



Enabling research participation in under-served populations in Sheffield



NHS
Sheffield
Clinical Commissioning Group

SEPTEMBER 2021

Dr Kate Fryer and Dr Caroline Mitchell
University of Sheffield



The
University
Of
Sheffield.



General Practice at the Deep End
Yorkshire and the Humber

Introduction

Funding and aims

Dr Caroline Mitchell (GP) and Dr Kate Fryer (Researcher) were awarded two grants to support a 6 month project aimed increasing the capacity for inclusive research in Sheffield. This work was funded by a research capability funding grant from Sheffield Clinical Commissioning Group, and the NIHR Local Clinical Research Network, Yorkshire and Humber, with a grant jointly to the Deep End and Township clusters.

The aim of this project was to increase the number of people from ethnic minority and deprived backgrounds taking part in research – both in Patient and Public Involvement work, and as research participants. This aim was met by the following objectives:

- Putting resources into practises to support recruitment
- Identifying interpreters to facilitate non-English speakers to participate
- Developing a diverse PPI group
- Developing relationships with community organisations



Dr Caroline Mitchell, GP



Dr Kate Fryer, Researcher

“Lack of diversity in clinical trials is a moral, scientific and medical issue” Clarke et al 2019

Putting resources into practices to support recruitment

Appointment of research nurse

We are delighted to welcome Johanna White to our team, a research nurse who will provide support to the Deep End and Township clusters in recruiting to research projects, and support PPI work in the clusters.

Johanna qualified as a Nurse in 2008 from University of Nottingham. Since 2013, she has worked as a Practice Nurse across Sheffield and Derbyshire. Prior to that she worked in Critical Care.

Whilst working in Primary Care, Johanna has witnessed the dramatic health inequalities that exist in today's society. Through her work as a Practice Nurse in the Page Hall area, Johanna has established close links with the Pakistani and Roma Slovak communities, working to understand and overcome the barriers that prevent people from accessing the support that they need to live healthier, happier lives.

When she is not working or looking after her young family, Johanna spends most of her free time at Greentop Community Circus, training in aerial arts and acrobatics.



Supporting non-English speakers to participate

Establishing and training a panel of interpreters

In order to support people who are not confident in communicating in English to participate in research, we identified interpreters who are experienced in interpreting in healthcare environments, and were interested in learning more about interpreting for health research. We now have 6 interpreters who have received an online training session in interpreting for research, and have so far translated materials and interpreted for Dr Shami Jayasooriya's lung health PPI consultations.

The panel cover the following languages:

Urdu/Punjabi

Pashto

Arabic

Roma/Slovak



Typical Interpreting Costs

| Online training | Transation of recruitment materials | Interpreting |
|---|---|---|
| <ul style="list-style-type: none">£40 per 1 hour online session | <ul style="list-style-type: none">£45-85 per document depending on length | <ul style="list-style-type: none">£20 per hourInlcude travel and debriefing time |

Building on an existing Deep End PPI panel

Strengthening and diversifying

A Deep End PPI panel was established at the Whitehouse surgery in 2017 by Dr Liz Walton, who supported the panel as they found their identity and gained confidence in giving their feedback to researchers, in regular PPI meetings. They also attended stakeholder meetings where they contributed alongside academics and GPs.

With Liz having moved on from her role in the Deep End, the group activities paused, and the COVID-19 pandemic further delayed the restarting of this group under the new Deep End leadership of Dr Tom Lawy.

The original Deep End members were contacted to ask if they were willing to be contacted by Kate, and 5 responded to this call. In addition to this, an extra member was recruited, from a South Asian background, to add further diversity to the group.

We had an initial introductory video meet, where we discussed a way forward. We continued to have regular video meetings, and in addition to this the panel took part in a wide range of PPI consultations with researchers from Sheffield and other organisations.



Cognospeak PPI event

The PPI group have shown amazing patience and resilience, persisting through technical difficulties, and their own personal challenges during the pandemic to make valuable contributions to research.

