

The EPIC Participant Advisory Panel met online on Monday 09 April 2021. There were seven participants and three researchers in attendance. Five participants sent their apologies for not being able to attend and we received two resignations.

1. Welcomes and housekeeping (All)

Panel members were notified that the meeting would be recorded for purposes of minute writing. The recording will then be deleted.

2. EPIC-Norfolk study update and Longitudinal Linkage Collaboration (NW)

NW gave a talk to the panel about UK Longitudinal Linkage Collaboration (UK LLC). The panel were informed that in response to the corona virus pandemic, the UK government has initiated six National Core Studies to conduct research in to the pandemic. The EPIC-Norfolk study is 1 of 20 cohorts that has had been invited to take part in the UK LLC. The UK LLC involves bringing together information from longitudinal study volunteer with their routine records in a secure way. Researchers hope that by combining the data in this way we will be able to better understand the impact of the pandemic that was not possible before this way of working was set up. It is hoped that this resource will help researchers work towards improving health and wellbeing throughout and beyond COVID-19. Researchers will be able to track which participants have had COVID-19, if and when participants had a vaccination, and any other relevant health related information. The research will also consider the wider impacts of COVID-19, particularly lockdown and the disruption of the normal functioning of the economy and government services, on health and wellbeing. Only approved researchers will be able to access this data and the EPIC-Norfolk study management team will continue to review each application. The panel were unanimous in their backing of this linkage project and agreed that it was in line with participants expectations of how the data would be used.

NW discussed with the panel how much information should be sent to the EPIC-Norfolk participants about the UK LLC. NW showed the participants the UK LLC participant information sheet (PIS). The panel agreed that the

information presented in the UK LLC PIS, may cause confusion with some participants and unnecessary concern. It was agreed that the information should be summaries so that the main points of the collaboration are sent to the cohort. The panel felt what was written in the EPIC-Norfolk newsletter that they had been asked to review, was enough information to send.

NW discussed with the panel whether they felt the study team should add an opt out option on the newsletter under the UK LLC article, considering that this had never been done for any other linkage work the study had carried out. The panel discussed this for some time and agreed that provided the contact details for the study team were clearly presented for participants to see, should anyone have any concerns or queries about the UK LLC or wished to opt out they could clearly see who to contact.

Matters arising from previous minutes.

Website feedback

How much the website is used and whether this has changed from the old website?

AB and NK discussed this with the Comms team, unfortunately it is not possible to report back on the use of the new website at this stage, however the team will continue to investigating into this, as all agreed this would be useful to know and monitor.

Picture on the home page updated to a series of rolling images encompassing what the study was about.

Panel suggested that a description of the picture was also added as it was unclear what some of these pictures were, particularly the biological samples collected in liquid nitrogen. **Action taken:** [Short description added to pictures on homepage](#)

Ongoing action point: [Members to email NK with suggestions for future meetings.](#)

4. Panel feedback: 2 new secure online forms (All)

The panel reviewed two online forms designed so that participants could update their addresses as well as a form to collect their email address should they prefer to receive future newsletter electronically. Feedback included:

1. Long names are lost at the end of lines. **Action taken:** Formatting amended to allow more space for longer names
2. When entering a change of address you currently have to type the address in a continuous line rather than the standard address practice of a line for road, town, county and postcode. Panel agreed it would be preferable to format addresses this way. **Action taken:** Formatting of addresses updated to enable street, town, etc. to appear on a new line.

5. Panel feedback: EPIC-Norfolk participant newsletter, Summer/Autumn 2021 (Appendix 1) (All)

Panel reviewed the EPIC-Norfolk Summer/Autumn 2021 newsletter. Open discussion collecting feedback from EPAP with focus on the following areas:

Feedback included:

Panel liked colours of the newsletter and the text to photo ratio

Suggested that Nick should include in his opening statement an introduction, so that it aligns with the meet the team section.

Rather than separate photos the panel thought it would be better to have a group photo of the team together.

Panel discussed whether the articles were in the correct order. It was agreed that if Nick's statement included an introduction to the UK LLC, the article about UK LLC would be better positioned on the front page and swapped with the website section

Panel agreed that there was sufficient information in the UK LLC article explaining what this project involved. **Action point:** NK to circulate the participant information sheet (PIS) for the UK LLC to the panel members.

Panel asked to contact NK if they felt there was anything else that should be included in the text of the UK LLC article following reading the PIS.

Panel agreed that the article about EPAP would be better if it was from the panel members. **Action point:** HJ kindly agreed to reword this section, then pass on to NK to circulate to other panel members for comment, a deadline of the end of August.

A list of current EPAP members should be added so that participants can see who it is that represents them.

Typing errors identified

Action point: NK to circulate an amended draft to panel for further comments

The next meeting will be on Monday 6th December 2021.