



N2 – A Shared Resource to Raise Clinical Research Literacy

Linda Bennett

Executive Director, Canadian Rheumatology Research Consortium

Member, Network of Networks

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

February 27, 2014

N2 Membership

- 35 Institutions
 - 13 Disease-oriented Networks
 - 10 Universities
 - 5 Industry
 - 3 Government
-
- Leverage the expertise within the group
 - Build materials that will serve a cross-section of stakeholders

Concerning Trends in Trials

- Recruitment and retention continues to worsen
 - Highly variable site performance
 - ~half the sites meet/exceed their targets
 - ~ half under-enroll or fail to enroll a single patient
- Experienced trial sites are closing
- Erosion of public and patient trust in the research eco-system

Source: CISCRP Presentation - Tufts CSDD 2011 & CenterWatch Report on Recruitment

CISCRP Perceptions of Study Volunteers

Network of Networks (N2)



Desperate

- (~29% believe only seriously-ill participate)

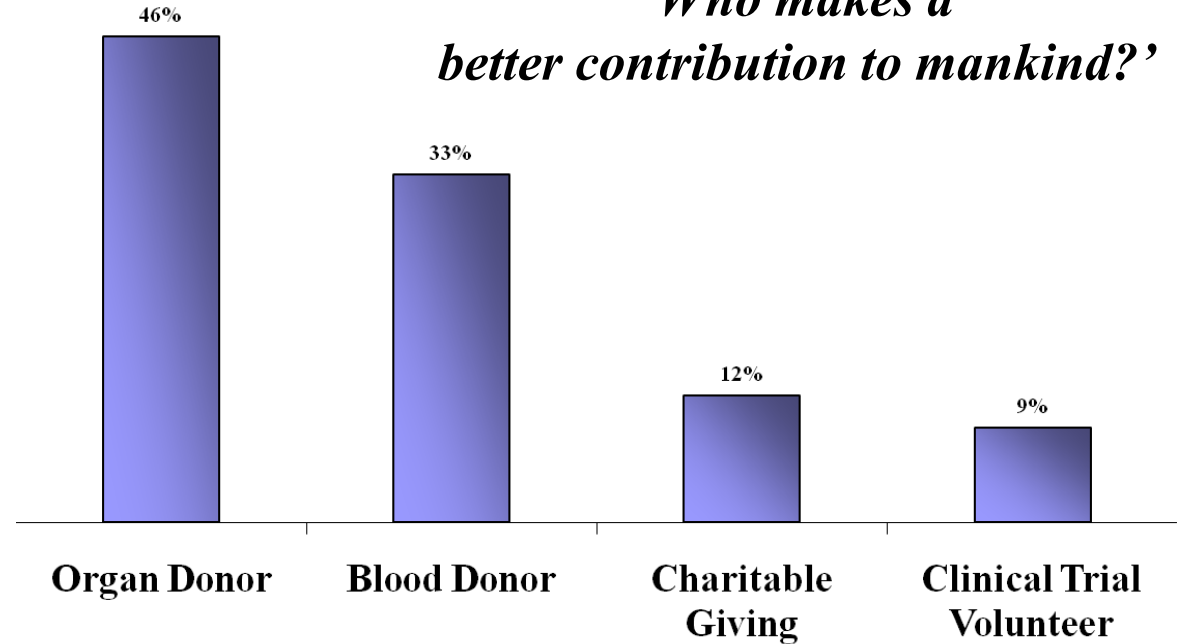
Risk Takers

- (80% believe participants are 'gambling' with their health)

Ambivalently respected

- (34% 'Don't Admire' study volunteers)

'Who makes a better contribution to mankind?'



Source: CISCRP, 2006; N=900

Patient Perspectives on Trials – BC Pilot Survey

A pilot study by CanMed, Vancouver Island (Trytten, Pommerville, Waldner, deBoer, 2011)

- Top reasons for **declining**
 - 65% Health benefit not guaranteed
 - 55% Placebo
 - 48% Inconvenient
 - 42% "Guinea Pig"/danger
 - 26% GPs did not support
 - 26% Families did not support

BCCRIN is currently conducting a clinical trial participation survey to determine why patients in BC (n=1000) partake or refuse to partake in CTs.



Patient Perspectives on Trials – BC Pilot Survey

- A pilot study by CanMed, Vancouver Island (Trytten, Pommerville, Waldner, deBoer, 2011)
- **Top reasons for consenting**
 - 97%/96% Liked/trusted the Study Coordinator and PI
 - 85% Safety risks were acceptable
 - 83% Benefit to society
 - 77% Access to health care services
 - 75% Improved health outcomes anticipated
 - 48% Free medication

BCCRIN is currently conducting a clinical trial participation survey to determine why patients in BC (n=1000) partake or refuse to partake in CTs.



Building Trust - Education & Community Engagement

- We must address:
 - public's lack of trust in trials
 - public's lack of knowledge about trials
- Educational materials
 - Highlight the value of research to our collective health
 - Informs best practices in disease prevention & management
 - General clinical trials information
 - How we safeguard patient well-being & research integrity
 - Participants rights & responsibilities
 - How to weigh the risks and benefits of participation
- Meaningful engagement at the community level - patients as research partners



Tools to Support Trials Education & Awareness

- Create a web-based repository for use by the public & stakeholders
 - General trials/research information
 - Current, credible, independent, lay language
 - Consistent key messaging across materials
 - Pamphlets, blogs/papers/info sheets on research issues, YouTube videos, researcher lectures, participant experiences, twitter feed, face book page
 - Links to search for ongoing trials
- N2's web site as a gateway for the public
 - Starting point to learn about research
 - Wrap up and anchor the overwhelming amount of material available on the web
 - Create linkages to resources that would provide more specific information
 - Disease-specific
 - Other organizations & initiatives



Strategic Roles

- Expert clearinghouse for topical research news
 - Drive this out to member organizations & interested stakeholders
- Coordinate/support large regional/national outreach initiatives (Canadian CISCRP campaign)



N2 Progress

- Trials Education & Awareness Committee
 - Many meetings with CISCPRP – Center for Information & Study on Clinical Research Participation
 - Robust set of materials and methods that could be adapted for Canada
 - N2 – limited by funding
 - Bilingual general information pamphlets – clinical trials & pediatric trials
 - Web site scoping document – vendor RFP
 - Member-generated materials & those in the public domain