Contribution to research

Here is a list of the projects that our PPI panel have participated in, during the last 6 months – quite an achievement given the pandemic, which entailed doing most of this work online:

| Name of project and organisation | Nature of PPI involvement | Current project status | Feedback |
|---|--|--|---|
| New remission care pathway: Diabetes Adaptive Weight management Network (University of Oxford) | Phone consultations to provide feedback on project proposal, presented as report. | Awaiting outcome. | <i>"That is incredibly helpful, and so interesting to read thank you for all your work on this"</i> |
| Brain-body axis stimulation in Long-Covid (B-BASIL) (University of Sheffield) | Phone consultations to provide feedback on project proposal, presented as report. | Project not funded, but commended for excellent PPI input. | <i>"The study design appears to be co-developed by stakeholders from the community who have suffered from long COVID. Special consideration has also been given in PPI to ethnic minority groups"</i> |
| The development of a microsite for research in Sheffield (Yorkshire and Humber Clinical Research Network) | Online focus group to discuss design and content of website. | Website nearly ready for launch. | <i>"It was great to get these perspectives and we got some excellent suggestions on how to make the microsite more accessible"</i> |
| Joining up primary and specialist care for people with complex mental health difficulties | Phone consultations to provide feedback on project proposal. | Funded | <i>"We were able to get PPI input at last minute, representing the populations that we most need to target"</i> |
| NHS 111 Online Study (University of Oxford) | Online focus groups to 'sense check' findings. | Project completed and report in progress. | <i>"We love the chance to speak to real people, especially when they are so open and happy to share"</i> |
| Decolonising Sugar-Related Public Health Practice (University of Sheffield) | Researcher attended monthly PPI meeting to get feedback on her fellowship application. | Application in progress. | <i>"It was really good to hear people's views. If the application is successful it will certainly inform the way I approach things"</i> |
| CognoSpeak: An automated cognitive assessment tool based on language | In person focus groups to explore how the CognoSpeak concept would be received in different communities. | Project ongoing. | <i>"Lovely, very engaged people and great input and expressions of interest going forward"</i> |

Community engagement

Developing relationships with community organisations

We acknowledge that there are complex reasons why people from ethnic minorities may be less likely participate in research, and recognise that community organisations hold a position of trust within ethnic minority and deprived communities. We wanted to begin to work with these organisations, to better understand the needs of communities in relation to research.

Community organisations in Sheffield mobilised during the pandemic to respond to the needs of their communities, providing an outstanding level of support to those in need. Part of this response has involved creating structures for the dissemination of important health messages.

We wanted to see how these structures might be utilised going forward from the pandemic, for wider health messages, including information about the importance of health research, and how to get involved.

We made contact with several community organisations in Sheffield, including SOAR, Faithstar and SaCMHA, to discuss ways of working together, and will be looking to further strengthen these partnerships over the next 6 months, in relation to specific projects around cancer (led by Dr Qizhi Huang), dementia (led by Dr Josie Reynolds), respiratory health and sexual and reproductive health (led by Dr Emma Linton).

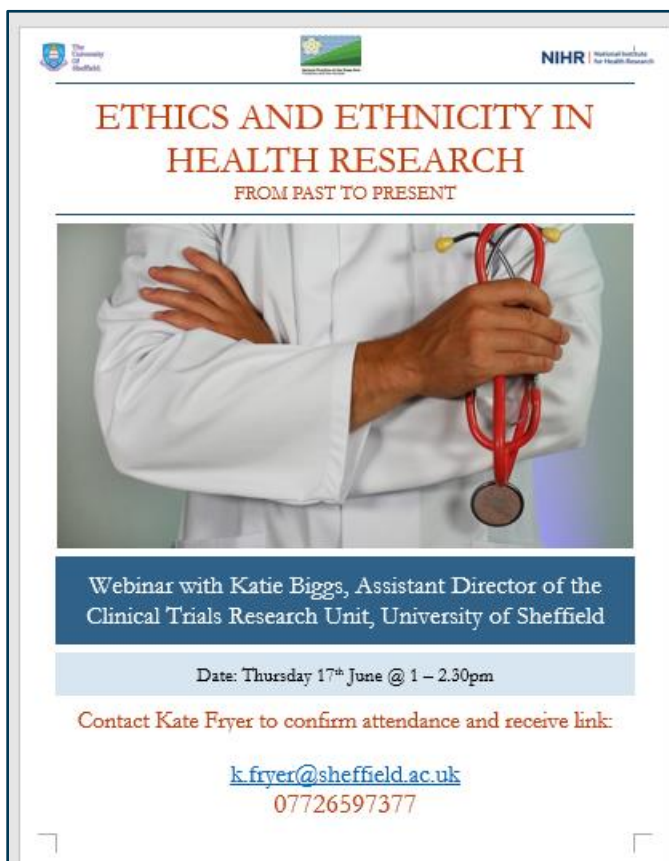
Ethics and ethnicity in research webinar

During our engagement with community groups we were told that people from ethnic minorities may be fearful of medical research because of well-known previous research and medical ‘scandals’, many of which affected specific ethnic groups. As researchers, we are aware of changes in law that mean such abhorrent practices should no longer

be possible, but we haven't necessarily passed this on to the general public and those communities who need to hear it.

