





The EPIC Participant Advisory Panel met at the Assembly House in Norwich on Monday 21st October 2024. There were twelve participants and four researchers in attendance. Three participants sent their apologies for not being able to attend.

Welcomes:

The panel welcomed Jackie Chipping, Clinical Manager of the NOrfolk Arthritis Register (NOAR) and Patient and Public Involvement (PPI) lead who joined the meeting on Zoom. As well as Paul Browne, Senior Communications Manager at the MRC Epidemiology Unit.

Talk - "NOrfolk Arthritis Register (NOAR)"

Jaqueline Chipping (JC) provided an overview of NOAR as the largest community-based study globally focused on inflammatory polyarthritis. NOAR was originally aimed to determine the incidence and prevalence of rheumatoid arthritis to inform treatment strategies and funding. Comprehensive data is collected on demographics, medical history, comorbidities, lifestyle factors, and annual blood samples stored in a biobank. Research areas include Cardiovascular Risk, Mental Health, Cognitive Impairment, Biomarker and Genetic Research. JC went on to highlight some of the impacts of NOAR as a significant data resource with >5,000 participants and over 100 global publications and has had a notable impact on understanding the incidence/prevalence of rheumatoid arthritis. The talk concluded by hearing about ongoing and future Studies. Further information can be found on the NOAR website where there are various useful resources and links.

Talk- "Research communication: from press to podcasts"

Paul Browne, Senior Communications Manager, MRC Epidemiology Unit provided an overview of the work of the Communications Team. Along with Knowledge Exchange and Public Partnerships, key activities involve website and online presence (including social media), maintaining publications databases and engaging with Media for press releases. Newsletters, podcasts,







video and web content are used to raise public awareness of the research and its wider impacts. Paul welcomed any input about local journalists and media contacts. An interactive Q & A session followed with the group, discussing suitable communication channels for EPIC-Norfolk news, how to assess effectiveness and success and outreaching to different audiences.

Newsletter:

A hard copy of the newsletter is available and feedback was invited. The newsletter was edited down, with an extended version available via email, including additional content such as publication links. Efforts have been made to capture more email addresses for future editions (note on the newsletter and participants can update their preferences on website).

Meeting Schedule:

Future meeting dates were discussed.

Appreciation for the team's efforts in maintaining high accessibility for these meetings was noted, especially for people with hearing difficulties. The dedication to making meetings inclusive was praised.

Participants showed willingness to contribute to shared discussions/potentially a podcast. Lastly, the group thanked and highlighted the significant support provided by Nicola.