

**Patient and Public Involvement in Decentralised Clinical Trials** 

Dr Amy Rogers University of Dundee

Mr Ken Tait Trials@Home PEP







## In association with...













































































## **Disclaimer**

The research leading to these results was conducted as part of the Trials@Home consortium. This presentation only reflects the personal view of the stated authors and neither IMI nor the European Union, EFPIA, or any Associated Partners are responsible for any use that may be made of the information contained herein.







# What is a decentralised clinical trial (DCT)?



"trials that make use of digital innovations and other related methods to make them more accessible to participants"

"moving trial activities to the participant's home or to other local settings"





"minimising or eliminating physical visits to a clinical trial centre"

Adapted from: https://trialsathome. com/trialshomeglossary/







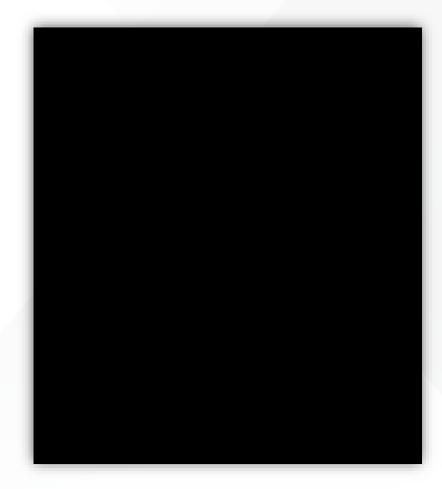


# Trials@Home Patient Expert Panel (PEP)

Up to 8 members + coordinator



- Voluntary
- · Flexible participation, mainly online
- Travel and expenses + annual stipend















ORIGINAL ARTICLE 🙃 Open Access 💿 😯 🦠

Learning from remote decentralised clinical trial experiences: A qualitative analysis of interviews with trial personnel, patient representatives and other stakeholders

Joanne Coyle M. Amy Rogers, Rachel Copland, Giorgia De Paoli, Thomas M. MacDonald, Isla S. Mackenzie, on behalf of the Trials@Home Consortium

First published: 23 July 2021 | https://doi-org.libezproxy.dundee.ac.uk/10.1111/bcp.15003 |



Research | Open Access | Published: 30 July 2022

A secondary qualitative analysis of stakeholder views about participant recruitment, retention, and adherence in decentralised clinical trials (DCTs)

Joanne Coyle, Amy Rogers ☑, Rachel Copland, Giorgia De Paoli, Thomas M. MacDonald & Isla S. Mackenzie on behalf of the Trials@Home Consortium

Trials 23, Article number: 614 (2022) | Cite this article



https://paperpile.com/shared/28ydSr









# **Defining PPI**

"The active, meaningful, and collaborative interaction between patients and researchers across all stages of the research process, where research decision-making is guided by patients' contributions as partners, recognising their specific experiences, values and expertise"

Patient Engagement in Research Working Group of the ISPOR (International Society for Pharmacoeconomics and Outcomes Research) Patient-Centered Special Interest Group









# **Differing perspectives**

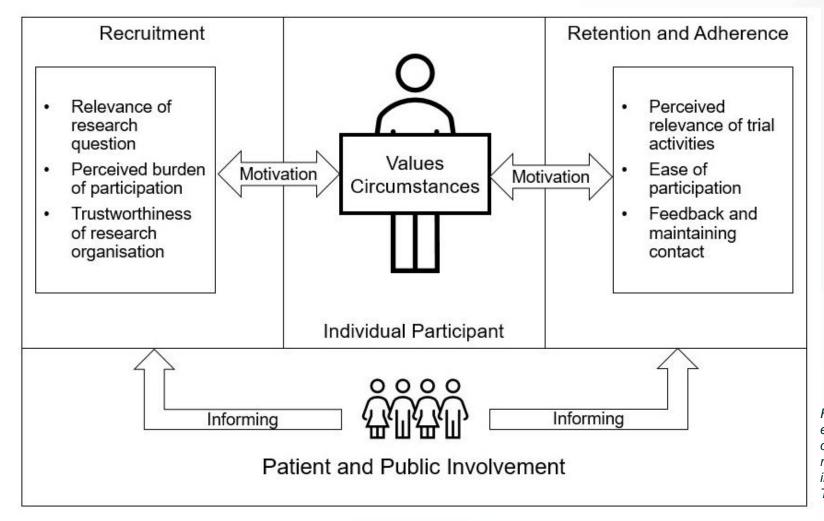


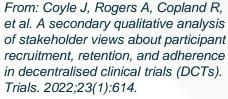






## How PPI can contribute to a successful DCT













# **Challenges of PPI**

#### **Lessons learned from case studies**



Early implementation



Supporting PPI contributors



Seeking diversity









## So, what makes DCTs different?

#### Spoiler: they are not that different when it comes to PPI

- Perceived need to balance lack of in-person contact
- Greater emphasis on role of PPI in developing and strengthening trust
- Technologies can act as barriers and facilitators to effective PPI





#### Amy Rogers University of Dundee



a.rogers@dundee.ac.uk



dramyrogers

trialsathome.com



trialsathome@umcutrecht.nl



@TrialsatHome



imi-trials-home



