

Assessment of the quality of life of children and young adults with congenital heart disease

Location: Quebec ([online questionnaire](#))

This study will be at the provincial level. We are aiming to pair the study data with the demographics from the ministère de la Santé et des Services sociaux (MSSS), the Régie de l'assurance maladie du Québec (RAMQ), and the Institut de la statistique du Québec (ISQ) in order to connect a person's results with their condition. This data will only be used for the pairing with the clinical data and will never be shared or sold.

Number of participants: 1000+

Recruiting period: 6 months

Description:

In this study, we want to better understand what impacts the quality of life of people with congenital heart disease. The study involves adolescents and adults with congenital heart disease as well as parents of children under 18 years old with the condition. To gain this understanding, we wish to collect information about the patients' perception of their quality of life. The participants will complete 3 online questionnaires, which take about 10 minutes. We want to have them fill out the questionnaire once a year for 3 years to see the evolution of their answers; a reminder will be sent to them once a year. The information collected will be linked to the type of congenital heart disease and the different procedures or surgeries the participants may have had. It will help us to better understand what affects their quality of life.

Languages: French and English

Eligibility criteria:

- Adults 18 years and older with congenital heart disease (any type)
- Adolescents 14 years and older with congenital heart disease
- Parents of children under 18 years old with congenital heart disease

Participation requirements:

Ideally, complete a short 10-minute online questionnaire once a year for 3 years. We ask for the RAMQ number to match the participants with their clinical data (including the exact characterization of their defect). This provides us with valuable information to understand the differences between the conditions. However, this information is optional.

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