
- Working Group
- Panel
- Club
- Other...

["**Committee**" will be used as the default term.]

2. Develop Philosophy, Vision, Mission, Goals of Committee and Identify Areas of Focus:

- Hypothesis building
- Protocol/scientific review
- Ethics review
- Recruitment of participants
- Community/research liaison
- Advocacy
- Trial participation
- Cultural impact
- Other...

3. Role Creation

- Create role/job description for CRs (identify ideal qualifications, interests, abilities)
- Describe the structure of the committee and how CRs interact with other members/roles (e.g., health care providers) or committees

4. Recruitment Plan

- Identify sources of potential CRs, both "known" and "unknown"
- Identify sources of potential conflict of interest between CRs and committee roles
- Design recruitment strategy (who approaches candidates, what information is provided etc.)
- Generate interview questions

5. Recruit and Interview Potential Candidates

- Assess qualifications (**Note**: this process could affect/broaden understanding of what is needed so feedback loop to **Role Creation** provided)
- Are people being "mapped to the right partnerships"?
- Assess understanding of role and function of committee
- Invite candidate to join committee

6. Identify Educational Needs and Sources of Education and Support

Education and Implementation Tools Developed to Support Members

Target:

- CRs on all-lay boards
- CRs on other types of boards
- **Non-CRs** working with CRs

7. Provide Initial Support and Education (e.g., online course, group discussion mentor)

8. Functioning Committee

Activate CR membership or lay committee and revise as needed

9. Evaluate Progress and Further Needs as CRs Added

10. Annual Formal Evaluation

11. Feedback

12. Provide Ongoing Support and Education