



Canadian
Cancer Clinical
Trials Network

Network of Networks (N2)



Optimizing Lay Representation in Health Research

CTO Conference, Toronto Feb 27, 2014

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Objectives

- Some background
- Discuss Lay Representation
- Provide a potential structure
- Encourage critical thinking around Lay Representation
- Set the stage for the next speakers.



Background

- OICR High Impact Clinical Trial Program (HICT)
 - Lay representative for protocol review committee
 - Canadian Cancer Action Network
 - Role confusion
- Canadian Cancer Clinical Trial Network (3CTN)
 - Lay representative involvement desired
 - How?
 - Working group
 - Build on what was started under OICR-HICT
- Premise:

NOTHING ABOUT US WITHOUT US...



Definition

- What does Lay Representation mean?
- Is it meaningful?
- What does meaningful mean?
- Is it a one way street? Do we as HCP decide?
- What is our responsibility as HCP?
- What roles should and can Lay Representatives play?



Roles for Lay representatives:

- Multiple:
 - REB
 - Scientific Review,
 - Support
 - Participants in research
 - Advocacy
 - Etc.
- Often:
 - Not clear
 - No “job descriptions” or outline of expectations and responsibilities
 - No process
 - Not working very well....

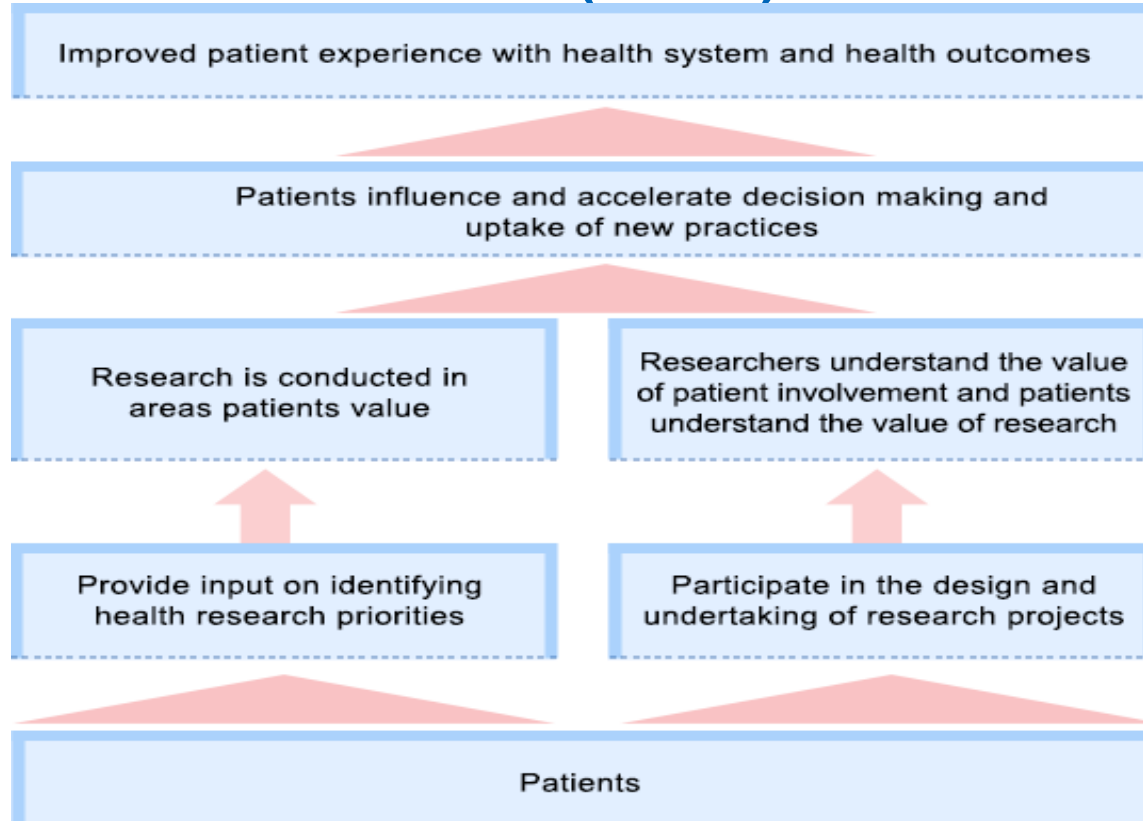


Aspects to consider

- Responsibility for meaningful relationship rests with both “parties”
- Needs to be more than “lip service”
- Can we build a framework?
- Current focus is often on some tools without bigger picture
- Applicable across many areas
- “Hot Topic”, significant interest from stakeholders
- What evidence exists around meaningful Lay Representation?



