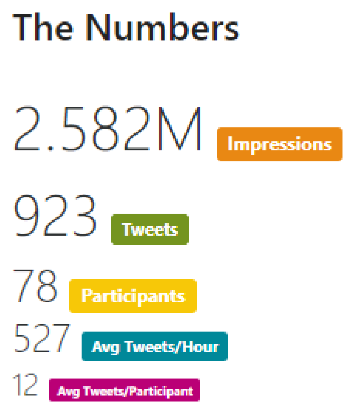
#WhyWeDoResearch

"ENGAGE & INVOLVE PATIENTS, PUBLIC, CARERS with all COVID-19 health and social care research"

TweetChat 6: 28th April 2020



The Numbers

2.582M Impressions

923 Tweets

78 Participants

527 Avg Tweets/Hour

12 Avg Tweets/Participant

The sixth #WhyWeDoResearch 2020 weekly tweetchat explored ***engaging and involving patients, public and carers*** *with COVID-19 research. The theme for this #WhyWeDoResearch tweetchat was a result of previous tweets commenting on the lack of patient involvement in research and patients reporting that they were no longer being included in research design and delivery. 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 28.04.2020) is available: click here. This Tweetchat was preceded by a similar event from Australia hoted by @praxisau and @AnneMckenzieAM – we will post their report when received.*

Health & Wellbeing

We start each #WhyWeDoResearch tweetchat asking everyone how they are feeling and how the past week has been. People tweeted about being 'zoomed out' and how tiring virtual meetings were, "struggling with the kids at home more than I am struggling to work", missing family, friends and hobbies, and having "ups and downs like a yo-yo". Others spoke how they were coping well and teams tweeted "we're all looking after each other".

People tweeted how difficult it was to hear about the death of friends and colleagues from COVID-19. Ken Lambatan, Cardiac Research Nurse with St George's Hospital in London, had passed away after contracting COVID-19 and he was very much in our thoughts during the #WhyWeDoResearch tweetchat.

Research wanted by Public, Patient & Carers

Research clearly needs to be inclusive of all ethnic and social backgrounds (it was tweeted that more attention is needed in exploring why the Black, Asian and Minority Ethnic community have a higher proportion of COVID-19 mortality compared to the Caucasian population in the UK and America). Research needs to serve the needs of everyone affected - not just a select group. It's important that we include all communities and reach often under-represented groups. Other tweets asked if they would they need to return to the hospital to continue research participation.

There were not many suggestions on what research was needed as many did not know what was currently available or if aware of COVID-19 studies did not know how to get involved. This speaks of the need to do more engagement and promotion of available studies. Others said that they would like to be asked about what research was being considered and how it will help them and others. Concern was also raised in a few tweets that the processes for identifying health research and service delivery pre- and during COVID-19 was unclear. Both rehabilitation and stroke Twitter accounts asked what research COVID-19 studies the public, patients and carers would like to see.

The clarity of language was identified was an issue that needed to be addressed. Research, especially during the urgency of COVID-19 research, needs to avoid jargon and communicated in a way that is accessible to all, with a clear purpose. Open data communication/sharing were also viewed as essential elements of research. It was felt by some that the more information the better, although there were no tweets on how data management should be addressed.

Need for Patient Engagement and Involvement with COVID-19 Studies

"I feel like #PPI [Public Patient Involvement] in COVID-19 research is akin to 'measure twice cut once' which can be challenging with time pressures". This tweet was reiterated during the #WhyWeDoResearch tweetchat with comments such as "Astonishes me that PPI is still not mandated within research, even rapid pandemic research can still be done WITH the patient/carer voice"; " …the best people to ask this question of are the public themselves, & participants sharing their experiences are so valuable to starting the conversation...but that’s just strong belief that PPI is now more important than ever”, “I understand there is a rush but #PPI is so important in the long run it will make better research” and “I think the 'public' element in PPI is particular important and valuable at the moment, when the whole world is invested in Covid health research”.

Many tweets stated that most of the COVID-19 studies they were working on or come across had no public or patient involvement or a public contributor on the steering committee. Tweets discussed people’s worries that researchers in a rush to get COVID-19 studies going believed that engaging and involving patients, public and/or carers is not feasible in a tight time frame. It was highlighted by some that pre-existing relationships are useful resources as they would already be familiar with how members of the team worked. Through approaching people who are familiar with involvement and what's required, they may find that it can be done by the deadline. One tweet noted that the many examples from the geographically spread Rare Disease community would show that engagement and involvement with patients is possible during a pandemic.

Through engagement and involvement with patients for COVID-19 studies, and indeed all research, it avoids research waste, can help prioritise which studies to run and “anything worth doing is worth doing well and that lack of time is not an excuse”.

Diversity with patients who are engaged and involved with research was discussed and how ‘diversity’ is determined. One of the popular suggestions, during the #WhyWeDoResearch tweetchat, was asking COVID-19 patients (who were admitted to hospital) and were in the process of being discharged home what would they appreciate/recommend participating in research. This would mean adapting things in different ways to suit different needs but would reflect the opinions of those who had “come out the other side”.

