

## Enhancing Public Engagement in Clinical Trials – Pulling Together a Framework

Linda Bennett

Executive Director, Canadian Rheumatology Research Consortium

Member, Network of Networks

(lbennett@mtsinai.on.ca)

CLINICAL TRIALS ONTARIO CONFERENCE 2014: CHALLENGES, OPPORTUNITIES AND NEXT STEPS

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# Clinical Trials Ontario – Strategic Pillar

- Pillar 3: Improving Patient Recruitment and Retention
  - Improving patient recruitment and retention through education and by engaging patients and the public in recognizing the benefits of clinical trials.

# Objectives

- Explore how key elements from this session might come together to form a framework to better engage the public in research
- Utilize the expertise here today to shape & inform next steps
- INPUT FROM YOU:
  - Are these the key pillars of a framework?
    - Gaps? Concerns?
    - Perspective of constituencies (i.e. patients, health charities, researchers, sponsors)?
  - What are the most immediate needs?
  - Are there any “low-hanging fruit”?
  - Is there a specific role for Clinical Trials Ontario?

## Raising Research Literacy - Education & Awareness (N2)

- Create national resources to support shared needs
- Function as an expert clearinghouse for general research information
- Build content & communication tools/processes
  - N2 website – repository for educational materials & tools
    - Resources for other stakeholders (health care providers, researchers, patient organizations)
    - Gateway for the public to BEGIN to learn about research
    - Links to more specific resources
      - Disease-specific
      - Other stakeholders & related initiatives

# Community Engagement to Enhance Reach & Relevance

- Create a forum of community groups that engage patients directly
  - Representatives who can speak on behalf of large constituencies
    - Patient groups, health charities, research initiatives
      - Identify gaps in knowledge and unmet needs
      - Inform the development of educational materials & approaches
    - Build a communication plan
      - Key core content/messages & templates
      - Central resource (N2 & others) could generate the core content for the stakeholder groups to refine and disseminate
      - Value of this approach
        - » Community-oriented & needs-based
        - » Leverage the expertise of the full stakeholder group
        - » Reduce the workload at the individual stakeholder level

# Information: General to Specific

- Trials information that might be relevant at a community/individual level
  - What is already known about my disease (disease literacy)
  - What research is ongoing and what will it tell us?
  - What is it like to participate in a study in my disease area?
  - What do I need to know to decide whether or not to participate?
  - How would I find a trial?
  - What are the results of completed studies?
  - How do the study results impact the disease prevention & management for people with my disease?

# Optimizing Consumer/Patient/Public Engagement – Partners in Research

- Cultivate, support & utilize patient/consumer advisors & ambassadors
  - Framework for optimal engagement
  - Depth of expertise in a breadth of areas
  - Active role in KTE
    - Bring the experience of their “constituents” to the research agenda
    - Engaged throughout the continuum of research activities
    - Distilling & disseminating the research findings
    - Facilitating uptake – optimizing care / policy advocacy
- ACE – led by people with arthritis & working for people with arthritis, their families, friends, government and the public.
- Lay representation - nothing about us, without us!

# Building a Framework for Enhancing Public Engagement in Research

## Panel Q&A and Discussion

### Framework Pillars

- **Raise the general research literacy**
    - Common education materials & communication tools/processes
  - **Strategic Community Engagement**
    - Inform resource development & facilitate public outreach
  - **Optimizing Consumer/Patient/Public Engagement**
    - Cultivate, support & integrate patient/consumer advisors & ambassadors into the research eco-system
- Are these key pillars of a framework?
    - Gaps? Concerns?
  - Does this make sense from your stakeholder perspective?
  - What are the most immediate needs?
  - Are there any “low-hanging fruit”?
  - Is there a specific role for Clinical Trials Ontario?