CIHR Strategy for Patient-Oriented Research (SPOR)



Results of a Literature Search on the Role of the Lay Representative in Research

Report from O'Hara Consulting

Dr. Rodney Schmaltz & Dr. Paddi O'Hara

- We are not alone!
- There are 2 sides to this “lay reps” coin: lay reps themselves and non-lay members (e.g., health care providers).
- Initial recommendations from report:
 - 1) Variety of terms used to define public representation on boards – clarity of roles and expectations essential.
 - 2) Non-community board members need information on the role of community members.
 - 3) Education is a critical component of successful public representation.
 - 4) Ongoing support, training and mentorship is important.
 - 5) Need systematic review of best practices in all aspects of identifying, training and utilizing community members.
 - 6) Expand recruitment strategies for community members to include the press, social media, patient-focused groups and former patients and research participants.

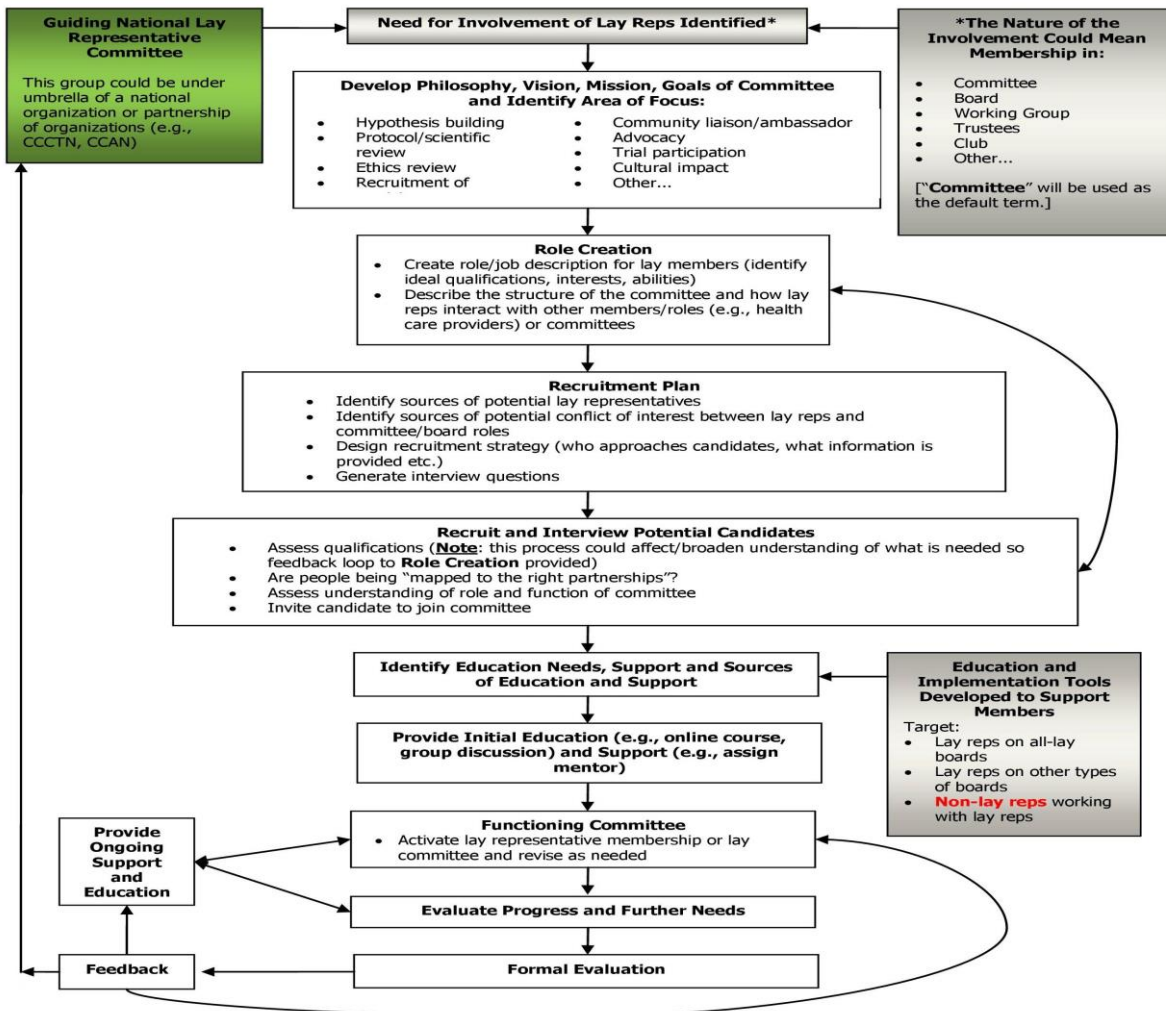
3CTN-WG on Lay Representation

- Members: Lay representatives (5), CCAN, 3CTN, Consultants
- Deliverables: Recommendations for:
 - Lay representation across 3CTN activities;
 - A process for conceptual framework development;
 - Support, training and education, “tool” kit of best practices, tools, processes and systems for lay representation.
- Process:
 - Formal literature review
 - aimed at validating existing concerns and perceptions of the difficulty of creating meaningful roles and representation for lay representatives.
 - Draft conceptual framework helpful for establishing meaningful lay representation
 - Map role descriptions, tools, education and training, recruitment sources and process for lay representation to the framework.
 - Complete formal framework
 - Provide recommendation to 3CTN

