

# What do Parkinson's researchers and patients think the future of Parkinson's will look like?

Lead Investigator: Jonathan Kimmelman

Co-Investigators: Daniel Benjamin, Patrick Kane

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## Introduction

You may have heard how Nate Silver's [fivethirtyeight.com](http://fivethirtyeight.com) effectively predicted the outcomes of U.S. elections. Or how a group of researchers, known as the [Good Judgment Project](#), has identified individuals who can very effectively predict geopolitical events – known as "[Superforecasters](#)." Perhaps you have also heard of how "[prediction markets](#)" and the "[wisdom of the crowd](#)" can be used to make more accurate judgments than their individual members.

Our lab is trying to apply similar methods to medical research. Specifically, we are using sophisticated survey methodologies to combine the judgments of experts into highly accurate forecasts for both near and long term events. This particular project seeks to apply these techniques for forecasting milestones in Parkinson's disease research. Teaming up with Michael J. Fox Foundation, we have designed a survey that will allow us to combine the judgments of Parkinson's disease experts (and lay people living with Parkinson's) into forecasts that can help to guide research initiatives and funding decisions over the next 10 years.

## Design

Our survey was developed in collaboration with three leading Parkinson's disease experts: [Anthony Lang](#) (Director of the Edmund J. Safra Program in Parkinson's Disease at University Health Network, University of Toronto); [Roger Barker](#) (Professor of Clinical Neuroscience at the University of Cambridge), and [Todd Sherer](#) (CEO Michael J. Fox Foundation for Parkinson's Research).

We will collect forecasts on 11 important research milestones in Parkinson's disease from researchers and lay people. 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). Surveys will be sent initially by email from the Michael J. Fox Foundation. 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 Parkinson's patients and/or lay people.

## Why Does this Work Matter?

Our study has numerous aims. First, it will help evaluate approaches for synthesizing expert and lay opinion –which could potentially be used for setting research priorities or decisions about the launch of new research initiatives. Second, our study will determine whether patient and lay person expectations about progress in Parkinson's disease are in synch with the perspectives of Parkinson's experts.

## Who We Are

This study is being led by Jonathan Kimmelman, head of the STREAM research group and James McGill Professor of Biomedical Ethics Unit / Social Studies of Medicine department at McGill University. [STREAM](#) studies ethical and policy issues in development of new treatments and diagnostics. Our previous work on forecasting in medicine was covered in [STAT News](#), as well as NPR's [All Things Considered](#).

The project manager is Patrick Kane, a postdoctoral fellow with a PhD in Decision Sciences.

## 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).