

FRONTIER^{MAG}

clinical research community news

Patient story: **Ann's research legacy**

Page 6

Bowled over by SW stroke success

Page 8



CONTENTS



PATIENT STORY:

Ann's research legacy



FRONTIER^{MAG}

Editor: Wendy Shaw

CRN SWP Communications Lead

01752 431944

wendyshaw1@nhs.net

Issue: JUNE-JULY 2017

02 Contents

04 Welcome to FRONTIER

05 Patient Experience

06 Our Story:

Ann Bennett makes a 200-mile round journey for hospital appointments because she values the opportunity to take part in a respiratory research study.

08 Stroke recruitment success

10 Once in a lifetime experience for research duo

11 SW home grown study open

12 Patient Involvement flagship event

14 News in brief



Abi developed an interest in clinical research when she saw first-hand the benefits for her dad as a study participant. She felt the research nurses went out of their way for him and he gained more confidence from taking part in the trial as part of his treatment.

Her current role with Plymouth Hospitals NHS Trust involves recruiting people into clinical research studies and follow-up contact with participants face to face or on the phone. Some of the research Abi supports involves taking blood or tissue samples as well as data collation. She has been working closely with research colleagues in Neurology and is currently contributing her skills to 24 studies.

Abi works closely with the Research and Development team and Principal Investigators to help study set-up preparations.

#iamresearch

“ I feel very privileged that research participants are allowing us a very small window in their lives and we are lucky to spend the time with them. When our surgical patients are admitted to hospital they are anxious about what lies ahead and so having met them and their families earlier in a research capacity we are a familiar and reassuring face for them. I love the fact that together we are changing the future of medicine. ”

FRONTIER MAGAZINE



Helen Quinn
Chief Operating Officer
Clinical Research Network
South West Peninsula

Welcome to the second issue of Frontier with news on the achievements, opportunities and events for the research community in the South West.

Patients and the public are at the heart of who the research community strives to serve and benefit.

It is testimony to the Network partner organisations that the feedback from our latest Patient Experience Questionnaire (see page 5) reaffirms how much participants feel valued by research delivery staff and for the contribution they make to research activity in our region. Recommendations informed by the feedback will seek to enhance participant experience further.

Patients like Ann Bennett who shares her positive participation experience on page 6 travels some 200 miles each time to attend hospital appointments despite having a chronic respiratory condition. Her motivation for doing so is to help others who have the same lung disease in the future. And patients, like Ann, often get involved in a voluntary capacity as advocates to raise awareness of their health condition or to lobby and inform changes to improve the quality of life, education and support for others.

A new video describing what the NIHR is and does in a nutshell is now available to watch on the NIHR YouTube channel as part of the Who are the NIHR? #WeAreNIHR campaign.

This film focuses on the following key areas: Research, Funding, Innovation, Training, Collaborations, Hope and the Future. This is a useful resource for presentations to lay and professional healthcare audiences.

In a letter to the Chief Executive of Royal Cornwall Hospital NHS Trust, participant Roger Caudwell said:

"Based upon my experience I would have absolutely no hesitation in encouraging warmly others to participate in clinical trials conducted by the Rheumatology team."

Research experience

Feedback from people who took part in clinical research in the third annual Patient Experience Questionnaire (PEQ) conducted by the Clinical Research Network for the South West Peninsula has been published.

Patient experience of research participation is fundamental to the continued engagement of patients in clinical research to support the NHS in providing the best healthcare.

The PEQ findings this year included:

- **43%** of participants expected to be asked to participate in research
- **97%** strongly agreed or agreed that staff who treated them were friendly and helpful
- **89%** strongly agreed or agreed that they could contact staff to answer their questions
- **94%** felt their participation in research was valued
- **65%** learnt more about their condition
- **92%** thought that research should be a normal part of healthcare
- **87%** would be happy to take part in another research study
- **89%** had a good experience of taking part in research
- **91%** would recommend taking part in research to other people

The way in which the survey was carried out this year has increased results in some health specialty areas. As well as the positive feedback respondents have informed where the Network can pro-actively improve experience for study participants. For example sharing with participants the results or findings of the study they took part in.