Patient engagement and involvement with COVID-19 studies

Recent data from the Health Research Authority has indicated that patient involvement with COVID-19 research is currently at 20% compared to 78% pre COVID-19.

iHealthFacts (organisation with support from across the island of Ireland to check the reliability of a health claims) have three public and patient representatives on their evidence-advisor board. iHealthFacts was created in response to COVID-19 health claims being circulated by the press media and on social media. Other organisations such as RMEngagement and Cochrane Consumer Network are involving patients, carers, family members in rapid reviews.

Nottingham University Hospital have set up a rapid response group and are involving those in the community recovering from COVID-19 who are unable to participate in inpatient studies. Another participant tweeted about a public engagement project (co-creating engagement) with young adults about COVID-19 and related research.

Patients, taking part in the #WhyWeDoResearch tweetchat, spoke about working with researchers, commenting on research protocols and helping to train PhD students with patient interviews (both with King's College London), taking part in core outcomes set research and being a co-applicant on COVID-19 grants.

Virtual Engagement and Inclusion:

It was tweeted how the way of working with public contributors is changing. That interactions were more 'virtual' and 'remote'. Others noted how researchers would frequently, pre COVID-19, get feedback that projects using texts/apps/web based were inaccessible to a lot of people but now it's almost all we have.

Aspects that need to be considered with virtual engagement and inclusion is that setting up virtual groups was more challenging to build relationships and that virtual meetings can be very tiring. Also, who pays for the computer/laptop, software to open and comment on files, WiFi, printer etc.

All patients who participated in the #WhyWeDoResearch tweetchat said that they bore costs for equipment and services with patient and public involvement activities. Tweets also commented that for patients without internet connection, computers or those that required additional supports to access remote information may be excluded from engaging and being involved with research. Some patients tweeted about payment as a member of the research team. The majority of patients involved in the #WhyWeDoResearch tweetchat did not receive any pay for giving their time and advice to research studies. It was felt that if the researcher gets paid to work on the protocol then why not the patients too?

Some asked for ideas how to improve virtual relationship building and one researcher had some success twinning an online dance class with some public and patient involvement. The group meets and dances on zoom then chills out with tea.

Summary of the key elements from the #WhyWeDoResearch tweetchat:

The statement below was posted across three tweets as a quote (source: Nuffield Council on Bioethics's "Research in Global Health Emergencies") during the #WhyWeDoResearch tweetchat. We think this statement sums up the key elements of the need and value for engaging and involving patients in all research (health and social).

"In the absence of pre-existing relationships and effective systems, it is highly unlikely that everything can be in place in the early stage of an emergency to facilitate full engagement from the very start of the research endeavour. However, equal respect demands clear communication from research teams from the very beginning, accompanied by real commitment to start developing the relationships necessary to build two-way processes as quickly as possible. Fairness demands that those efforts include consideration of the experiences and views of marginalised parts of those communities, alongside those of more influential and powerful members"

Links to Resources shared during the #WhyWeDoResearch tweetchat:

- INTENT; IMAGINE + IGNITE: Impressions on Involvement in Ireland
- Nuffield Council on Bioethics: Research in Global Health Emergencies
- British Society for Immunology: Connect on Coronavirus: public engagement resources
- BMJ Rapid Recommendations

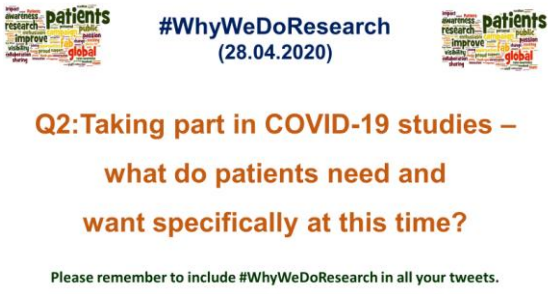
- Health claims – Fact checked (funded by Health Research Board, Republic of Ireland's equivalent to the NIHR, and one of the partners is Northern Ireland's 'Public Health Agency: Research and Development')
- Eastern Academic Health Science Network (AHSNs)
- We set up a YouTube clip to explain why we had set up this Tweetchat and help with the discussion: youtu.be/_CG6gXGsZyE

Questions


#WhyWeDoResearch (28.04.2020)

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

Please remember to include #WhyWeDoResearch in all your tweets.


#WhyWeDoResearch (28.04.2020)

Q2:Taking part in COVID-19 studies – what do patients need and want specifically at this time?

Please remember to include #WhyWeDoResearch in all your tweets.


#WhyWeDoResearch (28.04.2020)

Q3: What good examples/experiences of involvement do we know about by scientists, researchers, patients/public, charities, etc.?

Please remember to include #WhyWeDoResearch in all your tweets.


#WhyWeDoResearch (28.04.2020)

Q4: What are the opportunities to engage and involve public and patients/carers/service users in healthcare research through Covid-19?

Please remember to include #WhyWeDoResearch in all your tweets.


#WhyWeDoResearch (28.04.2020)

Q5: How do we keep involvement going when we can physically meet?

Please remember to include #WhyWeDoResearch in all your tweets.


#WhyWeDoResearch (28.04.2020)

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

Please remember to include #WhyWeDoResearch in all your tweets.