

NEWS RELEASE

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BC's Clinical Researchers Seek Public Feedback

(Vancouver, BC) Have you been asked to participate in a clinical trial? If so, British Columbia's clinical research community wants to hear from you, through a large scale survey.

Clinical trials are a form of medical research that studies new ways to prevent, diagnose, and treat diseases in people. The studies commonly assess if these new methods are effective and safe.

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) hopes to improve this by providing unique opportunities for the public to provide feedback 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 associate dean research, UBC Faculty of Medicine.

A pilot study led by Dr. Peter Pommerville, director of research at Can-Med Clinical Research in Victoria, was conducted on Vancouver Island in 2010. The majority of the respondents who did participate in clinical trials felt the safety risks were acceptable and that they were benefiting society by participating. In addition, 77 per cent felt that they would have better access to health care services and 75 per cent felt their health would improve.

The results also showed that 69 per cent of individuals who had declined participating in a clinical trial felt that their health would not benefit and 55 per cent did not want to receive a placebo (inactive treatment). The respondents also cited inconvenience and a perception of potential danger as other reasons for not choosing to participate.

These results are concerning to the clinical research community who depend on trials to inform their research and patient needs. "New therapies and ways to provide health care require clinical trials to prove what works best. This depends on all of us working together," says Dr. Anne Junker, director of the Maternal Infant Child & Youth Research Network of Canada. "People need to be involved to say what matters most to them in terms of their health condition. For instance, while mental health researchers are keen to

understand the cause of psychiatric disorders, kids with these conditions and their families really want to know how to navigate the health care system and get the best service possible."

To further understand how to engage patients and the public in clinical research, BCCRIN is launching a considerably larger study involving 1000 people across the province. The results will enable the clinical research community to target areas where more education and information is needed to address the public's questions and concerns.

"Clinical research can both help patients and help our health care systems find better, safer health care, says, Dr. Jim Russell, chief medical officer of BCCRIN and professor in the UBC Faculty of Medicine. " We really do need to understand much better why people choose not to participate in studies. Can we then improve our communications and approaches based on guidance from patients and the public to better our clinical studies in BC?"

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 BC.

The anonymous survey can be accessed at: www.bccrin.ca/survey.

About BC Clinical Research Infrastructure Network:

The British Columbia Clinical Research Infrastructure Network (BCCRIN) was formed in April 2010 as a response to the trend of decreasing industry sponsored clinical trials in BC and Canada. It has since grown to become a pan-provincial network of 23 member organizations representing research institutions, health authorities, universities, granting organizations, and the life sciences industry. These members are committed to the goal of developing and promoting BC to become a premier international location for clinical research to benefit all stakeholders especially patients.

For more information please visit www.bccrin.ca.

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