

Remote working in a pandemic on an urgent public health trial – challenge or benefit for patient and public involvement (PPI)?

Sprange K¹, Godfrey M¹, Leyland V¹, Robinson K¹, Belfield K¹, Daunt W¹, Armstrong-Buisseret L¹, Rick C¹, Bath P¹ on behalf of the PROTECT-CH triallists

¹University of Nottingham

Background

Prophylactic Therapies in Care Homes (PROTECT-CH) was an urgent public health trial responding to the need to reduce the spread and severity of COVID-19 incorporating embedded PPI. In line with government pandemic guidelines remote working became the norm for many trial teams including collaborating with PPI partners. However, the fundamental processes, equipment and interactions needed to support this new way of working need to be better understood to inform decisions on how to best work with PPI going forward. We reflect on our experience of organising, planning and conducting a PPI group online during the set-up of the PROTECT-CH trial.

Methods

The PPI group, consisting of 2 lay members and 5 trial team members, was formed during the trial set-up phase and was in operation for 8 months until the decision was made that the trial was no longer feasible due to the changing epidemiology of COVID-19 in the UK. There were plans to increase lay membership to improve national representation but the trial was stopped before 3 identified individuals could join the group.

Findings

BENEFITS OF REMOTE WORKING

Due to the lockdowns and enforced online working the group had more time to dedicate to the PPI role and therefore develop more 'buy-in' to the project and more impetus to engage in the trial

Working online enabled the group to meet frequently and at short notice for ad-hoc or urgent requests as expected in an urgent trial which would not have been possible with in-person meetings

There was no travel time required to work online which was more convenient for those group members with caring responsibilities and also saved on costs and difficulties finding and booking meeting venues

The online environment was seen as a less hierarchical space where group members were equal parties unlike organisational premises which were deemed to be researcher territory and therefore could be intimidating

It enabled efficient working and rapid turnaround of tasks in real time deemed essential for an urgent trial e.g. editing documents together using TEAMS Share

CHALLENGES OF REMOTE WORKING

The size and composition of the group was deemed important for working online to be successful. A larger group would have been more complex to manage online and may have impacted the dynamics of the group

Working online could be isolating, but group cohesion was created through establishing a safe and equal space for members, development of friendships, maintaining regular contact and having social time

Individuals need access to appropriate IT equipment and software to enable engagement, one PPI member only had access to an iPad which required creative ways of working. This was a particular issue when using Microsoft applications

Although the level of PPI IT literacy using video conferencing platforms was very good in this group, training and ongoing support should be offered throughout the project to support engagement

Maureen: "Being in this trial embedded all my experience of PPI in such potentially vital research. Remote working during lockdown made it possible and facilitated the very intense involvement and progress the initial complicated stage of set up of a platform study"



University of Nottingham Community Volunteer of the Year (Group) award 2021

Val: "There was no sense of 'them and us', paid staff vs lay members. We all gelled and quickly developed mutual respect, building on each others' strengths. The urgency of the project facilitated this"

Discussion

- The intense engagement required to establish an urgent public health trial during the pandemic was enabled by online working.
- The PROTECT-CH PPI group was successfully convened online and contributed to the set-up of the trial.
- Researchers should consider the needs of their PPI members as well as those of the trial when planning and organising PPI groups.
- Alternative models of working should be explored and agreed with PPI to maximise engagement.



University of
Nottingham
UK | CHINA | MALAYSIA

PROTECT-CH
Prophylactic Therapy in Care Homes Trial

FUNDED BY

NIHR

National Institute for
Health and Care Research