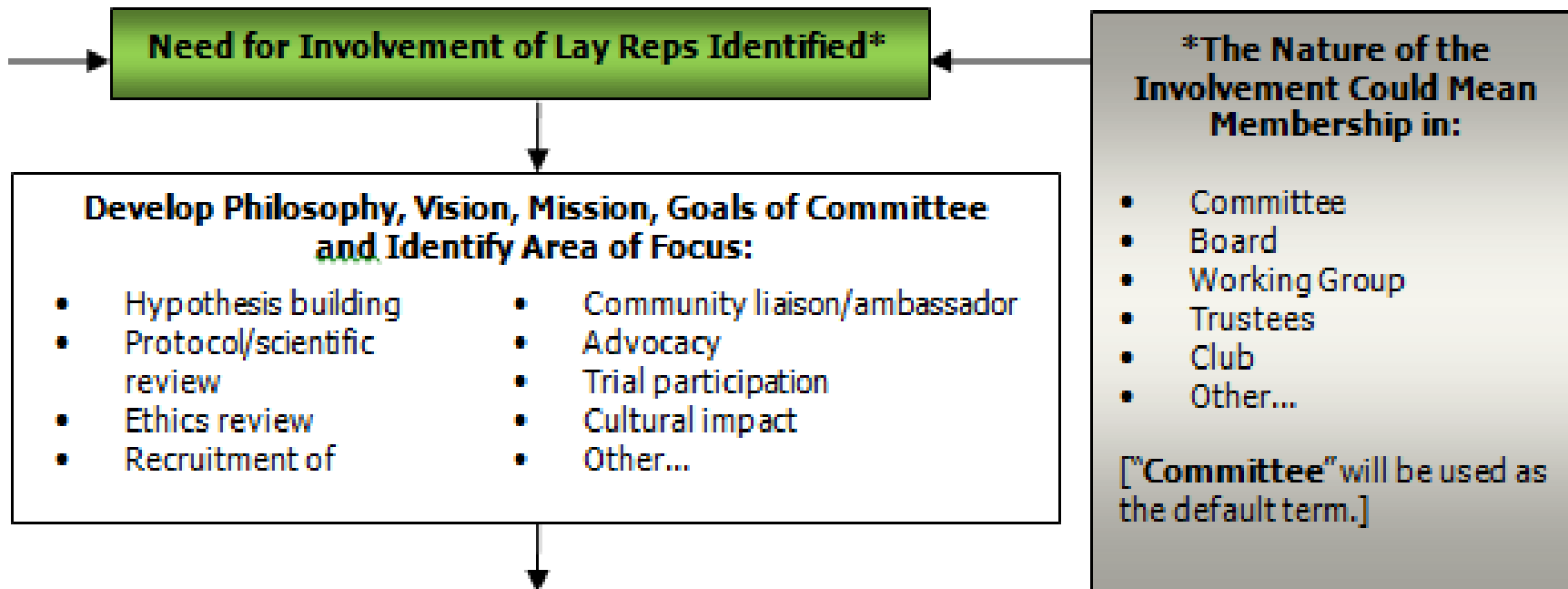




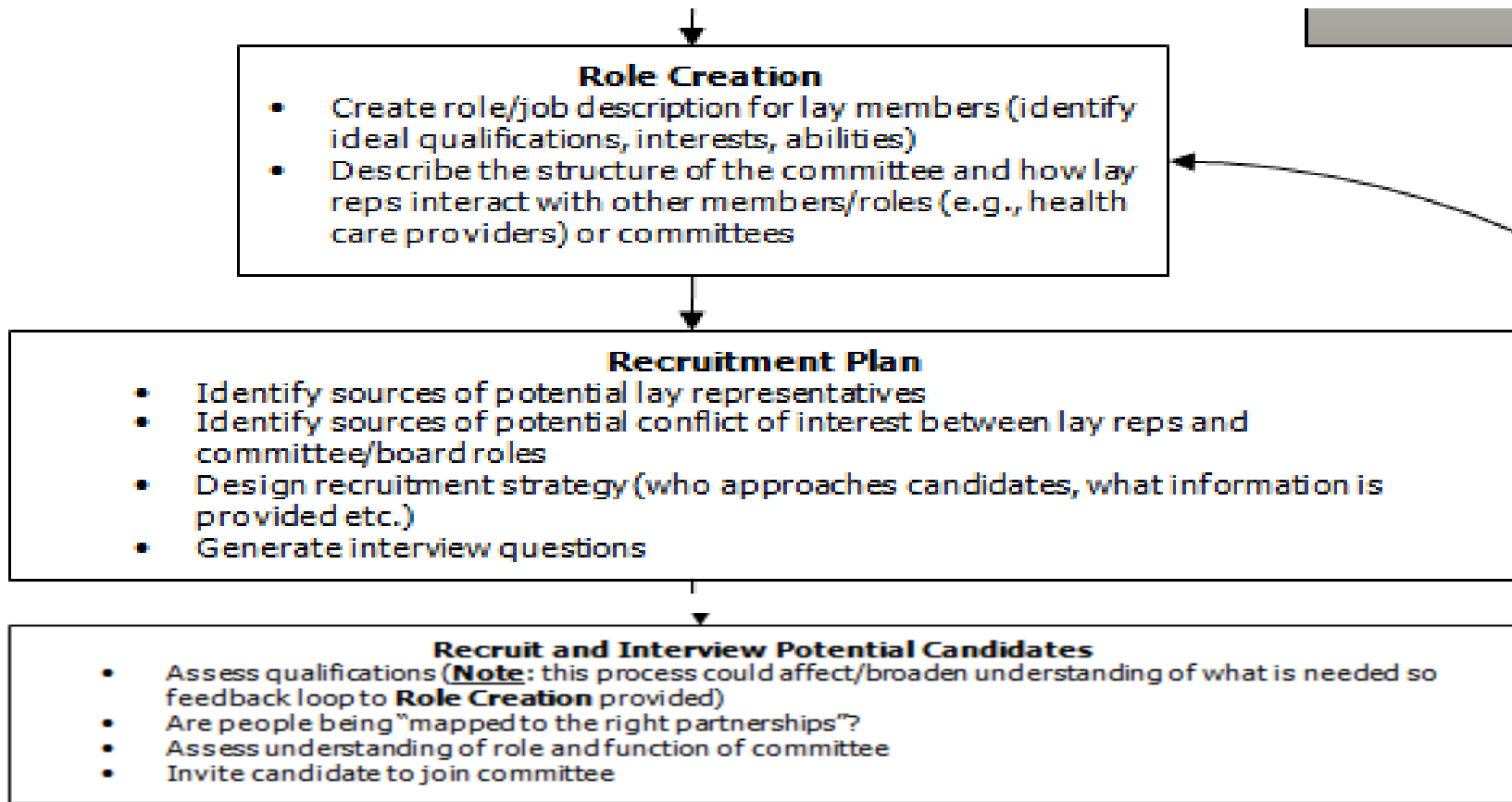
Lay Representation Framework



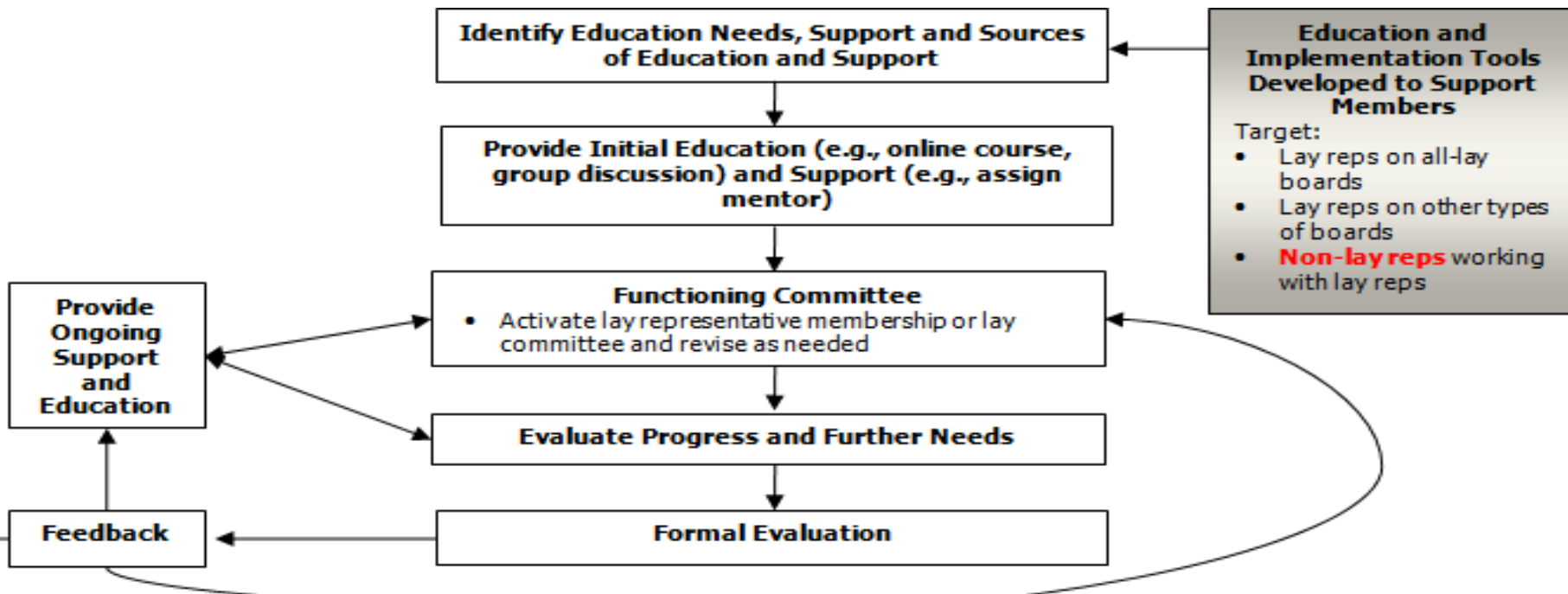
Lay Representation Framework



