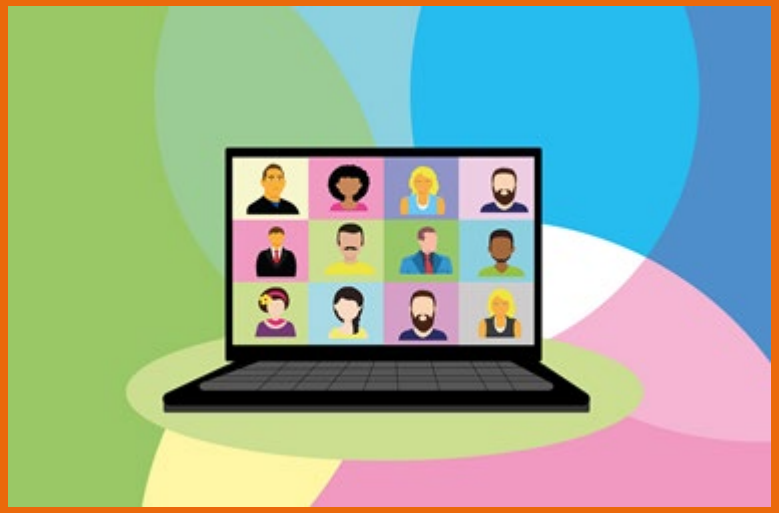
NIHR | Cambridge Biomedical Research Centre

CUH Patient and Public Involvement
Winter 2024 Newsletter
News and updates on PPI in the East of England

Welcome to the Winter 2024 edition.

Save the dates for upcoming events, webinars, and gatherings, whether virtual or in-person. This quarterly update is your go-to source for the latest on local and national events, PPI news, training opportunities, riveting research articles and more.

Please email **cuh.ppi@nhs.net** to update your choices or if you would prefer to be removed from our subscriber list.



Online Researcher PPI Training sessions 2024

Our online PPI training sessions for researchers are held on Zoom. They are open and free-of-charge for UK-based research students and staff employed or funded by the NIHR, NHS, academic institutions and charities. The sessions cover a range of relevant PPI skills and activities.

We also host information sessions on PPI aimed at members of the public.

Although the content in the researcher training can relate to all audiences, please be aware that we do not specifically cover PPI with children or young people.

A work-associated email (e.g. .nhs.net, .ac.uk, etc.) is required to confirm registration.

PPI Toolkit: Ways to involve the public in research
Tues 13 February - Full
This session looks at some of the methods that can be used for PPI to help researchers find ways that might be suitable for their project. The session covers activities that can be used throughout the research cycle, with examples from research taking place on campus.

How to build and maintain PPI groups

Mon 18 March 12:30pm - 2:30pm
Forming a PPI group can be an effective way of involving people in your research. This session looks at the different ways a PPI group can work, how to recruit group members and how to keep them involved throughout the lifecycle of your project. Includes one of our CUH PPI panel members and a researcher who will share their experiences.

Running successful PPI groups
Tues 16 April 1:00pm - 3:00pm
Focus groups can be a great way to support discussion about your research with a group of interested people. In this session, we will look at how focus/discussion groups can be useful for PPI, when they might not be appropriate and how to plan, organise and follow up on a successful session.

Planning inclusive PPI
Thurs 2 May 10:00am - 12:30pm
To maximise the impact of PPI and improve research for everyone, we need to
involve a diverse range of people and communities. This session encourages participants to think about ways to design inclusive PPI opportunities that work for the communities they wish to involve. We will look at best practice and examples for relationship building, recruitment, planning and follow-up.

Evaluating PPI
Wed 22 May 10:30pm - 12:30pm
PPI is seen as essential to improving the value and relevance of research, but how can we evaluate the impact that our PPI has had to know whether it has worked well and how it can be improved in the future? In this session, we will look at why traditional evaluation is difficult for PPI, how best to plan for success, and monitoring and recording your impact.