Recommendations from the PEQ for 2017-18 include:

- Working with Chief Investigators of studies closing this year to develop ways to support the dissemination of study findings to participants.
- Development of a survey specifically for children and for people with mental health conditions.
- Partner Organisations undertaking patient walkthroughs of study protocols to identify practical arrangements of the study. Evidence of the impact of these walkthroughs will be collated and reviewed.
- Use of the Local Portfolio Management System to identify reasons for non-participation to inform more targeted awareness raising or recruitment campaigns.

A summary report of the SW PEQ survey 2017 findings and recommendations and posters for display in research clinic settings are available to download at:

www.nihr.ac.uk/news/glowing-feedback-from-south-west-clinical-research-participants/6421

Patient story:
Respiratory research specialty



“ I feel it is very important to explore all the avenues in the search for a cure for IPF. At present there is only medication available which might slow down the damage caused by this disease but there is no cure. I consider taking part in research to improve treatments my legacy for patients in the future. ”

Ann Bennett

About 6,000 people are diagnosed with Idiopathic Pulmonary Fibrosis every year in the UK.

In 2016/17, 272 people were enrolled in the South West across 20 NIHR portfolio respiratory studies conducted by acute hospital trusts and GP practices.

The British Lung Foundation

Ann Bennett of Cornwall hopes her commitment to taking part in research into the treatment of a chronic lung condition will be her legacy for future patients.

Idiopathic Pulmonary Fibrosis (IPF) scars the lungs and reduces the efficiency of breathing. The build-up of scar tissue called fibrosis causes the lungs to stiffen and lose their elasticity so they are less able to inflate and take oxygen from the air breathed.

Ann's symptoms developed over a six year period from a cough to increasingly becoming breathless even when walking around in her bungalow home. A CT scan in 2014 confirmed a diagnosis of IPF.

Ann says: "The diagnosis of IPF was devastating as the only treatment I was offered was oxygen. As well as being concerned about the deterioration in my own health, I was also very worried about the impact on my role as a carer for my husband Peter.

"As I became more breathless I was unable to continue my active lifestyle until I was assessed for oxygen therapy. My general health is fine but I have to factor in how I can continue to receive the oxygen when I am out and about and I am more vulnerable to coughs, colds and infections. In 2015 I was offered medication to

try to slow down the progress of IPF but this treatment involved travelling to London every 12 weeks."

Ann's care was transferred from the Royal Brompton hospital to the Royal Devon & Exeter hospital and in early 2016 Ann was offered the opportunity to take part in a research trial. She didn't hesitate in accepting: "I had nothing to lose and so much to gain whether I was receiving the actual drug being trialled or the placebo because I am closely monitored every three months for any changes in my condition.

"I feel privileged to be part of a research study and being part of scientific progress which may benefit me and other people. I don't know whether I am receiving the drug or placebo (dummy version) but I have felt my health has improved. Within five weeks of being on the study, my cough had improved and people commented on how well I look. I am reassured by the regular and thorough check ups and respiratory tests I have done."

Although Ann no longer has to make the arduous journey to the capital city for treatment, she does travel from her home in Falmouth to Exeter to participate in this research trial.

Back in Cornwall her research participation commitment takes pretty much a whole morning once a week when a nurse, engaged by the pharmaceutical company leading the trial, visits her at home to administer an injection and observe Ann afterwards. Ann also liaises with the Royal Devon & Exeter hospital regarding the delivery by courier of drugs and storage of her medicines.



Dr Michael Gibbons

Clinical Research Specialty Lead for respiratory disorders, CRN South West Peninsula

Dr Gibbons said:

"Respiratory conditions can require more effort to carry out everyday tasks so we do not underestimate the determination and commitment patients make when they travel and take part in research studies. It is a privilege to work with patients like Ann who generously support research to benefit future generations."

STROKE SPECIALITY



Dr Martin James

CRN SWP Clinical Research Specialty Lead for Stroke, said clinical research has informed national clinical guidance for the treatment of stroke.

Dr James, who conducted his first stroke research study in 1990, said his interest in research “comes from a desire to find answers to problems in every day practice. I always have had a curiosity and the most important question in medicine is why? This question has been the starting point for great discoveries and medical advances in treatment and patient survival.”

An inherent aspect of emergency stroke medicine requires research staff to approach patients or their families in difficult circumstances about the opportunity to participate in research. Dr James said: “I find that pretty much every one we talk to understands the value of medical research even in an emergency situation.”

