

FOR IMMEDIATE RELEASE

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Canada's Clinical Research Community Needs Public Input



Clinical researchers would like to learn about Canadian's experience with clinical trials.

Clinical trials are a form of medical research that is important in helping researchers prove the effectiveness of new treatments, new ways of using current or known treatments, detection and diagnostic procedures and equipment. The value of a potential new treatment is weighed against possible or potential side effects with the ultimate goal being better outcomes and better quality of life. Clinical trials help everyone who has or someday may have a particular illness or condition by providing evidence

that potential treatments are helpful or not. Clinical trial patients are key to this research.

Until recently, there has been little effort to engage and learn from patients and the public about the clinical trial process. The British Columbia Clinical Research Infrastructure Network (BCCRIN) is improving this by providing unique opportunities for the public to provide input and advice on their experience with clinical trials, especially people who have declined to participate in a clinical study.

"Medical advances depend on people and it is up to us as a research community to listen and learn from the public," says Dr. Robert McMaster, Vice President Research, Vancouver Coastal Health and Chair of the Board of BCCRIN.

In April, BCCRIN completed a provincial survey of 596 people who either participated or declined to participate in a clinical trial. The majority of the respondents who did participate in clinical trials felt the safety risks were acceptable and that they would have better access to health care services. In addition, 87 percent felt they were benefiting society by participating and 70 per cent felt their health would improve.

The results also showed that 34 per cent of individuals who had declined participating in a clinical trial felt that their health would not benefit and 46 per cent did not participate because they did not want to receive a placebo (inactive treatment). The respondents also cited inconvenience and a perception of potential danger as other reasons for choosing not to participate.

To further understand how to engage patients and the public in clinical research, BCCRIN is pleased to announce the expansion of the clinical trials participation survey to a pan-Canadian audience. This expansion will enable Canadians from across the country to help inform clinical research practices around patient engagement and communications about clinical trials, building from the information already collected in BC.

To facilitate this expansion, BCCRIN will enter into a partnership with the Network of Networks (N2), which is an alliance of Canadian research networks and organizations working to enhance national clinical research capability and capacity. Heather Harris, Director of Operations at BCCRIN explains, "Partnering with N2 is critical to the success of this next phase of the survey. N2's broad membership base reaches the majority of stakeholders in the clinical research enterprise in Canada- essential to reaching the sample size needed to compare results between provinces and examine regional differences within our country".

BCCRIN acknowledges the national survey would not be possible without the support and funding provided by the Canadian Clinical Trials Coordinating Centre. "CCTCC is pleased to partner with BCCRIN on the national expansion of the BC Clinical Trials Participation Survey; collaboration among like-minded organizations is key to strengthening the clinical trials environment in Canada. A better understanding of what drives patient participation is vital to helping Canada regain its position as a global leader in clinical trials." says Elena Aminkova, Interim Director of Project Facilitation, CCTCC.

If you have participated in a clinical trial, were asked to participate and declined, or if you are the parent of a child who has been asked or has participated, your feedback is important to the future of research in Canada. The anonymous survey can be accessed at: www.bccrin.ca/survey

About BC Clinical Research Infrastructure Network:

BCCRIN is a collaborative partnership of provincial health authorities, research institutions, universities, industry associations and funding agencies, a first of its kind, focused on transforming the clinical research landscape in British Columbia, thereby enhancing our ability to compete in what has become a highly competitive global marketplace for clinical research. Our vision is that: *British Columbia will be among*

the world leaders in clinical research, driven by patient needs, and enabled by advanced science and methodologies. For more information please visit www.bccrin.ca.

Contact: Heather Harris, Director, Operations

About the Canadian Clinical Trial Coordinating Centre

The Canadian Clinical Trials Coordinating Centre was created to implement an action plan to strengthen and improve clinical trials in Canada and streamline processes for companies and researchers. Developed through extensive stakeholder consultation, the action plan includes nine key recommendations to improve the coordination of clinical trials in Canada, increase participation in trials, and strategically raise Canada's profile among international companies. More information is available about the CCTCC at www.cctcc.ca

Contact: Elena Aminkova, Interim Director Project Facilitation, eaminkova@cctcc.ca

About N2

The Network of Networks (N2) is a not-for-profit incorporated organization and an alliance of Canadian research networks and organizations working to enhance national clinical research capability and capacity. Bringing together trialists and clinical research professionals from across the country, N2 provides a common platform for sharing best practices, resources and research-related content to ensure efficient and high-quality research, integrity of clinical practices and accountability. The organization is truly representative of clinical research in Canada and 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. For more information please visit: <http://n2canada.ca>

Contact: Karen Arts, Chair