As a response to this, we joined forces with Katie Biggs, Assistant Director of the Clinical Trials Research Unit at the University of Sheffield, for a webinar, 'Ethics and Ethnicity in Research'. Katie detailed some of the research scandals that have taken place in the past, before describing measures that are now in place to prevent such things happening again.

We then had a panel discussion where questions were answered by Katie, Michelle Horspool, and Dr Josie Reynolds (GP). The session was attended by community leaders, Deep End PPI contributors, GPs and academics. The feedback from the webinar was extremely positive, and it has inspired a series of webinars by the EMRI group. However, moving forward, these webinars will focus more on hearing from the communities about their own experiences.



The poster is for a webinar titled "ETHICS AND ETHNICITY IN HEALTH RESEARCH" with the subtitle "FROM PAST TO PRESENT". It features a central image of a person in a white lab coat with their arms crossed and a red stethoscope around their neck. Logos for The University of Sheffield and NIHR (National Institute for Health Research) are at the top. Below the image, it says "Webinar with Katie Biggs, Assistant Director of the Clinical Trials Research Unit, University of Sheffield". The date is "Thursday 17th June @ 1 – 2.30pm". Contact information for Kate Fryer is provided at the bottom.

ETHICS AND ETHNICITY IN
HEALTH RESEARCH
FROM PAST TO PRESENT

Webinar with Katie Biggs, Assistant Director of the
Clinical Trials Research Unit, University of Sheffield

Date: Thursday 17th June @ 1 – 2.30pm

Contact Kate Fryer to confirm attendance and receive link:
k.fryer@sheffield.ac.uk
07726597377

“I really enjoyed the webinar yesterday, it was so interesting and very well thought out. The presentation and panel were really good and there was a lot of interesting discussion and things we can all take away from that. I really enjoyed it.”

Qualitative Research Project – ‘Including Diverse Communities in Health Research’

We were hearing so many interesting and important messages during our community engagement that we have decided to carry out a small qualitative research project to enable us to explore these in a more structured way. The research questions and design of the project were presented and clarified during a stakeholder meeting which included PPI members, GPs and academics. The project will use focus groups and interviews with community leaders and patients to answer the following questions:

- What are the barriers and facilitators/motivators to participation in research by people from ethnic minority and deprived backgrounds, at service, societal and personal levels?
- What strategies and resources are needed to overcome barriers to participation in research by people from ethnic minority and deprived backgrounds?

The findings from this study will inform our own future work, and we plan to publish and present the work in community and academic forums to help other people working in the same area.

Budget

Please see the breakdown of our budget below:

| | |
|--|-----------|
| Budget total | 10,957.25 |
| Interpreter training (online training session for 6 interpreters @ £40 each) | 240.00 |
| Research Nurse time to support GP practices | 1813.00 |
| Research cluster meeting venue, lunch and welcome gifts | 683.84 |
| PPI vouchers for attendance at cluster meetings (5x£30) | 150 |
| Budget remaining | 8070.41 |

- All other PPI involvement was funded by researchers.
- The remaining balance will be used to fund our research nurse in the coming months.

Get in touch

If you would like to find out more, please get in touch:

Kate fryer – k.fryer@sheffield.ac.uk

Caroline Mitchel – c.mitchell@sheffield.ac.uk

<https://www.sheffield.ac.uk/medicine/research/research-themes/primary-medical-care>

Acknowledgements

We would like to thank our funders:

NIHR Research Capacity Fund (RCF) grant from Sheffield Health and Social Care Trust/ NHS Sheffield Clinical Commissioning Group Yorkshire and Humber CRN Strategic Business Case Grant

Thank you also for continuing support and guidance from:

- Shameen Khan, Tom Lawy (leads Sheffield Deep End CRN), Allison Smith / Qizhi Huang (leads Sheffield South East /Township) CRN)
- The LCRN Yorkshire and Humber Core Team | NIHR Clinical Research Network (CRN): Christopher Rhymes, Srdjan Ljubojevic, Duncan Courtney, Gail Baggley
- Dr Michelle Horspool: Deputy Director Research Sheffield Health and Social Care NHSFT/ NHS Sheffield CCG
- The YH NIHR EMRI (Ethnic Minority Research Inclusion)Group