

EPIC-Norfolk Newsletter

A Celebration of 25 Years of Research

Over the past 25 years, people in Norfolk have been part of one of the largest population studies worldwide. The participants from Norfolk have led the way in helping us understand what we can do to improve health through better understanding of the role of lifestyle and biological factors.

To note your remarkable efforts, we are sending this anniversary newsletter to give you an update on the important work to which you have contributed. This newsletter is dedicated to everyone who has contributed to the study including those who are no longer with us.

Message from Professor Kay-Tee Khaw (Principal Investigator)



Dear EPIC-Norfolk participants,

The European Prospective Investigation into Cancer in Norfolk (EPIC-Norfolk study) was established in 1993 as part of a ten country study, EPIC, with half a million participants, one of the largest population studies world wide and a remarkable example of international scientific collaboration which has continued for over two decades and has made enormous contributions into our understanding of causes and prevention of cancer.

The EPIC-Norfolk study though part of EPIC, is special for many reasons; EPIC Norfolk has from inception broadened its scope to encompass major determinants of well being and health. As we have reported back to you over the years, findings from this study have had a huge impact on clinical guidelines and health policy in UK and internationally, as well as enabled the training of new generations of physicians and scientists.

None of this would have been possible without all of you, as participants in EPIC-Norfolk who have so generously given your time and effort completing numerous questionnaires, providing biological samples, attending new examinations having ever more assessments of their cardiovascular system, eyes, bones, cognition and muscle function. We have looked to the EPIC Participants Advisory Panel in particular as an invaluable source of new ideas, constructive criticism and wise advice. It has been a privilege to be part of this study as principal investigator over the past 25 years and Professor Nicholas Wareham will be continuing to lead this study into the future. As I retire, I would like to send EPIC participants my profound appreciation for their generosity and altruism in contributing to this study over the years, and to wish you all the very best in the future.

Thank you all so much.

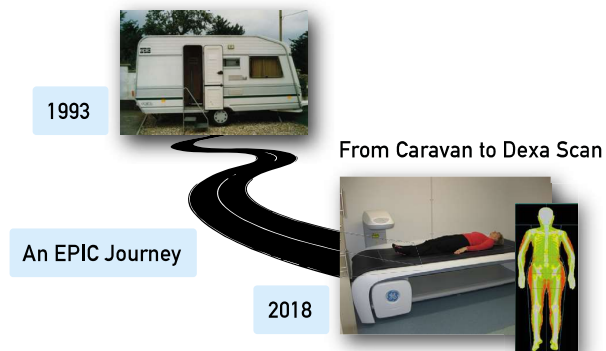


Professor Kay-Tee Khaw

25 years of participant contributions

An overview from the Operations management team: Shabina Hayat, Nichola Dalzell, and Robert Luben.

From the moment the Principal Investigator (PI) secures funding, it is up to the research team to implement the research plan proposed by the PI. Our aim is to collect consistent, accurate and reliable data.



This is a complex process with many things to consider from the outset. This includes how the data will be collected and kept safe, training staff to ensure that they are competent and confident in the tasks that they are required to do and ensuring that our research is conducted to the highest standards possible.

Giving the 'personal touch' to our health checks

We are hugely grateful to all of you for taking part in the study. We recognise that EPIC participants are central to the success of our research and are proud of the relationship we have built with you over many years. Throughout the study we have worked hard to ensure that you (and your needs) remain at the forefront of all data collection and follow-up. As such, our procedures are constantly monitored to ensure that any participant who wishes to take part, can take part. We acknowledge that without you, our EPIC participants, there would be no data. The research teams in Norwich and Cambridge would like to thank all EPIC-Norfolk participants. It has been a pleasure and a privilege to work with you.

Feedback matters

We have always welcomed and encouraged honest feedback from our participants and this feedback has had a direct impact on research planning and implementation.

- “Early appointment times mean us oldies have to tackle rush hour traffic.”
- We have extended our appointment times and introduced shift working to enable appointments to take place later in the day and on some Saturdays. Later appointment times also allow participants to use their free bus passes or to be brought to appointments by working relatives.**
- “Very helpful in arranging my appointment with my brother-in-law and sister so we could travel in together.”



Data that you have kindly provided

The health checks and data we collect have become more complex over time. Initially, all information was hand written on paper, but over time, we had to develop electronic systems to handle, store and manage the complex data collected from each participant. We have provided a study timeline on the back of this newsletter which summarises the data collection phases and methods. The timeline clearly shows the huge amount of data and samples you have very kindly provided.

