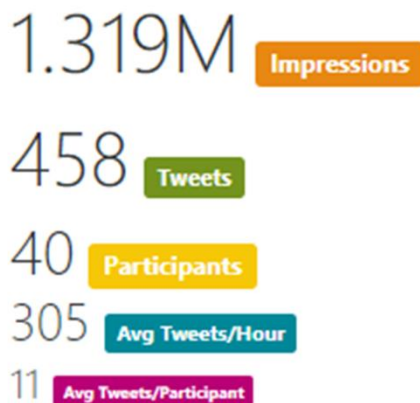


#WhyWeDoResearch

“Positive Changes/Improvements During COVID-19”

TweetChat 7: 5th May 2020

The Numbers



*The seventh #WhyWeDoResearch 2020 weekly tweetchat explored **Positive Changes/Improvements During COVID-19**. The theme for this #WhyWeDoResearch tweetchat was a result of previous tweets commenting on obstacles being removed for research to happen. For example, people working across disciplines and less travel to meetings. Below is a summary of everyone’s tweets merged under different sub-headings. 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 seemed to be well received in the previous chats. The transcript of the #WhyWeDoResearch tweetchat (held on 05.05.2020) is available: [click here](#).

Health & Wellbeing

We start each #WhyWeDoResearch tweetchat asking everyone how they are feeling and how the past week has been. One of the big positives of the #WhyWeDoResearch tweetchat was reflected in some of the tweets which said that the weekly tweetchat was “like our little social club on a Tuesday night” and how it brought everyone (researchers, healthcare staff and patients) together.

Midwives said that had had celebrated International Day of the Midwife but missed the usual celebrations from previous years. People tweeted about continuing with new hobbies that had started at the beginning of the restrictions such as; gardening, learning a new language and playing musical instruments. Some spoke of feeling lonely, getting used to working from home and some patients reported that they were involved in developing research “bringing the patients adventure and experience to the front of the #health

agenda". Others tweeted about getting too acclimatised to life in lockdown and it was our new reality. Some spoke that having a chronic disease meant being very adaptable to change.

Positive and Potential Opportunities – Overall

One of the main tweet themes was how research is now in the news all the time. Research is now more visible in hospitals and the public are more aware of research and have a greater appreciation of research.

Others tweeted how research staff were able to engage with clinicians and whole teams who were not previously 'research active'; gave examples of people working more efficiently and working across disciplines; multi-team collaboration to get things done quickly and new ways to do involvement in research.

People tweeted that they hoped research will come out stronger and more integrated and part of everyone's patient journey in the future. It will now mean that we check in with how much of our research is meaningful and how we continue to do more meaningful research using appropriate and inclusive methods.

Potential Opportunities – Patient Involvement

This #WhyWeDoResearch tweetchat asked about the positives that had come from COVID-19. The strongest theme that dominated most of the conversation was a hope for better opportunities with patient involvement. Most people said that would like to see a greater awareness of Public Patient Involvement (PPI) and research literacy. A few patients said that COVID-19 had brought back/reinforced their motivation to improve research.

Many expressed that they did not feel that the patient voice and experience was part of COVID-19 research development and delivery. Some were surprised to learn that 'Patient Research Ambassadors' are only available in England and not across the United Kingdom. Patient involvement needed to be at beginning otherwise it is always a step behind and an afterthought. The [Patient Led Research Hub](#) based at Addenbrooke's in Cambridge (aims to support and co-produce clinical trials as proposed by patient organisations) was highlighted as an example of patient involvement in research from the very start of study development.

One tweet stated “if you save somebody’s life don’t you then have a duty of care to try and make that life worth living?”. This was seen as a key reason why research needs to not only focus on the patient during the study but also ensure that support is there after the event (i.e. psychology support following ICU discharge). It was hoped that with the focus on mental health during COVID-19 that more attention will now be given to not just the ‘there and now’ of patient care during the event/ study but also consider their needs in the home, community and work once the event/ study had passed.

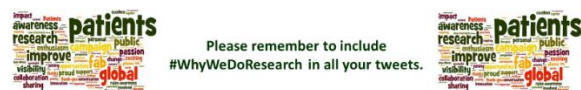
Lack of inclusion, for patients, also came across. Many stated that they were not informed of results from studies that they participated in even after they had requested that findings from the research was shared with them. Some stated that they themselves were the power, as if they did not participate in the research there would be no studies. If the sponsor/ site did not share the results with them they would not consent to take part in any other study. Some reported that if sharing results with participants was not included in the protocol than many sites felt they did not need to share the findings. It was suggested that part of the feasibility assessment should include how results are shared with patients at the end of the study.

Questions



Q1: We would like to ask first & foremost, how are you all?

Q2: What positive opportunities have you seen or heard for research as a result of Covid-19?”



Please remember to include #WhyWeDoResearch in all your tweets.



Q3: How do maintain these advantages after Covid-19

Last question of the eventing: Tell us a joke. Let’s keep ourselves laughing!