Using PPI to communicate your research
Mon 10 June 11:00am - 1:00pm
Join us for this interactive session as we look at writing for lay audiences, other formats for communication and tools for sharing our research and involvement opportunities. How patients and the public can help write, produce and share information about your research in an accessible way.

Unable to attend?
We have seen a lot of no-shows with our online training sessions. As we offer a small number of places, please consider allowing other researchers the opportunity to take your place if you are unable to attend for any reason.
If you need to cancel your ticket, either log into your Eventbrite account or **email:** gan23@cam.ac.uk

Topics we will cover in the Research Information talks in 2024

We have research information talks from Cambridge researchers up until April 2024, which will cover the following topics:

- **Professor Christi Deaton, Clinical Academic Posts - What are they and what role do they play in the NHS?**
- **Professor Roger Barker, What is Cell Therapy?**
- **Dr James Whitworth, Identification of Genetic Cancer Predisposition and Why Mosaicism Can Make It Difficult.**

These talks are open to anyone involved in research across Cambridge, and the links will be shared with both CUH PPI panel members and public involvement and engagement staff in our network.

Do you have any topics you would like to hear more about?
Please email cuh.ppi@nhs.net with any ideas, suggestions, or requests for information talks.

Recordings from talks in 2023 are now available on YouTube:

How AI is impacting healthcare research: https://youtu.be/mLQwoz_yVyQ
Dr Joshua Kaggie is a Senior Research Associate and MRI Physicist from the Department of Radiology, University of Cambridge. Dr Kaggie discussed research projects involving the use of artificial intelligence, which are becoming more common and tools and treatments involving AI that are starting to be used within the NHS and outlined how some AI technology works and how it might make a difference to health care in the future.

How does Gene Therapy work? https://youtu.be/hSgUKNIfozM
Dr Benson Chen, a neurologist and neuro-ophthalmologist from the Cambridge Clinical Vision Laboratory, NIHR Cambridge Clinical Research Facility. Dr Chen discusses gene therapy for mitochondrial diseases, exploring the progress that has been made and some of the controversies!

What does a Research Ethics Committee do? https://youtu.be/zmmPCEUBtrA
Ellie Hall, Principal Advisor, Health Informatics, Eastern Academic Health Science Network, explains what the Research Ethics Committee does. You will hear about what they are looking for from researchers and what researchers need to do to demonstrate to the REC that their research is safe and ethical.

If you are a researcher who would like to contribute to this series, or if you have public contributors who may wish to attend, please get in touch at cuh.ppi@nhs.net

Do you know anyone who might be interested in joining the CUH PPI panel?

We're constantly seeking new members to join the CUH PPI panel and actively participate in the ongoing research conducted at Cambridge University Hospitals and the Cambridge Biomedical Research Centre.

We need to increase the number of people on the CUH PPI panel - do you know anyone who might be interested in joining?

Membership of the CUH PPI panel is free and open to members of the public who are aged 16+, live in the East of England and do not currently work in health research or the media. Panel members choose which research projects they would like to be involved in and we have a mix of online, digital and in-person opportunities to choose from.

Click here to read more

Watch a PPI panel member share her experience about being involved in research:
Abi: https://youtu.be/3bYLmz5BsNc

Researchers' feedback to CUH PPI panel members

It's been a busy time with researchers needing your help. What difference did your involvement make to their research?

Check out the feedback they gave on the academic research projects **Click here**
Feedback has been shared from projects conducted in 2023.

These files are password-protected and only available to CUH PPI panel members.

Events

Rare Disease Day – Public Webinar Event

Thursday 29th February 2024 from 12.30 pm to 1.30 pm on Zoom

Join us over the lunch period (with your food!) for a 60-minute session for Rare Disease Day highlighting rare disease research with a patient focus. Our speakers will share their unique perspectives, knowledge, and experience of rare disease patient research before joining a panel discussion and Q&A session. Audience members are encouraged to submit their questions about rare disease research to the panel in advance as well as asking live questions on the day.

