NIHR | National Institute for Health Research

COVID Connect

WHAT MORE CAN THE NIHR CRN DO TO SUPPORT RESEARCH DURING THE COVID-19 PANDEMIC AND HOW CAN THE PUBLIC SUPPORT THIS?

Led by Dr William van’t Hoff, Chief Executive NIHR CRN

November 2020

About COVID Connect

COVID Connect brings together CRN leaders and members of the public to discuss key topics related to the delivery of research during the COVID-19 pandemic. If you would like further information, or would like to hold your own COVID Connect conversation then please contact the PPIE team: crncc.ppie@leeds.ac.uk

Six members of the public, including some who have lived experience of participating in COVID-19 therapeutics (treatment drug) trials in hospital, joined Dr William van’t Hoff, NIHR CRN Chief Executive to discuss:
What more can the NIHR CRN do to support research during COVID-19 pandemic?

> *I believe the more, that we as an organisation, and the people who work in our organisation, hear from members of the public and patients, the better our work will be, and the more relevant our work will be. Therefore, the better the service that we can offer to other people taking part in health research will be.*

Dr William van’t Hoff

> *People have actually sat up and listened, [people] in positions that I would never have even thought I'd have been able to speak to. They've really taken on board my views and feedback, [ideas] that they never thought of, or never realised could be an issue. So I think involvement is something that's so vital to research, not only locally, but across the country.*

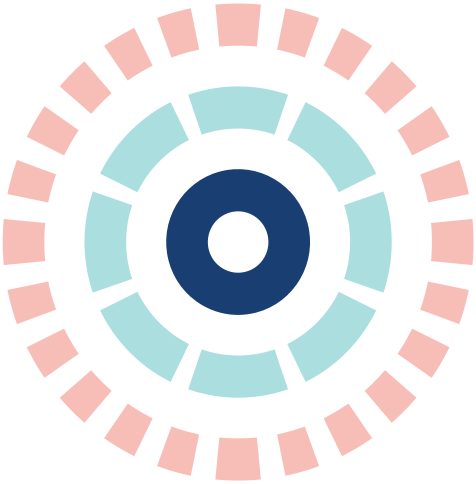
Public contributor

Themes from the conversation

Research matters to patients and the public and they want to be involved.
We asked public contributors what research meant to them and this is some of what they told us:

- "What research means to me is everything, because I wouldn't be here if it wasn't for research."
- "Research is tomorrow's treatments."
- "Learning and hope is what research means to me"
- "To prevent people going onto ICU [Intensive Care Units] that'd be fantastic - I think I'm living proof that it works."

Use COVID-19 as an opportunity to engage more people with research, and involve the public in sharing key messages.



- People are motivated by their lived experiences. Using specific conditions as hooks (e.g. COVID-19) to talk about broader research may increase engagement by making it more relevant.
- There is a mixed response to vaccines within people's social networks. Concerns about the speed of development and vaccinations being made mandatory, and credible information about vaccines research appears limited to a few specific online sources. It is not more widely distributed across online and offline channels. Engaging Research Champions to promote research through their social connections could help.

- Ensuring that research opportunities are accessible to all members of the community is vital and Research Champions can help with this.

- It is important that information about research is in the public domain in accessible formats, so the public can look for it, find it, ask questions and initiate their own conversations with doctors about it.

There is a greater role for public partners in the NIHR CRN.

- There is a strategic commitment to ensuring that involvement of members of the public within NIHR CRN is meaningful and makes a real difference.

- Members of the public are keen to be heard at a strategic level, and provide new insights into challenges faced by the NIHR CRN.

- Having public members within the Urgent Public Health process*, has been really valuable as those members really think about why they would, or wouldn't take part, and can help shape the discussion about the study.
  **The process by which the COVID-19 studies have been assessed and recommended to be taken forward and then added to the NIHR CRN Portfolio.*

- To facilitate public engagement we need to raise the profile of the NIHR CRN and its role in research delivery, and also ensure Research Champions have an induction to NIHR CRN.

> *I think people having an understanding about what the NIHR CRN is trying to achieve, gives people a feeling of being included and valued.*

Public contributor

> *As a Network, we coordinate and link, we don't design new research or fund research but we pick up the research protocols and we make it happen.*

**Laurie Oliva,
Head of Public Engagement, NIHR CRN**

The public needs locally-specific information about research participation.

- Information about specific, local hospital settings, is central to ensuring people feel safe to return to research. This is powerful in visual formats, so people understand what the hospital and staff in PPE [Personal Protective Equipment] will look like when they go in.
- We need to keep talking about other areas of research during this time.
- People need clear information about travelling for research - including whether they can opt to take part in a study that's far away from home.
- Reiterating the safety of clinical trials is essential when communicating with patients about returning to hospital [for research opportunities].

> *People need to understand that it's safe to go into a hospital environment, and that the trials are safe, because they've gone through a rigorous process of checks and balances.*

Public contributor

> *From the people I have spoken to, most are welcoming the vaccine. Some are scared it hasn't been tested thoroughly and the [possible] side effects are scary too. There are others who still think we are being forced to take this or hold some more outlandish, fear-mongering views.*

Public contributor