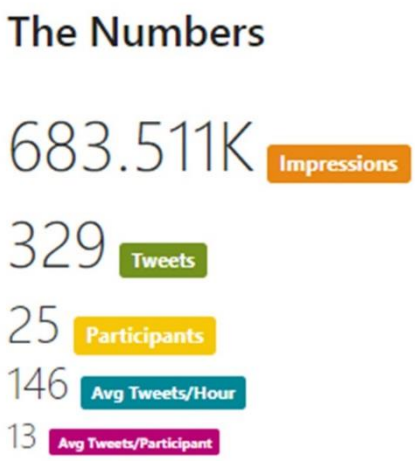
#WhyWeDoResearch

"Restarting non COVID-19 Research"

TweetChat 10: 26th May 2020



*The tenth #WhyWeDoResearch 2020 weekly tweetchat explored **Non COVID-19 Research**. The theme for this #WhyWeDoResearch tweetchat was a result of discussions around 'recovering' original research services whilst maintaining COVID-19 studies, perhaps until time when a vaccine may become available. Below is a summary of the #WhyWeDoResearch tweetchat. Please note that the representative examples may vary depending on the location and the experiences of individuals. We decided to video record the questions as this medium of interaction, which seemed to be well received in the previous chats. The transcript of the #WhyWeDoResearch tweetchat (held on 26.05.2020) is available: click here.*

Health & Wellbeing

In comparison to other #WhyWeDoResearch tweetchats the overall mood seemed to be low. Most people spoke of loneliness, missing extended family and friends, feeling down, and fed up being stuck in the house. Some spoke of how #WhyWeDoResearch tweetchats "will lift my mood". Only one person spoke how they had baked (a hobby that had been re-focusing on during the restrictions) to help with feeling frustrated.

It was decided that the next #WhyWeDoResearch tweetchat (2nd June 2020) should focus on self-care. We wanted a space for the #WhyWeDoResearch community to share with each other the hobbies and skills etc that they are using to support and protect their health (physical and/or mental).

Non COVID-19 Research

The need for non COVID-19 studies to support the health of the population was mentioned throughout the #WhyWeDoResearch tweetchat. People tweeted how non COVID-19 studies, either existing, had been paused or had their start-up postponed, should change "to take account of the 'new normal'". With the amendments/changes to studies it was asked if studies were not 'restarting' but instead different versions were being launched.

Public Patient Involvement

Many wondered how the process, and who will be part of the process, for deciding which studies will start, what amendments need to be made etc will be shaped. The National Institute for Health Research (NIHR) have published "A framework for restarting NIHR research activities which have been paused due to COVID-19"but many patients wanted greater acknowledgment and clarity on the importance of involving the service users in determine which studies to recover and what amendments are needed.

Studies need to be "flexibility…as will involving patients/ participants in thinking about solutions". One tweet asked "Is the research question, methods, measures, outcomes etc still relevant to people living with the disease?". This linked in with questions around consent. Participants, on either paused or on-going research, had consented to the study pre-COVID19. As so much has changed, are patients still happy to take part and do they know what changes have made? Also, for studies with patients who are at high risk of Covid-19 complications, "…they would not want to go anywhere near a hospital or other health facility anytime soon. Even non-high risk participants may feel the same".

Virtual Assessments

Virtual assessments were discussed as way for study participants to avoid travelling for research assessments. It was highlighted that some assessments would still need to be done face-to-face and that we don't know yet what impact virtual versus face-to-face assessments has on the quality of the data collected. Other concerns were that the platform chosen to collect data virtually may not be suitable to the needs of the study participants, patients may not have access to computers or internet and that for some the cost of the

paying for the internet would make virtual assessments inaccessible. However, overall, most people felt that virtual assessments, were possible, should be utilised.

Hospital Resources

The capacity for Trusts to delivery non-COVID19 research was another topic. Some sites had reduced research staff as they had been deployed to other areas (although they were starting to return to their research roles) and some sites had gained additional research staff, from other areas, to support COVID-19 studies but would need to return to their original departments soon. All sites reported that COVID-19 research "is keeping us busy even without most of the old studies that we had to pause".

Capacity needs to be built up slowly (to ensure that studies are implemented safely). Also, there remains a risk of additional waves of COVID-19 and this will mean that research staff will be redeployed again so there is potential for a lot of stopping, restarting and disruption. The "studies that are picked up at this point will have to be those we could also put down again if we need to be flexible. Some pre-Covid19 studies will not possible to run at the moment".

In needing to determine what non-COVID19 studies to run it has presented sites the opportunity to reassess their operational standards and how they evaluate which studies to set-up and support.

Study Sponsors

"Sponsors have some big decisions to make re changing protocol"; "Are they [sponsors] ready for the study to be 'restarted', can they facilitate the amendments that need to be done, has the lost data actually meant that the study will not be able to assess the endpoints etc?" Others tweeted how most of their studies would need big changes in their protocols to be restarted and "although I'm expecting that how the clinical side operates will be changed somewhat in the mid/long term, the studies don't seem to be yet".

Some were worried that with each Trust deciding which research to restart that studies will struggle to collect enough data to achieve their sample sizes to analyse their end-points and

asked “should we all prioritise some so we don't risk all studies failing?” One tweet asked “Some studies also follow the same patients over 12 months, for example, so if they miss timepoint capture do they have to start collecting data again from the first timepoint?”

Post COVID-19

The knock-on effect of COVID-19 and the potential implications on how studies will run was discussed. This included how current restrictions were stopping older people and people from other demographics taking part in research which hinder our ability to learn and develop new treatments for this section of society.

Another area discussed was the need for follow-up on COVID-19 patients and those that participated in COVID-19 studies. Post COVID-19 care (mental health, respiratory care, physiotherapy etc) were all seen as equally important as the care provided while admitted for COVID-19.

Questions

#WhyWeDoResearch
(26.05.2020)

Last question of the eventing: Tell us a joke.

Let's keep ourselves laughing!

Please remember to include
#WhyWeDoResearch in all your tweets.