The link https://bit.ly/RDDbrc to the Eventbrite website for you to book.

Join us for the Cambridge Festival

We have two exciting events lined up for this year's Cambridge Festival!!

Health Data event for over 16 year olds.

Save the date for a hybrid event on Thursday,14th March from 5:30pm to 7:00pm. This event will focus on using health data in research at the William Harvey Lecture Theatre, Cambridge School of Medicine, Cambridge Biomedical Campus, CB2 0SP. We will be exploring the theme 'No Simple Choices - Privacy and Consent in Health Data Research.' Booking is essential, so check our website for details.

CAST- family friendly

There is also an in-person event scheduled at the Cambridge Academy for Science and Technology on Saturday, 16th March, 11am to 4pm. There’s no need to book – just turn up on the day.


NIHR
National Institute for Health Research
Cambridge Biomedical Research Centre
New treatments, innovations in healthcare and cutting edge technology are being developed by scientists and doctors at the Cambridge Biomedical Research Centre
Find out more here:
Your local hospital
Main Outpatients
Clinic 14
Eye unit
Bus Station

Discovering research with NIHR Cambridge BRC!

Did you know that medical research is happening all over the Cambridge Biomedical Campus, though you probably won't ever see it going on! But behind the scenes, researchers, scientists, doctors, nurses, midwives and other health professionals are working on important research to help sick people get better.

To help you visualise the stages involved, visit us during the Cambridge Festival and take part in our giant board puzzle with places to visit and clues to solve. Prizes for all puzzle-solvers!

This is a free event suitable for all ages, taking place from 11am-4pm on Saturday, 16 March at the Cambridge Academy for Science and Technology Robinson Way, Cambridge, CB2 0SZ. There's no need to book – just turn up on the day.

Articles

Research into neurological conditions including dementia, MS and Parkinson's

In the summer,NIHR announced funding into two new studies for dementia. The first is testing a revolutionary image recognition test known as 'Fastball'. The test aims to improve early detection of dementia and Alzheimer's disease. It uses a special headset to monitor brain activity when remembering images. The second study, Melodic, is assessing whether music therapy can reduce patient's distressing dementia wards.

In November, the PROTECT study showed that brain health in over-50s deteriorated more rapidly during the pandemic. Researchers analysed brain function tests from more than 3,000 people in the UK. The results showed that cognitive decline quickened significantly in the first year of the pandemic - potentially putting people at risk of dementia later on. Many participants were recruited using the NIHR's Join Dementia Research service.

Beyond dementia, a huge multiple sclerosis (MS) trial called Octopus opened in the UK. The trial hopes to find new treatments for progressive forms of MS up to 3 times faster by testing multiple treatments at the same time.

A study supported by NIHR found that eye scans can identify signs of Parkinson's disease up to seven years before symptoms may appear. Researchers hope this new technique could eventually offer a way to pre-screen people at risk of the disease. Meanwhile, researchers in Wales are looking at using the 'hunger hormone' to diagnose Parkinson's disease dementia.

Accelerating how new drugs are made with machine learning

Researchers have developed a platform that combines automated experiments with AI to predict how chemicals will react with one another, which could accelerate the design process for new drugs.

A deeper understanding of the chemistry could enable us to make pharmaceuticals and so many other useful products much faster.
Emma King-Smith

Predicting how molecules will react is vital for the discovery and manufacture of new pharmaceuticals, but historically, this has been a trial-and-error process, and the reactions often fail. To predict how molecules will react, chemists usually simulate electrons and atoms in simplified models, a process that is computationally expensive and often inaccurate.

Now, researchers from the University of Cambridge have developed a data-driven approach, inspired by genomics, where automated experiments are combined with machine learning to understand chemical reactivity, greatly speeding up the process. They've called their approach, which was validated on a dataset of more than 39,000 pharmaceutically relevant reactions, the chemical 'reactome'.