Significant positive developments in stroke care have been achieved in recent decades. Dr James cites this example of progress: “In 1999 the clinical guidelines for stroke covered one page. Eighteen years on, the fifth edition had 400 recommendations. Every day evidence-based clinical interventions are stopping people from dying or reducing the impact of stroke on their health and quality of life.

“It is one thing to discover what we should be doing but research only brings real benefits to patients when it is applied in every day practice. That’s when it can make a positive difference. But it doesn’t happen quickly. Thrombolysis treatment has been available in the NHS for eight years. We know that on average it takes 17 years from the first publication of research until it is widely adopted in clinical practice.”

Increasingly research is also focussing on the rehabilitation of people recovering from a stroke, with an exciting development in the use of robotics in this field.

For the second successive year Royal Cornwall Hospitals Trust (RCHT) has been confirmed as the top recruiting large acute trust in England for recruitment of participants to stroke research studies.

RCHT enrolled an impressive 360 participants to studies in 2016-17. Of the 19 stroke studies open for recruitment within the CRN SWP region, two were commercial and 17 non-commercial.

RCHT consultant stroke physician Dr Frances Harrington said: “The team put their success down to the several factors – a dedicated, flexible team; excellent support from the stroke clinical team including nurses and therapists, radiology, labs and pharmacy; and most importantly, patients affected by stroke and their carers.”

Main picture: Kirsty Bond (Senior Research Nurse), Toby Nisbett (Research Nurse), Andrea Lydon (Clinical Research Assistant), Julie Frost (Senior Research Nurse), Gillian Courtauld (Neurovascular Team Leader), Alison James (Research Administrator), Dr Christine Schofield (Specialty Doctor), Rose Ashwood (Research Admin Assistant).

The CRN SWP was the second highest recruiter of participants (979) for NIHR portfolio stroke research studies out of 15 Networks in England in 2016-17. (Adj for population)



Nicola Wedge and Dr David Strain

The recruitment of 2,434 patients to ProMOTe was achieved on time and target with the majority of participants enrolled by sites within the Clinical Research Network South West.

ProMOTe was investigating whether detection of a protein in urine in people who had been diagnosed having had a mini stroke or TIA would act as an effective marker to flag a higher risk of subsequently having a more serious and potentially damaging or life threatening stroke. The Chief Investigator for this study is Exeter-based Stroke Physician Dr David Strain and half of 14 sites conducting ProMOTe were within the CRN South West Peninsula.

Study manager Nicola Wedge said Royal Cornwall Hospital NHS Trust was an outstanding recruiter having enrolled 548 people to ProMOTe by making a commitment to attend every single clinic opportunity in Cornwall to identify potential participants.

Nicola said:

“This was a tremendous achievement given the clinics were taking place across a remote and spread out geographical area.”

Nicola added: “We were very grateful to Alere for providing equipment to analyse the urine samples which was an essential part of the study activity.” Reflecting on the success of the recruitment effort for ProMOTe, Nicola said: “Keeping a close eye on the activity at site levels throughout the life of this study enabled us to pro-actively identify and resolve any issues which could compromise or delay delivery.

‘We were on it from day one’ when it came to recruitment to the ProMOTe stroke research study in the South West.



ONCE IN A Lifetime EXPERIENCE

Dementias and Neurodegeneration specialty

A South West neurology research consultant and nurse had the experience of a lifetime as invited guests of the Pope in the Vatican City to raise awareness about Huntington's disease.

Royal Devon & Exeter hospital Consultant Neurologist Dr Tim Harrower and Senior Neurology Research Nurse Sarah Irvine were among invited international guests of Pope Francis. It was the first ever Papal audience with people affected by Huntington's disease.

Huntington's disease is an inherited condition that damages certain nerve cells in the brain which progressively worsens over time and can affect movement, cognition (perception, awareness, thinking, judgement) and behaviour.

The RD&E has conducted clinical research studies for Huntington's disease for seven years. Over 50 participants currently travel to Exeter, from as far afield as Cornwall and Wiltshire, to take part in this research. Three of the studies currently open for recruitment at Exeter are supported by the NIHR.

In his address to people with Huntington's, their relatives, caregivers, researchers, and advocates Pope Francis said, "For far too long, the fears and difficulties that characterise the life of people affected by Huntington's disease have surrounded them with misunderstandings and barriers, veritably excluding them."