Here are some facts and figures

- 500,000 letters posted.
- 300,000 questionnaires and forms stored.
- 40,000 photographs taken.
- 60,000 food diaries.
- 680,000 blood tubes.
- 800 litres of urine.
- 11 million genotypes per person.

EPIC-Norfolk contributions to health policy and clinical guidelines

EPIC-Norfolk has contributed to national and international (e.g. WHO) clinical and public health guideline reports. Department of Health initiatives, and the PIs have been invited to provide evidence to Select Committees on health issues in the Houses of Parliament. In addition, general findings from EPIC-Norfolk have informed publications from charities (e.g. Cancer Research UK, British Heart Foundation, Stroke Association, Age UK) on disease prevention and maintenance of health.

Influence on National health policy

Quantifying the association between four health behaviours (not smoking, modest alcohol intake, physical activity and consumption of 5 servings of fruit and vegetable intake) were associated with a 14 year longer life expectancy.

These findings directly influenced the Department of Health “Small Change Big Difference” national public health campaign which was launched from Downing Street underlying initiatives to promote health behaviour change and has been taken up in national guidance.

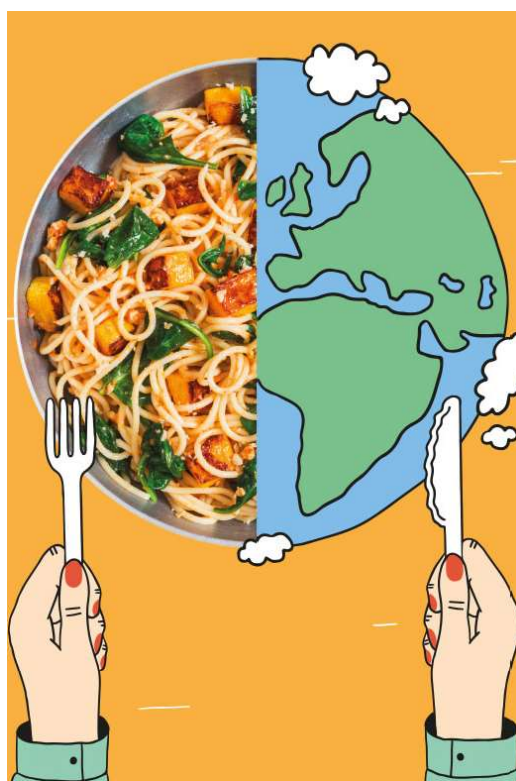
The government back our research, and launched an initiative to encourage people to make small changes to improve their health.

<http://news.bbc.co.uk/1/hi/health/4941910.stm>

“This is about showing people that there are everyday, simple choices they can make in their lives which will have a direct impact on their health”

Caroline Flint, Health minister, 2006

SMALL CHANGE BIG DIFFERENCE



Clinical Guidelines

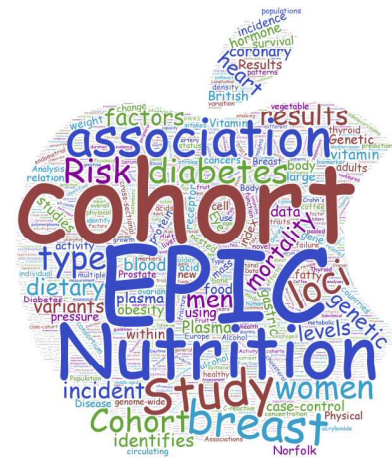
Screening for osteoporosis using heel ultrasound measures, a low cost and safe feasible assessment (Lewiecki EM et al, Official Positions for FRAX Bone Mineral Density and FRAX simplification from Joint Official Positions Development Conference of the International Society for Clinical Densitometry and International Osteoporosis Foundation on FRAX. J Clin Densitom. 2011 Jul-Sep;14(3):226-36).

Use of glycated haemoglobin in the diagnosis of diabetes. (RydenL et al, ESC Guidelines on diabetes, prediabetes and cardiovascular diseases in collaboration with the EASD- Summary. Eur Heart J 2013;34: 3035; Anderson T et al. 2012 update of the Canadian Cardiovascular Society guidelines for the diagnosis and treatment of dyslipidaemia for the prevention of cardiovascular disease in the adult. Can J Cardiol 2013;29:151-167).

Publications

Understanding what we can do to improve health and prevent disease and disability in ageing populations will have benefits for society and the general public.

We have worked with a large number of collaborators, locally, nationally and internationally resulting in over 1600 publications on a wide range of health topics, adding significant knowledge to the prevention of chronic disease and maintaining health in later life.