Lay Representation Framework

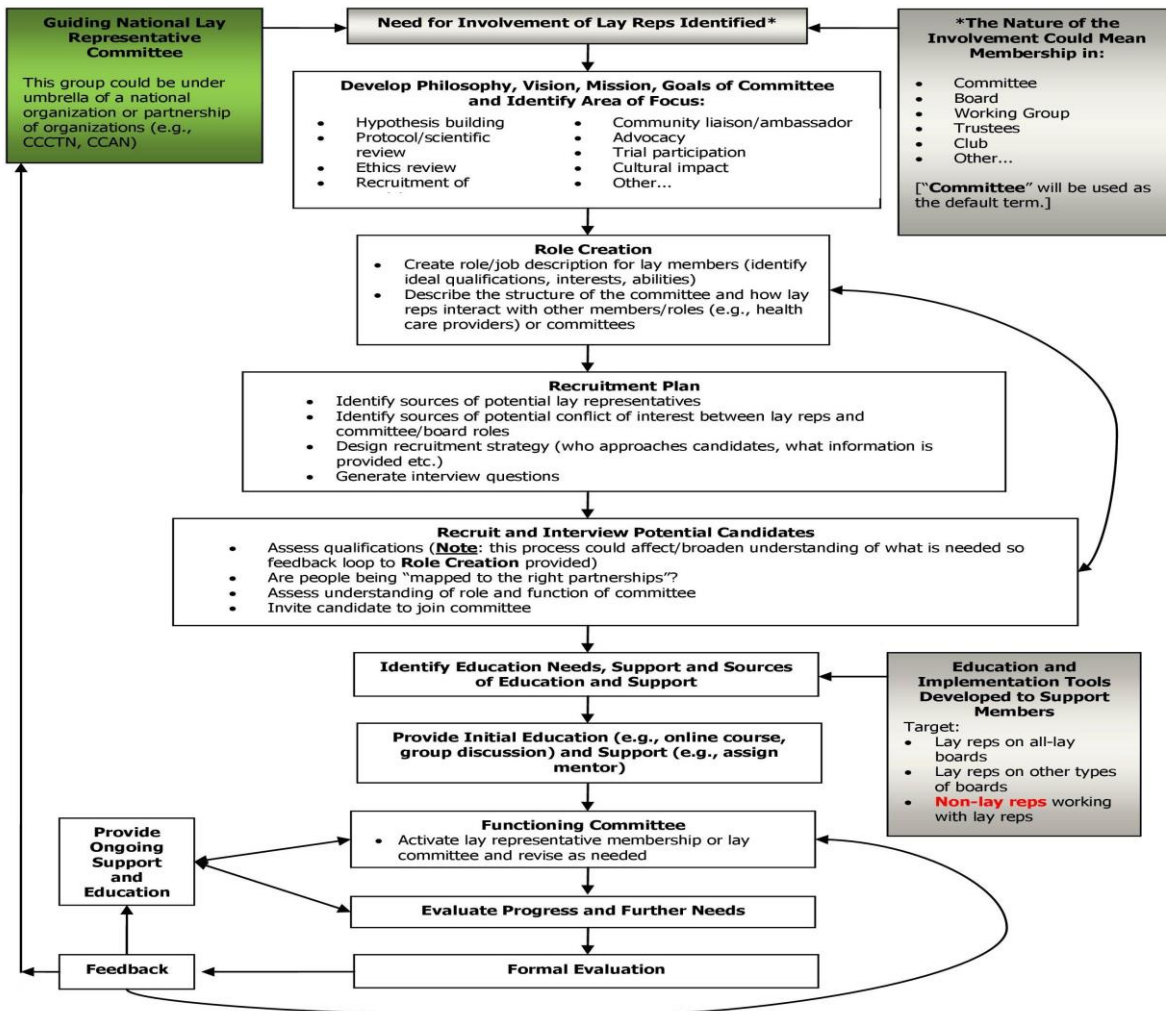


Lay Representation Framework





Lay Representation Framework



Next steps

- ++ Interest
- Continue the work and complete the framework
 - ?feedback
 - Add the body to the chart
 - Map tools to the framework
- Validate the framework
 - Survey through CCAN
 - Test and discuss with stakeholders
 - Lay Representatives
 - Health Care Professionals
 - Encourage use
- How does this apply to you?
 - Think about the role and plan
 - Think about what meaningful means
 - Understand paternalism....
 - Keep in mind for the next sessions!



