

Exploring the Barriers Preventing BAME Patient Engagement with Clinical Research

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Date: 28 January 2021

Introduction

Black, Asian and Minority Ethnic (BAME) groups make up approximately 13% of the United Kingdom (UK) population (ONS, 2011). Anecdotal evidence suggests that clinical trials recruitment does not mirror the UK population with respect to BAME population groups. BAME is one of the underserved populations as defined by Witham et al (2020). Improving representation of people from under-represented groups is important if we want to ensure that clinical research findings are widely applicable (Witham et al, 2020).

Witham, et al (2020) state one of the reasons of underrepresentation of BAME populations is 'trials often seek narrowly defined homogenous population to reduce variance and hence sample size, and strict inclusion and exclusion criteria leads to unrepresentative trial populations' Witham et al (2020). Farooqi (2018), states that the reasons for under-representation of BAME groups in research are complex, and barriers include language, cultural values, finances, mistrust and general accessibility to research in deprived areas.

As highlighted above, there are many factors to low uptake of clinical trials in BAME populations therefore, it's imperative to explore this further with the proposed project. As a first step a questionnaire will be generated to gain a better understand what the barriers to uptake of research are amongst BAME groups.

Improvement methodology

PDSA Cycle is the tool of choice for this QI project. This tool will help manage the project in a more methodical manner.

Cycle 1: Brainstorm with colleagues and develop questions for the questionnaire.

Cycle 2: Once questionnaire is complete this will be offered to all identified families.

Cycle 3: Analyse the data collected

Cycle 4: implement changes based on results. It is likely additional support will be required if there are financial costs involved in improvement.

The approach

What we were trying to accomplish

To gain a better understanding of how we can improve the uptake of BAME participation in clinical research.

What we measured to understand if our change was an improvement

Generate questions to improve/increase the uptake of clinical trials in the BAME population. This will be offered to families that are identified as eligible for participation in any active paediatric clinical trial. The questionnaire will aim to better understand family views about clinical research and what we as a Trust can do to make participation easier.

What changes we made / are making

The results from the questionnaire will determine the changes that can be implemented. I anticipate participant feedback will inform future direction of research.

The impact

- Findings from the questionnaire will help determine how services in paediatric clinical research can be improved, and how we can improve access and increase uptake of research for patients from all ethnic backgrounds.
- Improving uptake in clinical trials for patients from BAME backgrounds will contribute to results and findings being meaningful and representative of the wider population. This can help wider BAME communities make more informed decisions about their own healthcare when it is needed.

Leadership learning

- Although this QI project hasn't started, it has been possible to identify key stake holders and individuals that will help drive this project and contribute to quality and service improvement in practice
- Strategies have been identified to implement changes in practice, enabling improvement in trial recruitment/opportunities for BAME groups
- Increased confidence in leading on projects

Next steps

The results from the questionnaire will determine the next steps. However, I anticipate the following are some of the steps to follow on:

- Staff training/education
- Patient and Public involvement groups, specifically young people.
- Improved support for BAME families that want to participate in trials but lack the resources/funding/support