

The EPIC Participant Advisory Panel met in Norwich on Monday 27th March 2023. There were fifteen participants and four researchers in attendance. Three participants sent there apologies for not being able to attend.

Welcomes

The committee welcomed five new members to the committee. One resignation was received from a member of the panel.

Talk: "EPIC-Norfolk update" (Nick Wareham)

Nick gave the group an introductory talk about how the EPAP group was formed as well as it pivotal role in shaping the study and now in determining how the data and samples are used. .

EPIC-Norfolk Participant Advisory Panel (EPAP) was formed in 2010. EPAP is a consultative forum and has provided a participant perspective on how research is prioritised, planned, conducted, communicated and used. EPAP is viewed as a partnership between EPIC-Norfolk researchers and participants.

Members of EPAP have been involved in a variety of research areas including; the designing of health questionnaires, writing of lay summaries, reviewing participant-facing information, dissemination of results and providing a lay perspective on potential future projects and collaborations. More recently, members of EPAP have been consulted on the sharing of data and results that have been created by the study, and the appropriate use of samples. Having a voice of the people who made the donation is vital in a research study.

NW was asked in terms of outcomes that have benefitted the public how have these changed society and health policy.

The key impacts from the study include:

Link between sugar consumption and link to incidence diabetes.

1 can of coke a day increased risk of getting cancer by 20%. Findings from this study helped support the soft drink levy.

Risk scores for testing diabetes derived from the study has become part of NHS practice.

Glucagon-like peptide-1 receptor (GLP-1R) development of new obesity drug, created to impair appetite.

Genetics in EPIC have been beneficial in receptor reduction in heart disease.

Panel suggested that the findings such as the ones outlined in the talk by NW needed to be articulated in short news reports on the study website and newsletter for participants to see.

Talk: "Using genetics and blood protein levels to better understand diseases" (Mine Koprulu)

The panel welcomed Mine Koprulu to the meeting. Mine Kropulu(MK) is a PhD student on Gates Cambridge scholarship based at the MRC Epidemiology unit. Mine's PhD project focuses on the analysis of multi-omics data, particularly for diabetes and related metabolic disorders, with an aim of mapping pathways from variants to disease which can be targeted for intervention. MK gave the panel a very interesting talk about her work analysing EPIC-Norfolk data investigating "Using genetics and blood protein levels to better understand diseases?"

Actions from previous meeting

NK to look in to whether there is a suitable charity connected to the units work.

Instead of claiming honorarium payments, panel members asked whether they could instead donate the money toward a charity with links to the work carried out in the unit. NK still investigating charities that are linked to the unit work. It was discussed that panel members could also claim reimbursement and donate it to a charity of their choice.

NK to circulate a screener to panel members, so that they can see how much they adhere to the Mediterranean diet.

NK circulated the Screener questionnaire which calculates adherence to a Mediterranean diet. Some members of the panel had used the screener to see how they scored and reported that it would be good to include links to this

type of resource in future newsletters so that other participants have the opportunity to use these.

It was noted that other participants of the study outside of the group would like to hear about the continued work carried out on the samples and data supplied by the participants many years ago. It was asked whether the study planned to hold any public events that all participants could attend. It was explained that although there were no current plans to hold a public meeting we try to articulate study news through an annual newsletter. NK to feedback participant's thoughts at the next EPIC-Norfolk management meeting.

The next meeting will be on Monday 17th July 2023.