

# What do cystic fibrosis researchers and patients think the future of cystic fibrosis will look like?

Lead Investigator: Jonathan Kimmelman

Co-Investigators: Patrick Kane

Funding Agency: Genome Canada

Term: June 2021 – June 2031

## Introduction

Recently work in the decision sciences has led to major improvements in the forecasting of geopolitical events. Using sophisticated survey methodology researchers have been able to combine the judgments of experts in policy and intelligence analysis into highly accurate forecasts for both near and long term events. This project seeks to borrow these techniques for improving the accuracy of judgments and apply them to a different domain: forecasting milestones in cystic fibrosis disease research. Teaming up with cystic fibrosis researchers at SickKids, we have designed a survey that will allow us to combine the judgments of cystic fibrosis disease experts (and lay people living with cystic fibrosis) into forecasts that can help to guide research initiatives and funding decisions over the next 10 years.

## Design

We are conducting a study of the forecasts of cystic fibrosis researchers and cystic fibrosis patients with respect to 10 important milestones in cystic fibrosis disease research. We will then use cutting edge techniques to combine the forecasts of these large groups into a single prediction for each of the milestones. We will also be conducting secondary analyses, comparing the forecasts of researchers with those of lay people, testing the accuracy of different forecasters and how they relate to demographic and psychological variables, and testing different methods of combining group forecasts.

## Protections For Participants

Our protocol has been reviewed and approved by McGill's Institutional Review Board (IRB). When responses are received, the predictions will be automatically recorded in our database. The names of researcher participants will be retained for follow-up purposes, and will not be made public without explicit consent. All collected identifying information will be destroyed at the time of final analysis. No identifying information will be collected from cystic fibrosis patients.

## Who We Are

This study is being led by Jonathan Kimmelman, head of the STREAM research group and associate professor in the Biomedical Ethics Unit / Social Studies of Medicine department at McGill University. The project manager is Patrick Kane, a postdoctoral fellow in the Biomedical Ethics Unit at McGill University.

## Questions

Should you have questions or concerns about our study, please contact [jonathan.kimmelman@mcgill.ca](mailto:jonathan.kimmelman@mcgill.ca) or [patrick.kane@mcgill.ca](mailto:patrick.kane@mcgill.ca).