Having a clearer understanding of the mechanisms underlying diseases can be used to advise prevention and treatment. Knowing the risk profile for diseases can help to develop targeted screening and prevention programmes and understanding which behaviours influence health. This will enable us to improve the health experience and quality of life in populations as they age.

EPIC in the News

Numerous findings from EPIC-Norfolk have made news headlines.

More can be found on our website at **<http://www.srl.cam.ac.uk/epic/news.shtml>**

A recent paper published in *Nature Genetics* (first author Dr Anthony Khawaja, previous PhD student and current collaborator) on genetic variants that may predict glaucoma risk received considerable attention in the Media in May 2018.

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Glaucoma test on horizon to prevent most common cause of blindness



EPIC-Norfolk Participant Advisory Panel (EPAP)

Representatives of all EPIC-Norfolk Participants

EPIC-Norfolk actively promotes greater participant involvement in our research. In 2010 we set up the EPIC Participant Advisory Panel (EPAP); a group consisting of participants from the EPIC-Norfolk study who have volunteered their time to act as a consultation group. The panel's objective is to advise us on many aspects of our research, and to make us more aware of our participants interests and views on specific areas of our research. This panel recognises the partnership between EPIC participants and the research team. We are also extremely pleased when our panel was chosen as a case study for a new research project looking at Public Involvement in Research.

To find out more about EPAP, please visit http://www.srl.cam.ac.uk/epic/participant_panel.shtml

Statement From The Panel

"The panel members see themselves as representatives of the participants, reviewing and safeguarding their experiences, on paper and in person at the health checks.

We are regularly consulted about all aspects of participants' involvement. We have often expressed strong views about proposed practices in the health checks and the suitability of monitoring equipment. We have been consulted about ethical issues, for example the long term storage and use of human tissue samples.

EPAP has developed Terms of Reference and feels continuity of membership is important if its contributions are to be worthwhile. There is a strong camaraderie and mutual respect which encourages everyone to take part.

The panel has been led by Nichola Dalzell since its inception. She has imbued the members with a strong sense of their worth and she highly values the wide ranging influence of the panel. We have a sense that we can, and do, influence how the research is planned, conducted and communicated to all participants.

We engage in detailed reviews of all documentation, focusing particularly on communications with the body of participants.

The panel has enjoyed generous professional presentations from EPIC researchers and so members have felt equipped to represent and promote EPIC at events large and small.

We look forward: seeking to anticipate developments and changes. We are aware of imminent changes in EPIC's management and funding, and will seek clarity about our future role."



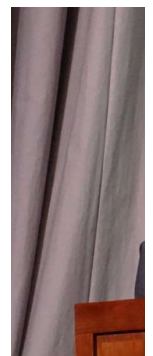
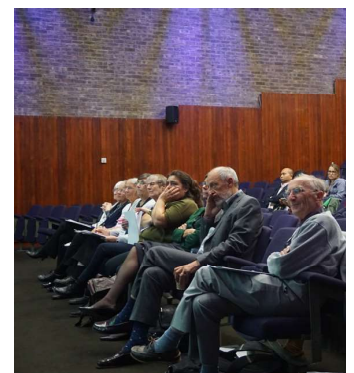
Celebrating 25 Years of EPIC

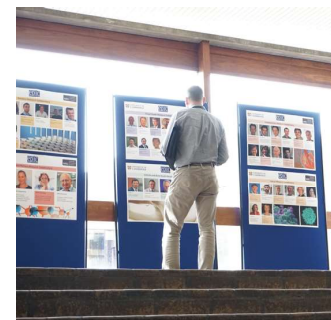
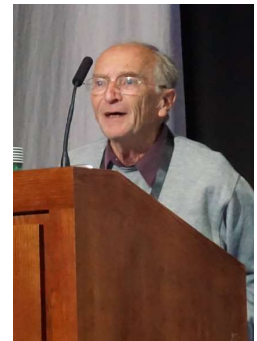
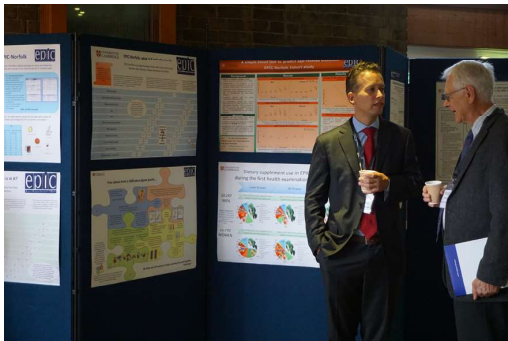
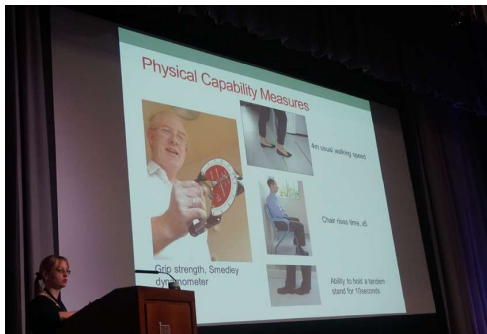
The EPIC- Norfolk Research team celebrated the 25th anniversary of the study on Friday 14th September 2018 at Churchill College, Cambridge.