Their results, reported in the journal Nature Chemistry, are the product of a collaboration between Cambridge and Pfizer.

“The reactome could change the way we think about organic chemistry,” said Dr Emma King-Smith from Cambridge’s Cavendish Laboratory, the paper’s first author. “A deeper understanding of the chemistry could enable us to make pharmaceuticals and so many other useful products much faster. But more fundamentally, the understanding we hope to generate will be beneficial to anyone who works with molecules.”

The reactome approach picks out relevant correlations between reactants, reagents, and performance of the reaction from the data and points out gaps in the data itself. The data is generated from very fast, or high throughput, automated experiments.
“High throughput chemistry has been a game-changer, but we believed there was a way to uncover a deeper understanding of chemical reactions than what can be observed from the initial results of a high throughput experiment,” said King-Smith.
“Our approach uncovers the hidden relationships between reaction components and outcomes,” said Dr Alpha Lee, who led the research. “The dataset we trained the model on is massive – it will help bring the process of chemical discovery from trial-and-error to the age of big data.”

In a related paper published in Nature Communications, the team developed a machine learning approach that enables chemists to introduce precise transformations to pre-specified regions of a molecule, enabling faster drug design.

The approach allows chemists to tweak complex molecules – like a last-minute design change—without having to make them from scratch. Making a molecule in the lab is typically a multi-step process, like building a house. If chemists want to vary the core of a molecule, the conventional way is to rebuild the molecule, like knocking the house down and rebuilding from scratch. However, core variations are important to medicine design.

A class of reactions known as late-stage functionalisation reactions, attempts to directly introduce chemical transformations to the core, avoiding the need to start from scratch. However, it is challenging to make late-stage functionalisation selective and controlled – there are typically many regions of the molecules that can react, and it is difficult to predict the outcome.

“Late-stage functionalisations can yield unpredictable results and current methods of modelling, including our own expert intuition, isn't perfect,” said King-Smith. “A more predictive model would give us the opportunity for better screening.”
The researchers developed a machine learning model that predicts where a molecule would react and how the site of reaction vary as a function of different reaction conditions. This enables chemists to find ways to precisely tweak the core of a molecule.

“We trained the model on a large body of spectroscopic data – effectively teaching the model general chemistry – before fine-tuning it to predict these intricate transformations,” said King-Smith. This approach allowed the team to overcome the limitation of low data: there are relatively few late-stage functionalisation reactions reported in the scientific literature. The team experimentally validated the model on a diverse set of drug-like molecules and was able to accurately predict the sites of reactivity under different conditions.

“The application of machine learning to chemistry is often throttled by the problem that the amount of data is small compared to the vastness of chemical space,” said Lee. “Our approach – designing models that learn from large datasets that are similar but not the same as the problem we are trying to solve – resolves this fundamental low-data challenge and could unlock advances beyond late-stage functionalisation.”

The research was supported in part by Pfizer and the Royal Society.

Other research studies!

Of course, research in 2023 wasn’t limited to any particular area. There’s always plenty more to discover when it comes to health and care. Here are some more studies we found interesting.

In Scotland, researchers showed how eye scans could be used to detect kidney disease earlier. There are often no symptoms in the early stages of kidney disease. And current screening tests can’t detect the condition until half of the kidney function is lost. Researchers could track the progression of disease by looking at changes in the retina.

Over the summer, it was revealed that even half the recommended amount of exercise protects against early death, heart disease and cancer. Researchers estimated that 1 in 10 early deaths could be prevented. The conclusions from looking at a number of research studies covering 30 million people suggest even an hour and a quarter of moderate-intensity exercise per week gives people significant benefits.

