

EPIC-NORFOLK NEWS

October 2021

We are delighted to circulate this newsletter, which contains updates about previous members of the team who have retired or moved to new jobs and introduces you to new members of the team.

I have been involved with EPIC-Norfolk since the mid-1990s and took over the role of Chief Investigator in 2018 when Professor Kay-Tee Khaw retired.

I am absolutely delighted to have been entrusted with the responsibility of continuing the work of the study and of maximising the scientific opportunities that stem from your willingness to provide so much helpful information over the years.

Our new website, highlighted in the newsletter, contains updates on recent findings and is well worth reading.

Of course the last 18 months has been dominated by the COVID-19 pandemic, and sadly many participants in EPIC-Norfolk have been among those affected by it.

The availability of all the historical health and behaviour data, which we have assembled in EPIC-Norfolk with your help, creates an opportunity for us to contribute to national efforts to investigate susceptibility to COVID-19 and its consequences.

The article below summarises this national initiative and I hope that you will agree that our involvement in this is an



illustration of the continued importance of the EPIC-Norfolk study to research in the UK and beyond.

**Nick Wareham, MRC
Epidemiology Unit Director
& EPIC-Norfolk Principal
Investigator**

UK Longitudinal Linkage Collaboration

In response to the coronavirus pandemic, the UK government has initiated six National Core Studies to conduct research into COVID-19.

EPIC-Norfolk has been invited to take part in one of these studies – the UK Longitudinal Linkage Collaboration (UK LLC).

The UK LLC will bring together information from longitudinal study volunteers with their routine records in a secure way. This will help researchers work towards improving health and wellbeing throughout and beyond COVID-19.

Access to the health records of participants in the EPIC-Norfolk research will help researchers 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.

If you have any questions about the EPIC-Norfolk study participation in the UK LLC, please visit www.epic-norfolk.org.uk/for-participants/uk-llc/ or contact the study team using the details at the bottom of the page.



Meet our team

Pictured, left to right

Angela Mulligan. Angela has been a nutritionist with the EPIC-Norfolk study since 1994. Over the years she has worked on the processing, checking and cleaning of dietary data to enable researchers to investigate various diet-related hypotheses. More recently, she has been working with the team to create tailored dietary data requested by researchers.

Abi Britten. Abi is a data manager for the EPIC-Norfolk study. She joined the team when the study transitioned into the MRC Epidemiology Unit at the end of 2018. Prior to this she was a member of the Unit laboratory team for 11 years, working with EPIC-Norfolk biological samples. She has worked to transfer the study data into the Unit and now helps to look after the data: updating processes and preparing data for data releases.

Nick Wareham. MRC Epidemiology Director and EPIC-Norfolk Principal Investigator.

Nicola Kimber. Nicola is the Study Coordinator for EPIC-Norfolk. She also joined the team when the study transferred to the MRC Epidemiology Unit. Nicola previously worked with the Unit for over 11 years, supporting many of the Unit's studies, in particular the Fenland Study. Nicola is the main point of contact for study participants and researchers requesting data from the study. She also organises the EPAP meetings (see right).

Silvia Mendonca. Silvia joined the team in March 2020 as a data manager. Her work involves organizing and processing study data and preparing data for individual research projects. More recently, she has been processing the data from the cognitive tests carried out at health check 5 and the physical performance tests done at health checks 4 and 5. Her aim is to make sure we make the best use of the available data and that we give appropriate support to researchers using the data.



Past team members



Kay-Tee Khaw

KayTee was a principal investigator in EPIC-Norfolk until her retirement in 2018. Since then, KayTee has two new granddaughters born during the COVID-19 pandemic: in April and July 2020. She has been so happy

to be able to see them (and her other two older grandchildren) with the easing of restrictions. She received a World Heart Federation Award in 2020 for Outstanding Contribution to Cardiovascular Health in recognition of 30 years coordinating international training seminars in prevention of cardiovascular disease. She continues to be immensely grateful to all EPIC-Norfolk participants for all they have contributed over three decades to research understanding health and helping others.



Robert Luben

Robert was the senior data manager of the EPIC-Norfolk study. He completed his PhD thesis on the epidemiology of hospital admissions using record linkage to the EPIC-Norfolk

cohort. Robert is now a research fellow at the UCL Institute of Ophthalmology in London, which has very close links to Moorfields Eye Hospital. During the Third Health Check (2006-2011) the EPIC-Norfolk researchers collected many measurements from the eye and took images using specialised equipment. Robert's current research is linked to this data, as he investigates the fundamental causes of glaucoma, and aims to identify novel treatments and identify people who are at the highest risk of blindness from glaucoma.