European Prospective Investigation into Cancer and Nutrition (EPIC) was established in 1993 and is one of the largest cohort studies worldwide with more than half a million participants from ten European countries, coordinated by Professor Elio Riboli now at Imperial College. The EPIC-Norfolk study with over 30,000 participants resident in Norfolk, is one of the British collaborating centres that was established by Professors Nicholas Day, Kay-Tee Khaw and (late) Sheila Bingham. Professor Nick Wareham joined as Principal Investigator (PI) in 2000. Professor Wareham will continue as PI for EPIC-Norfolk when Professor Khaw retires in December 2018.

The aim of the symposium was to acknowledge the essential contributions from the many partners without whom EPIC-Norfolk would not have been possible. These included research staff, collaborators, funding agencies who provided support for research as well as the general practices and health agencies in Norfolk who provided the infrastructure for recruitment and follow up of the participants.

We were extremely privileged to have Professor Elio Riboli give his presentation on the history of EPIC and the rationale behind the wider European study. Professor Riboli gave a very personal and heart-warming account of setting up the study in the early days.





We would like to pay a special tribute to the wonderful late Suzy Oakes who was the original Research Coordinator for EPIC-Norfolk from 1991-2000. Suzy successfully completed the mammoth task of the initial recruitment. She also made a major contribution to the Europe wide EPIC collaboration. Sadly, Suzy passed away on 31st July 2011.



Frequently Asked Questions

1. I am an EPIC participant, but I have not heard from EPIC for a number of years. Why was I not invited to a particular health check?

We approach participants by GP practice. The length of the health checks varies depending on the tests included in each phase and the ability of individuals completing the tasks asked of them. We aim to invite the maximum number of participants to each health check within the funded timeframe, but unfortunately this means that we are unable to invite every participant to each and every health check. When planning each health check we do prioritise inviting those participants who may have been missed during the previous health check.

2. How does EPIC-Norfolk follow-up on participants?

The great value of the EPIC-Norfolk study is in understanding what happens to the health of participants over many years as they age, and to get as complete a picture as possible of health in the community. Aside from previous health checks and questionnaires, we will continue to monitor the health of our participants through an ongoing record linkage to general and hospital medical records and disease registries, to get a picture of patterns of health and disease over the years. Therefore, even if participants have not attended a health check or completed a questionnaire, their earlier contributions continue to be of benefit.

3. I made the decision to 'opt-out' of providing data to third parties via my GP practice. Will this affect the information received by EPIC?

You have the right to request that your data is not used beyond your own care and treatment. If you have indicated to your GP that you do not want your data to be used by third parties, but do not wish this decision to affect the updates EPIC receives regarding your health information, then please contact us. This will ensure that you will continue to contribute to the study, even if you are no longer attending the health checks. With your permission, we can make sure that the information you have given to us over the years can still be used.

4. I am an EPIC participant but I have moved out of the Norfolk area. Can I still participate in future research?

You are very welcome to take part in future EPIC-Norfolk research activities from your new address. If you are planning to move location in the future, please let us know your new contact details via our Freephone number 0800 616911.

5. I have either been unable to attend the latest health check, or I have turned down the opportunity to attend. Am I still a participant on the EPIC-Norfolk study?

If you have been unable to attend a previous health check, you are nonetheless still classed as an active member of our study and would be approached in the future. Should you no longer wish to be involved in future EPIC research activities, then please contact us via our Freephone number 0800 616911.

6. I now have an illness or health concerns, can I still continue to take part in EPIC?

Yes. Any information with regards to your health is extremely important to the study. Even if you have been unable to attend a health check or fill in a questionnaire, the information we are provided with from hospital records and disease registries is still very important.

7. Am I too old to participate?

There is no upper age limit to participate in any part of the EPIC study. We wish to follow-up our participants for as long as possible and it is an important part of our research that we are able to collect information as people age.

8. I withdrew from EPIC at some point in the past but I am now interested in participating again, can I?

Yes indeed. Let us know via our Freephone number 0800 616911 and we will be happy to re-enrol you, making you eligible for any future EPIC related activities moving forward.