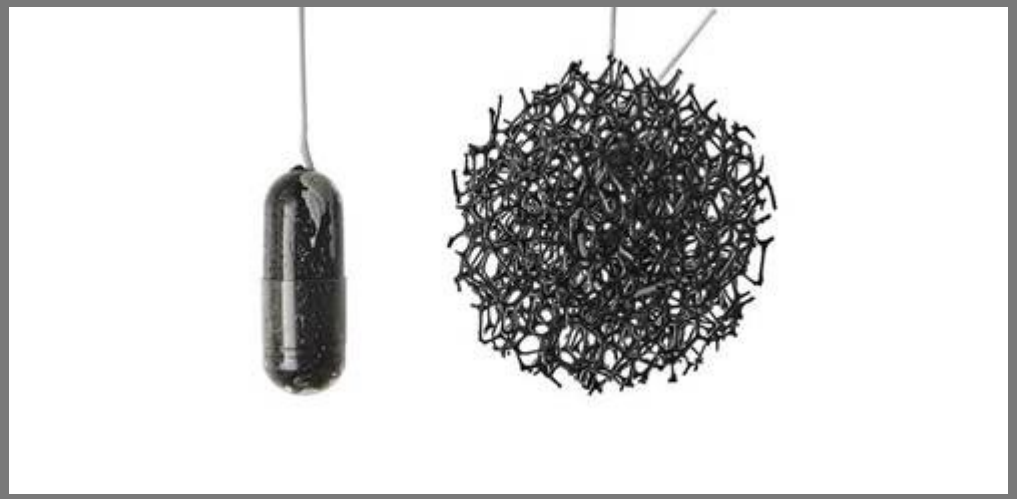
Researchers assessed the effectiveness of the NHS Diabetes Prevention Programme. They found the programme cut the risk of diabetes by 20% in people with pre-diabetes. Similar programmes have now been introduced in Scotland, Wales and Northern Ireland.

Researchers in Scotland have improved a blood test to detect heart injury. The enhanced test improved diagnosis for 1 in 5 patients and resulted in a nearly 10% drop in future hospital admissions and deaths. The test is being rolled out in emergency departments across the UK.

A cheap and readily available drug, used to treat high blood pressure, could help thousands of women who suffer from persistent acne. While another could improve symptoms of irritable bowel syndrome (IBS).

And a recent study has pinpointed the cause for nausea during early pregnancy - a major step towards better treatment.

We are really grateful to the millions of people who have taken part in studies or let researchers use their data to help reach these breakthroughs. Many more people across the world will benefit as a result.



Pill-on-a-thread and capsule sponge

A man from Cambridge is the first to join the surveillance part of a clinical trial that could see routine screening for oesophageal cancer introduced into the NHS, potentially halving deaths from this cancer every year.

The capsule sponge, a quick and simple test for Barrett's oesophagus, could halve the number of deaths from oesophageal cancer every year
Rebecca Fitzgerald

The capsule sponge, known as the pill-on-a-thread, is a quick and simple test for Barrett's oesophagus, a condition that can be a precursor to cancer. Heartburn is a common symptom of Barrett's oesophagus, a changing of cells in the food pipe.

The BEST4 trial launched at Addenbrooke's Hospital today is the final step to see if the capsule sponge can prevent oesophageal cancer when used to screen or monitor those most at risk of the disease. If so, it could become a national screening programme across the NHS, in the same way mammograms are used to screen for breast cancer.

The first stage of the trial, BEST4 Surveillance, is for people already diagnosed with Barrett's oesophagus. It will look at whether the capsule sponge test could replace endoscopies to monitor their condition. Participants will receive both examinations during the trial, with results used to assess their risk of developing oesophageal cancer.

The second stage of the trial, BEST4 Screening, opens in the summer and will recruit 120,000 people aged over 55 on long-term treatment for heartburn.

The multi-million-pound trial is jointly funded by Cancer Research UK and the National Institute for Health and Care Research. It builds on decades of research led by Professor Rebecca Fitzgerald from the University of Cambridge. She and a team of scientists, clinicians and nurses at the Early Cancer Institute, University of Cambridge and Cancer Research UK Cambridge Centre, invented and refined the capsule sponge test.

