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YOU'RE INVITED TO JOIN THE

COVID CHILDREN HOMECARE COMPLEX NEEDS STUDY

Do you have experience with children's home healthcare during COVID-19?

ABOUT

The COCOON Study looks at the impact of COVID-19 on home healthcare services for children with rare diseases and/or complex needs. Homecare services for this study include:

- Nursing
- Personal support work
- Respiratory therapy
- Physiotherapy
- Occupational therapy
- Dietician services
- Social work

Our goal is to bring attention to home healthcare services for this unique population of children and their families, and gather real-time information to help address concerns, challenges and gaps experienced by families and health care practitioners during the pandemic.

If you have experience receiving or providing children's home healthcare during the COVID-19 pandemic, we want to hear from you.

NUMBER OF PARTICIPANTS & ELIGIBILY

We are seeking 200 survey participants and 15 interviews per country. The study is open to adults 18 or older who are:

- A parent or family caregiver of child with a rare disease and/or complex care needs who receives home healthcare services, **OR**
- A children's home healthcare practitioner providing care in the home during the pandemic to children with rare diseases and/or complex needs

WHAT WILL I BE ASKED TO DO?

To participate in the study, you will complete a web-based survey. The survey will ask questions about your experiences with pediatric home healthcare services. The survey takes approximately 20 minutes to complete.

INCENTIVE FOR PARTICIPATION

For completing the online survey, you will have the option of being placed into a random draw to receive one of twenty-five electronic gift cards valued at $10.

RESEARCH TEAM

RYERSON UNIVERSITY
- Dr. Karen LeGrow
- Dr. Sherry Espin
- Dr. Karen Spalding

THE HOSPITAL FOR SICK CHILDREN
- Dr. Eyal Cohen
- Dr. Krista Keilty

VHA HOME HEALTHCARE
- Dr. Sandra MacKay

UNIVERSITY COLLEGE DUBLIN
- Dr. Suja Somanadhan
- Dr. Thilo Kroll
- Dr. Helen McAneney

QUEEN'S UNIVERSITY BELFAST
- Dr. Amy Jayne McKnight

QUESTIONS & CONTACT

If you have any questions about this research, please contact Lois Chui (lois.chui@ryerson.ca). If you have questions regarding your rights as a participant in this study, please contact:

Research Ethics Board c/o Office of the Vice President, Research & Innovation, Ryerson University
350 Victoria Street | Toronto, ON | M5B 2K3
416-979-5042 | rebchair@ryerson.ca

If you're interested in participating in this study,

Complete the COCOON Survey

This study has been reviewed and approved by the Ryerson Research Ethics Board (REB 2020-453). The study is funded by Ryerson University & the Norman Saunders Complex Care Initiative at the Hospital for Sick Children.