

Getting Involved in Research!

**Newsletter for Patients and the Public in the Eastern Region
Issue 1: June 2021**

Welcome to the first edition of the Clinical Research Network (CRN) Eastern's Getting Involved in Research!

This will be a monthly newsletter packed with information and ways of getting involved in research as patients, research participants and members of the public.

If you would like to continue to receive this newsletter please let us know by filling in this short online form by clicking on this link: <https://forms.gle/te5ee5WV8nGsAFJAA> (or copy and paste the address into your computer browser). Or you could email ann.rampling@nnuh.nhs.uk or call us on 01603 287670 to let us know you are happy to be on our mailing list.

Learn more about research

Free online courses for members of the public

Massive Open Online Courses

Are you interested in finding out more about research? The Massive Open Online Courses (MOOCs) offer free online courses to members of the public who are interested in research.

You can access the courses through www.futurelearn.com. The courses are free and once you have registered, you can work your way through the modules at your own pace at a time that suits you. Here are three courses, which you may find interesting:

1. Understanding the research behind the pandemic

This course looks at how scientists responded to the COVID-19 pandemic and how they carried out research into treatments and vaccines.

2. Improving Healthcare Through Clinical Research

On this course you will find out how treatments are discovered, tested and evaluated to improve healthcare for all.

3. What is Health Research?

On this course you will explore the world of health research and the role volunteers play in finding treatments and improving health care.

Join the Royal Papworth Hospital training session: Study Designs in Clinical Research

The Royal Papworth Hospital Research and Development Team is running an online training session for patients and members of the public.

The session explains:

- Some of the study designs used in clinical research projects,
- Describes the advantages and disadvantages of each design and
- Consider how results from different studies shape health practices.

The session will take place via the online platform MS Teams on Tuesday 22nd June between 11am and 12pm, with registration opening at 10.45am. If you would like to join the Papworth team at this event, please follow this link to register for a place: www.eventbrite.co.uk/e/study-designs-in-clinical-research-tickets-151197745527

The Royal Papworth Hospital team are also planning the following courses for patients and members of the public:

- September 2021 - Research Timelines, 'It's a waiting game'
- December 2021 - 'Understanding a Journal Article' presented by Rebecca Rowe (Clinical Outreach Librarian, Royal Papworth)

For more information please email: queries-papworth.ppi@nhs.net

Amazing new research guide: By children for children!

The Norfolk and Suffolk NHS Foundation Trust set up a children and young people's specialty research delivery team called CHEYENNE, to increase engagement with under 16s in mental health research. As part of their plan to involve young people as representatives, they worked with children and young people to design and produce two research activity booklets.

The booklets are designed to explain what research is, what their rights are when taking part in research and what to expect if you are taking part in a research study. The content of the booklets are written by children, in their own words, for children.

The youngsters also illustrated the booklets, creating wonderful characters including Raj the Red Panda who is the researcher and narrator in the younger children's booklet and Sammy the Squirrel who is a potential research participant.

Children who come to the department are given a welcome pack, containing the booklet, as an introduction to research, and postcards of the artwork. Younger children are also given stickers and a glitter pen in their welcome packs.

To view or download the booklets go to: www.nsft.nhs.uk/research-children-and-young-people

For more information on the booklets or children and young people's research at the Norfolk and Suffolk NHS Foundation Trust, please email the team: researchinfo@nsft.nhs.uk

For wider opportunities to be involved in mental health and dementia research, the Norfolk and Suffolk NHS Foundation Trust has a central self-referral system for both participation in current research studies and user involvement opportunities for research in development.

If you are interested in finding out more for yourself, a family member or someone you know, you could visit www.nsft.nhs.uk/be-a-part-of-research and sign up to the database. You could also email: researchinfo@nsft.nhs.uk or telephone: 01603 421397 to register your interest and the team will contact you within 2 to 3 weeks.

Can you help shape research in mental health?

Would you like to help identify important research and innovation challenges that could transform mental health? NHS England are looking for people with lived experience to take part in workshops to identify important health research questions. The workshop sessions are

running throughout June and July. If you would like more information or think you could help please visit: www.england.nhs.uk/get-involved/get-involved/opportunities/ or email: england.aacppi@nhs.net

Meet the Public Research Champions (Known as Patient Research Ambassadors in Eastern)

Public Research Champions are patients, carers, members of the public and people who have taken part in a research study before as well as those who haven't. Something they have in common is that they want to get involved in research to help improve care and treatment for everyone.