The EPIC-Norfolk Participant Advisory Panel meeting in July 2019

Current EPAP membership

Peter Gibley (Chair)
 Ron Brewer
 Edwina Hoffman
 Mary Graydon
 Christine Garrard
 Susan Grant
 Gordon Edwards
 Peter Cudby
 Annie Moseley
 Helen Jackson
 Janey Bevington
 Mary Vanderpump

EPIC-Norfolk Participant Advisory Panel

A message from the panel

Keen to maximise the value of research processes, and to understand what those participating in the study think and feel, the research team set up the EPIC-Norfolk Participant Advisory Panel (EPAP) in 2010.

EPAP is a partnership between EPIC-Norfolk researchers and participants. We are a group of people with various backgrounds and interests. We meet with, listen to and read about the issues the research team are working on, and give them feedback. This helps how they prioritise, plan, carry out and communicate about their work on EPIC Norfolk.

We usually meet together about four times a year at The Assembly House in the centre of Norwich (although recently it has had to be on Zoom!).



Shabina Hayat

Shabina was the Research Manager for EPIC-Norfolk, and is now working in the Cambridge Department of Psychiatry, and Cambridge Public Health. She is also involved in the NIHR Applied Research Collaboration (ARC)

East of England, which supports research that makes a positive impact on health and social care services. Through the ARC's Population Evidence and Data Science theme, and as a result of her knowledge on data linkage in EPIC-Norfolk, Shabina has been involved in a project to create an anonymised linked database from health and social care settings to investigate the predictors of mental health problems in children and young people. Shabina's main research interests, however, are those from her work in EPIC and her PhD, which is the epidemiology of cognitive function, frailty, dementia and ageing.

Members of EPAP have been consulted on a variety of research areas including:

- data sharing and the appropriate use of samples
- the design of health questionnaires and participant information
- lay summaries and the sharing of results
- providing a lay perspective on potential future projects and collaborations.

If you are interested in joining us please do let the team know:

- epic-norfolk@mrc-epid.cam.ac.uk
- 0800 616 911

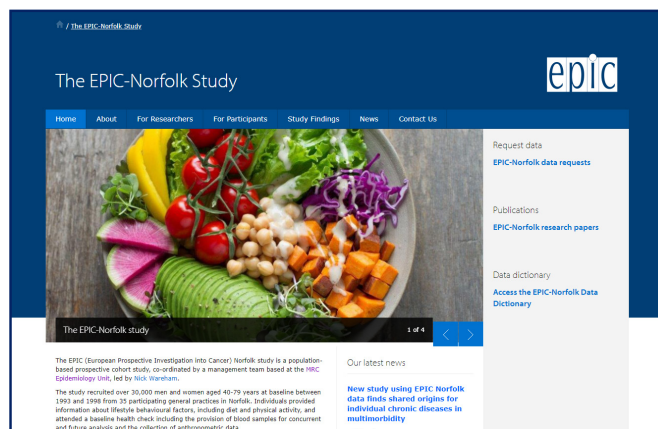
If it would be helpful, one of us can ring you for an informal chat to help you decide. No prior experience or specialist knowledge is required. All you need is an interest in research and a willingness to share your opinions.

New study website – www.epic-norfolk.org.uk

We have been working hard on a new website for the EPIC-Norfolk study.

It is regularly updated with new findings and news from the study and includes a full list of all publications that have used EPIC-Norfolk data. There is also now a section **For Participants** where those taking part in the EPIC Norfolk study can find lots of useful information.

We welcome your feedback. Go to www.epic-norfolk.org.uk/contact-us to find options on how to let us know your thoughts.



Future newsletters

Prefer email? Moved house?

In the future, we plan to provide more regular newsletters by email, with an annual printed version for those who are not able to receive emails. Please let us know:

- your email address if you are happy to receive future newsletters by email rather than through the post
- whether we have the correct postal address for you.

You can provide this information via a secure form at www.epic-norfolk.org.uk/details or by contacting us using the details at the bottom of this page.

How we protect your information

The European Prospective Investigation into Cancer in Norfolk (EPIC-Norfolk) is a study of approximately 30,000 men and women resident in Norfolk who originally consented between 1993 and 1997 to participate in this long-term study on lifestyle factors and health and who are being followed up for health outcomes.

In addition, we plan to access COVID-19 data for EPIC-Norfolk participants from Public Health England and participant health records from the NHS Data Sharing Centre as part of the UK Longitudinal Linkage Collaboration.

The information published here applies to the use of the personal information collected from participants as part of the EPIC-Norfolk Study.

The University of Cambridge is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical

records in order to undertake this research and will act as the data controller for this study.

This means that we are responsible for keeping your information secure and for using it properly.

The University of Cambridge will keep identifiable information about you for 15 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If you withdraw from the study, we will retain and use the information about you that we have already obtained.

To safeguard your rights, we will use the minimum personally-identifiable information possible.