9. I no longer wish to receive information regarding future EPIC research activities and questionnaires. How do I stop communications being sent to me from EPIC?

Please ring us on our Freephone number 0800 616911 and we will take your name off the mailing list. Your participation in EPIC is completely voluntary and you can stop your participation in research activities at any point in time. Once your name is removed from the mailing list you won't hear from us at all. Deciding not to take part in EPIC-Norfolk does not affect the treatment you receive as part of the routine care provided by your GP.

10. What results have EPIC come up with over the years?

We have published many papers over the years. For a full list of our publications, please see the Publications page on our website:

<http://www.srl.cam.ac.uk/epic/publications.shtml>

For general information on results, please also see the Summary Findings section on the website:

<http://www.srl.cam.ac.uk/epic/findings/index.shtml>

11. With the changes to the management of EPIC-Norfolk from January 2019, how will my previously collected data be handed?

Professor Kay-Tee Khaw who has up until now secured the grant funding for EPIC-Norfolk will be retiring by the end of the year and the EPIC-Norfolk study will transfer to the MRC-Epidemiology Unit, University of Cambridge from January 2019 onwards.

The study will continue under Professor Nick Wareham who is the other Principal Investigator for the study and Director of the MRC-Epidemiology Unit.

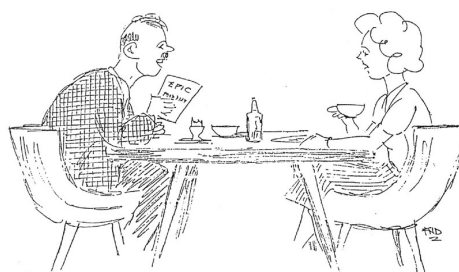
The MRC-Epidemiology Unit is a department within the University of Cambridge and as such, none of the data that you have so generously given to us will leave the University of Cambridge. The governance and security of your data will remain the same as it has always been.

The MRC-Epidemiology Unit will continue to use any previously collected data to conduct research analysis into the impact of diet, lifestyle and genetic factors on the onset of disease. In future, you may also receive communication from the MRC-Epidemiology Unit regarding any upcoming research activities.



"WHILE YOU'RE HERE, PERHAPS YOU'D LIKE TO SEE THE LAB..."

(NO ACTUAL PERSON IS DEPICTED HERE, WHETHER LIVING OR UNDEAD)



"BE SURE WHEN WE FINISH THIS DIARY, LOVE, THEN WE CAN HAVE A GOOD OLD FRY-UP"

"AND THE LAST THING HE SAID, DOCTOR, WAS 'ONE SLICE OF MARMITE, THINLY SPREAD'..."



Our heartfelt thanks to the late Mr Fred Davis, who provided these cartoons.

Privacy Statement

Key points from our new General Data Protection Regulation (GDPR) Privacy Statement:

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 to participate in this long term study on lifestyle factors and health in 1993-1997 and who are being followed up for health outcomes. 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.

You can find out more about how your information is used at the following address:

<https://www.medschl.cam.ac.uk/research/privacy-notice-how-we-use-your-research-data/>

To view the full EPIC-Norfolk GDPR Privacy Statement, please visit the following address:

http://www.srl.cam.ac.uk/epic/EPIC_Norfolk_Website_Privacy_Notice_V1.1_15_05_18.pdf



Message from Professor Nick Wareham (Principal Investigator)

This is the beginning of a new phase in the EPIC-Norfolk study, and it is a good time to reflect on the important medical insights that have been made possible by the dedication of the EPIC Norfolk team and the thousands of participants across Norfolk and beyond over the past 25 years. I look forward to helping us build on what we have already achieved together.

Closing Comments

We would like to thank all participants for your continued contribution and partnership with the EPIC-Norfolk study. Over the past 25 years you have enabled us to conduct quality research into a wide range of medical conditions, using information we have gathered through food diaries, questionnaires, and health checks. EPIC-Norfolk is one of the most important research studies looking at health and lifestyle, and we can only undertake this research with your continued participation. From all of us, we thank you for helping us achieve this milestone anniversary.

If you have any further questions that have not been answered in this newsletter, then please do not hesitate to contact us via our Freephone number **0800 616911** or alternatively you can visit our website **epic-norfolk.org.uk**

From **January 2019** we ask that you direct any queries to the MRC-Epidemiology Unit, using either the above Freephone number, or by contacting Gwen Brierley at the following email address:

epic-norfolk@mrc-epid.cam.ac.uk

Thank you from the current teams (October 2018)

Norwich



Cambridge



25 Year EPIC-Norfolk Study Timeline