Public Research Champions help to spread the word about health and care research to patients and the public, especially people who are less likely to take part. They also help research and health staff to understand about the experience of people who take part in research.

Julian Mogford, who has been a Public Research Champion for 2 years says:

"I am a member of the vaccine research patient panel. This has been an interesting experience as I have learned a lot about research and I have really enjoyed the experience of working with a diverse panel of health professionals, participants and people of different ethnicities and cultures from me."

Would you like to become a Public Research Champion?

Follow this link to [find out about Public Research Champions](#). If, like Julian, you are interested in becoming a Public Research Champion please contact Anne Sykes, Patient and Public Involvement Manager at CRN Eastern by email: anne.sykes@nihr.ac.uk or telephone: 01603 287670 for a friendly chat.

Or, you could find out more by joining us at one of our meetings

You are welcome to attend one of our Public Research Champions Development Sessions to find out more about what we do and meet other Research Champions. Coming to one of our meetings does not mean you have to become a Research Champion but it would be great to have the opportunity to meet you.

If you are interested in joining a meeting please contact Anne by email: anne.sykes@nihr.ac.uk or telephone: 01603 287670 to find out more.

Our next meeting date is on 6th of July 2021 from 1:25pm until 3:05pm.

This will be an online meeting. Don't worry if you've never attended an online meeting, we are here to help guide you through it.

What do research participants say about taking part?

Last year 2,428 research participants completed a survey telling us about their experience of taking part in a research study.

The feedback was generally positive:

- **94%** of respondents felt they received enough information to prepare them to take part in the study
- **91%** of respondents felt the researchers valued their taking part in the research.
- **97%** of respondents felt that the researchers treated them with courtesy and respect.

- **94%** of respondents would consider taking part in research again

The survey is an opportunity for research participants to tell us how we can improve their experience and to suggest things that could be done differently. Two examples highlighted in the survey are:

- Making it clear how to find out the results of the research study
- How we keep people updated on the research they are taking part in

Many of the people who completed the survey left comments about the kindness and professionalism of the research staff. Here are two quotes from last years survey:

“The entire team is **amazing** and **kind** and **helpful**”

“I was treated as an **individual** with **courtesy** and **care**”

If you would like to see the full results of the survey you can access the report [here](#). Or you could email ann.rampling@nnuh.nhs.uk or call 01603 287670 to ask for a copy to be sent to you.

Meet Rebo and Join in the Research Adventure!

Rebo's Research Adventure is the world's first online research video game. Rebo tells the story of how scientists found treatments for health conditions like diabetes through research. If you or your family would like to download the game for free please follow this link: [Rebos Research Adventure](#)

Jessica Coe, a Children and Young People's Research Champion says “Rebo is a really fun online game which helps to explain research to people. The game is popular with kids and they seem to enjoy playing the different levels of the game. It's free to download so if you'd like your children to learn a bit about research then it's a really fun way to do it.”

Be Part of Research

If you would like to find out more about health and social care research that is taking place across the UK please visit the website: www.bepartofresearch.uk

Join Dementia Research

Dementia affects more than 850,000 people in the UK
Research is the best way to make a difference

Could you help us and Join Dementia Research?

This is a programme for people with or without dementia. It is a national service where you can register your interest and be matched with suitable research studies. Dementia research is important. It can help people living with the condition now, as well as helping to prevent people from developing dementia in the future.

For more information go to the website: www.joindementiaresearch.nihr.ac.uk

Would you like to keep receiving this monthly newsletter?

If the answer is yes, please fill in this short online form by clicking on this link:

<https://forms.gle/te5ee5WV8nGsAFJAA> (or copy and paste the address into your computer

browser)

Or email ann.rampling@nnuh.nhs.uk to let us know you are happy to be on our mailing list.

**Got a question? Need more information?
Is there something you'd like us to include in the bulletin?
Then contact the team, we'd love to hear from you:**

Email us: crn-eastern-ppi@nihr.ac.uk

Phone us: 01603 287472

Write to us: PPIE Team, CRN Eastern, 20 Rouen Road, Norwich, NR1 1QQ

You can find out more about CRN Eastern by visiting our website:

www.local.nihr.ac.uk/lcrn/eastern