Professor Fitzgerald said: "The capsule sponge, a quick and simple test for Barrett's oesophagus, could halve the number of deaths from oesophageal cancer every year. Cases of oesophageal cancer have increased six fold since the 1990s. On average only 12% of patients live more than five years after diagnosis. Most don't realise there's a problem until they have trouble swallowing. By then it is too late.

"The first phase of the trial looks at whether the capsule sponge can be used as a cancer early warning system for patients diagnosed with Barrett's. Using the capsule sponge and a new set of lab tests, we will be monitoring patients to see if we can prevent more cases of cancer."
Tim Cowper, 49, a brewer from Cambridge, has had acid reflux, or heartburn, every night since he was 16. A routine health check while he was at university resulted in the shock diagnosis of Barrett's oesophagus. After his diagnosis, he has been monitored ever since.

Tim said: "I was alarmed when I was told that having Barrett's meant having pre-cancerous cells in my gullet. Cancer is never a nice word to hear, especially when you are so young, but luckily, I've had my condition monitored.

"Since my diagnosis, I've been going for an endoscopy at least once every three years to monitor my oesophagus. It is not pleasant at all. Each time I have a thick tube pushed down through my mouth and I can feel every single one of the biopsies taken by the camera. Swallowing a capsule sponge is a much better experience and I now get the test before my regular endoscopy appointment."

Barrett's oesophagus is currently identified via an endoscopy and a biopsy in hospital following a GP referral. It is time-consuming, unpleasant, and quite invasive for patients, as well as being expensive for the healthcare system.

The capsule sponge is a small, easy to swallow capsule on a thread, which contains a sponge. The patient swallows the capsule which dissolves in the stomach and the sponge expands to the size of a 50p coin.

The sponge is carefully pulled back up using the string, collecting cells for laboratory testing. The test takes just 10 minutes and can be done in a GP surgery.

Cancer Research UK and others have funded several successful clinical trials to demonstrate that the test is safe, accurate and can detect 10 times more cases of Barrett's oesophagus than standard practice.

The test is faster and cheaper than endoscopy, which is currently used to diagnose and monitor Barrett's oesophagus and oesophageal cancer. It has been piloted in health services in England, Scotland and Northern Ireland for patients who are currently on waiting lists for endoscopy because they have long-term heartburn or diagnosed with Barrett's oesophagus.

Executive Director of Research and Innovation at Cancer Research UK, Dr Iain Foulkes, said: "Around 59% of all oesophageal cancer cases are preventable. Yet endoscopy, the gold standard for diagnosing and treating this cancer, is labour-intensive. We need better tools and tests to monitor people most at risk.

"Backed by funding from Cancer Research UK, the capsule sponge has become one of the most exciting early detection tools to emerge in recent years. It's a remarkable invention by Professor Fitzgerald and her team, and previous trials have shown how powerful it can be in identifying cancer earlier.

"There are 9,200 people diagnosed with oesophageal cancer in the UK every year and the capsule sponge will mean they can benefit from kinder treatment options, if their cancer is caught at a much earlier stage."

The future Cambridge Cancer Research Hospital will bring together clinical and research expertise, including Professor Fitzgerald's work, under one roof. It will enable the development and discovery of more non-invasive devices like the capsule sponge, to detect cancer earlier, and save more lives.

The BEST4 Surveillance Trial is led from Cambridge University Hospitals NHS Foundation Trust and the University of Cambridge, with trial design, coordination and analysis of results by the Cancer Research UK Cancer Prevention Trials Unit at Queen Mary University of London.

Use MyChart?

Did you know you can set your research preferences?

Patients at Cambridge University Hospitals can now use the patient portal MyChart to set their preferences about hearing about research opportunities. Patients who give their consent for contact can be contacted by research teams at CUH about research opportunities that may be relevant for them.

MyChart is free to **sign up** to and available to all CUH patients. You can change your preferences about research contact at any time in MyChart.