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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
- Speech and language 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 & ELIGIBILITY

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 McAnaney

#### QUEEN'S UNIVERSITY BELFAST

- Prof. Amy Jayne McKnight

### QUESTIONS & CONTACT

If you have any questions about this research in general please contact Lois Chui (lois.chui@ryerson.ca). If you have any questions about participating in Northern Ireland, please contact Dr Julie McMullan (raredisease@qub.ac.uk)

If you're interested in participating in this study,  
**Complete the COCOON Survey**