

30 September 2021

Public Advisory Group meeting to discuss RECOVERY Flu – minutes

Attended by:

- Professor Richard Haynes, Professor of Renal Medicine & Clinical Trials and RECOVERY trial coordinator, Nuffield Department of Population Health (NDPH)
- Anne Whitehouse, Director of Communications and Public Engagement, NDPH
- Sophia Wilkinson, Senior Public And Patient Engagement and Involvement Officer, NDPH
- Seven members of the RECOVERY Trial Public Advisory Group.

Meeting agenda:

1. Briefing about RECOVERY Flu from Richard Haynes
2. Questions and answers about RECOVERY Flu
3. Provision of feedback to group on newsletter review from Anne Whitehouse
4. Writing to family of deceased trial participants – discussion

Minutes:

1. Briefing about RECOVERY Flu

Richard Haynes (RH) explained that the investigators of the RECOVERY Trial are looking to expand the trial so that it trials potential treatments for ‘flu’. He explained that between 5,000 – 20,000 people die annually from flu, but for those that end up in hospital there are no known treatments proven to work.

We will be adapting patient-facing RECOVERY Trial materials, including the patient information sheet and the animation, to support the consent process into the trial.

That is why the group are being briefed about the trial, as we will ask them to review these materials, to ensure they are easy to understand, and so that we can learn from their experiences.

RH said only people hospitalised by flu, with severe flu, will be recruited.

2. Questions and answers:

Overall members of the Public Advisory Group were supportive of the proposal to use the RECOVERY platform to test potential treatments for flu. They asked a number of questions, including why trials like this for flu haven’t been done previously and whether the trial could also operate in the community. (RH explained that there is another Oxford trial potentially interested in this and that they were collaborating as they did not want conflicting trials.)

In addition, there was concern expressed about whether doctors and nurses would be able to cope with the demands of running another trial, if the NHS is very busy with both COVID and flu.

3. Newsletters – feedback to the group on their contributions to the second newsletter

AW explained that the majority of suggestions had been incorporated into the revised letters, but it was not possible to shorten the letters because of obligations to include certain bits of information and because we have had to add some information, so as a result, the letter is no shorter.

There was a suggestion to break up the text with bullet points – where possible, this has been done.

It was also suggested that we should put what the treatment does first, followed by the medicine name, and this has been done where possible.

We have also incorporated grammar and wording suggestions.

4. Writing to deceased patients' families

AW explained that there had been a suggestion from other members of the public who had reviewed the early version of the patient materials, including the first newsletter, that we write a letter to the families of patients who were part of RECOVERY but had died from COVID-19. What did the group think about this?

Member 1: I would not like to receive a letter further down the line.

M2: I don't think it's a good idea. It'll still be too raw and upsetting.

M3: Some people might appreciate it, but I think more would be upset.

M4: I can see arguments both for and against.

M5: I can see both sides, but personally I wouldn't want it. Not a letter but perhaps to hear about the trial in other forms of media.

M6: If you wrote after a year, it would make things more complicated, would raise questions and upsets.

The consensus was that we should err on the safe side and not risk upsetting people. AW stated that there has been lots of media coverage, particularly around results from the trial. Flu will give us an opportunity to talk about RECOVERY COVID and the process again and remind people of the key results.