

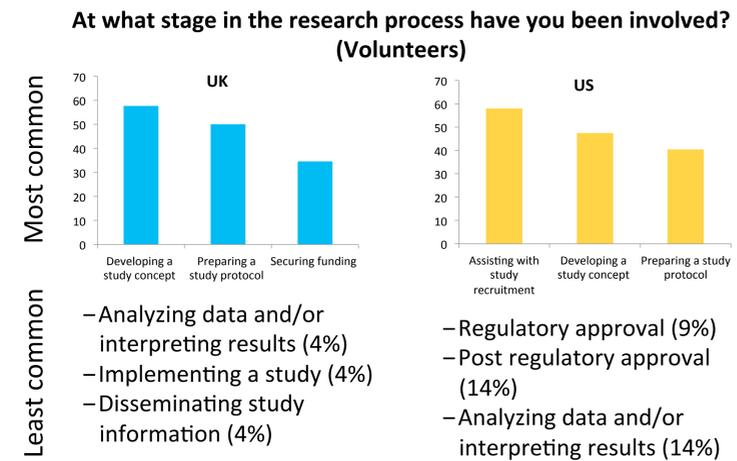


# Patient Engagement in Parkinson's Research: A Comparison of Attitudes and Impact in the UK and the US

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## Objective

To compare and contrast the attitudes and perceived impact of patient engagement on Parkinson's research among volunteers, researchers and study sponsors in the United Kingdom and United States.



## Introduction

In Parkinson's there is a global effort by patient organizations to support researchers and people affected by Parkinson's through collaboration in research. Parkinson's UK (PUK) and the Parkinson's Disease Foundation, a division of the Parkinson's Foundation (PDF), have led initiatives to facilitate partnerships among people affected by Parkinson's and researchers. These programs have trained and supported 288 patient advocates in the US and over 100 patient volunteers in the UK. A comparative analysis was conducted on attitudes toward, and impact of, patient engagement among Parkinson's programs based in two countries with organizational and systematic similarities and differences.

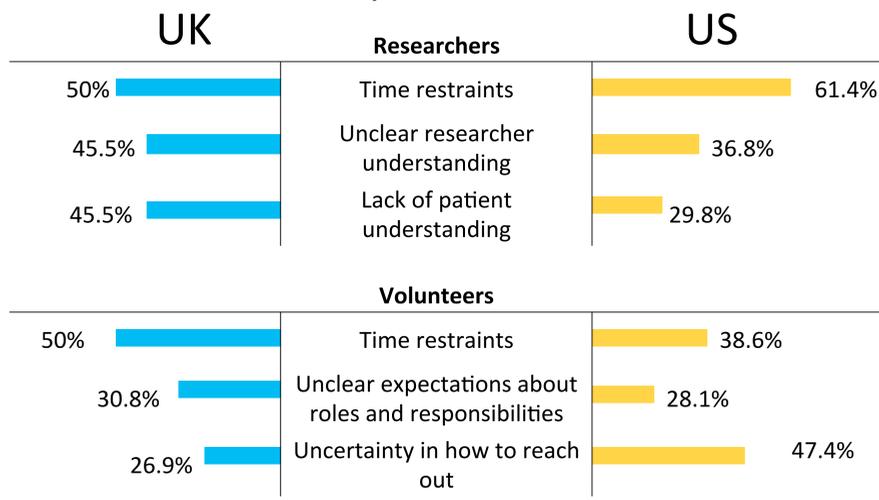
**Which aspects of your project were most impacted by working with people affected by Parkinson's?**

	1	2
UK Researcher	Made research more relevant (56%)	Improved communication (40%)
US Researcher	Made research more relevant (57.5%)	Improved recruitment (52.5%)
UK Sponsor	Validated research question (100%)	Made research more relevant (75%)
US Sponsor	Improved study design (55.6%)	Made research more relevant (44.4%)

## Methods

An online survey was conducted to identify differences in the attitudes and perceived impact of patient engagement in volunteers, researchers and study sponsors. Four PUK and PDF surveys were created to match professional and regional terminology between groups, however all content was uniform across surveys. A total of 101 academic researchers (44 UK, 57 US), 83 volunteers (26 UK, 57 US) and 16 study sponsors (5 UK, 11 US) completed the online surveys. Differences between groups and countries were analyzed using the chi-square test for independence.

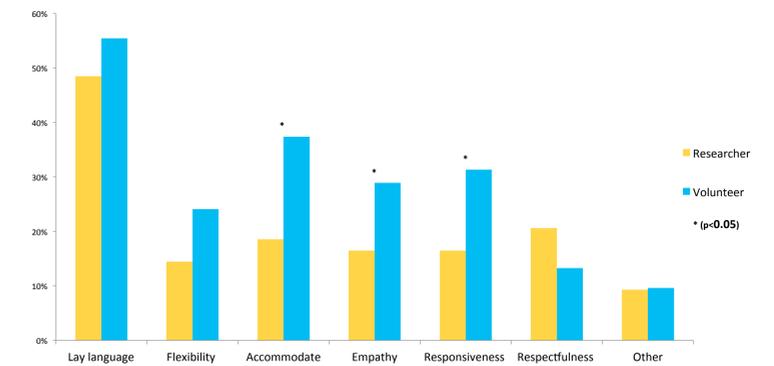
**What are the biggest challenges preventing researchers from involving people affected by Parkinson's in research?**



## Results

- Stages of Involvement in the Research Process**– Both UK and US volunteers reported prior engagement in developing a study concept and preparing a study protocol. However, US volunteers reported significantly more involvement in assisting with study recruitment ( $p < .05$ ).
- Patient Engagement Impact** – US researchers reported improvement in study recruitment significantly more than UK researchers ( $p < .05$ ).
- Perceived Challenges** – Respective to each group, both researchers (UK and US) and volunteers (UK and US) reported the same top challenges to patient engagement.
- Effective Engagement Qualities** – There were significant differences between researchers (UK and US) and volunteers (UK and US), however, both researchers and volunteers most frequently reported making research understandable to lay audiences (see chart).
- Expectations of the Advocacy Organization** – UK study sponsors reported expecting advocacy organizations to train volunteers significantly more than US study sponsors ( $p < .05$ ). UK researchers reported higher expectations regarding best practice guidance when compared to US researchers ( $p < .05$ ).

**What qualities do researchers need to successfully work with people affected by Parkinson's?**



## Conclusion

**There are a number of similarities in attitudes towards, and perceived impact of, patient engagement in Parkinson's research between volunteers, researchers and study sponsors across the UK and US.**

However, this work also highlights important differences between countries, particularly with respect to stages of involvement, impact of involvement and expectations. These differences indicate that there is a lot to be learned from cross-cultural collaboration to make global patient engagement stronger. Understanding the different attitudes between researchers, volunteers and study sponsors can help advocacy organizations better provide the tools and resources for effective and impactful patient engagement.

**What do you expect from an advocacy organization as it relates to patient engagement in research?**