Dr Harrower said: "For me personally the Pope was inspirational in his thoughts and ethical perspective about research in this disease which he discussed with passion during his address to our small but truly international group gathered in the Vatican City."

In Exeter Dr Harrower said the clinical research is looking at all aspects of Huntington's disease from Biomarkers at the time of

diagnosis and during the life of patients through to longitudinal observations of the effect of the disease. The RD&E is also collaboratively supporting recruitment of participants for studies in other parts of England in this field.

Describing the visit as being 'hugely symbolic and significant' Sarah Irvine said:

“Much of the modern understanding of Huntington's disease originated from Venezuela - a strongly Catholic country - and the disease presents ethical implications. For Pope Francis to embrace those affected and meet the scientists and clinicians working in this challenging field and who deal with ethical dilemmas on a daily basis, will hopefully change the way this disease is thought of and give hope to those living with it. Huntington's disease is in many regards still a hidden disease with a lot of stigma associated with it. Having a world leader taking an interest in what is happening regarding Huntington's disease can only be a positive influence.”

SW led nose bleed study: Injuries and Emergencies specialty

Fourteen NHS emergency hospital departments have opened a new clinical research study led by the Royal Devon & Exeter NHS Foundation Trust which could transform patient experience of the way serious nose bleeds are treated.

Dr Adam Reuben, Emergency Medicine consultant at the RD&E Wonford hospital is the Chief Investigator of the NoPac study.

NoPac is trialling the novel use of Tranexamic Acid to reduce the need for nasal packing to treat acute spontaneous nose bleeds. The NIHR awarded funding for this study through its Research for Patient Benefit Programme.

Dr Reuben (pictured) said: "Epistaxis or nose bleeds are an extremely common condition caused by a blood vessel bursting within the nose as a result of trauma or spontaneously. If bleeding cannot be stopped patients attending hospital Emergency Departments usually undergo anterior nasal packing which is an extremely uncomfortable experience and can require a hospital stay for several days. There can also be complications from nasal packing including infection, sleep apnoea and bleeding on removal of the packing. This procedure is tolerated only on the basis that there is at present little alternative ways to treat it."

Dr Reuben added: "Tranexamic acid (TXA) has been used in a variety of clinical and research settings to stabilise and stem blood clotting. We trialled at the RD&E hospital a local study to estimate the quantity of TXA applied to a material inserted in the nose and the results suggested that TXA could provide a promising alternative treatment to the current nasal packing practice and greatly enhance the experience for patients in the future."

The Research Design Service South West, Peninsula Clinical Trials Unit at Plymouth University and the Clinical Research Network SWP provided support and guidance on the study design, development, set-up and launch.



SW Hospital Emergency Departments conducting the NoPac study: Royal Cornwall Hospitals NHS Trust, Plymouth Hospitals NHS Trust, the Royal Devon & Exeter NHS Foundation Trust; Northern Devon Healthcare NHS Trust and Taunton and Somerset NHS Foundation Trust.

PATIENT INVOLVEMENT

People ARE MESSY

Over 100 Plymouth students learned about patient and public involvement in clinical research at an NIHR flagship event.

Stoke Damerel Community College students, aged 14-17 years old, watched a film called 'People are Messy' before discussing and voting on key themes and issues exploring the value of patient and public involvement in health research.

Lana Carlson, Subject Leader for Health and Social Care at Stoke Damerel Community College, said:

"It was a real privilege for us to be chosen as one of only 11 schools in the UK and the only one in the South West to take part in the event. This was a great opportunity for our students to find out more about clinical research, why and how it's conducted as well as the many career choices it presents."

The event also included an 'I Am Research' challenge where the students quizzed mystery guests who play a part in health research to find out what it is they do. Twenty one students guessed correctly and will enjoy an exclusive visit to the new £17m Plymouth University clinical research facility opening this year.



Describing the event as 'eye opening,' Year 9 Kiera Coath said:

"It wasn't what I was expecting – we found out so much about all aspects of research and how many different roles there are and how each is as important as the other. It's been a really interesting day."

Year 9 student Georgia Pine said:

“It's been really inspiring. The film was really interesting and I've learned lot today about what is involved in research like this.”

THANK YOU to staff from Plymouth Hospitals NHS Trust, Plymouth University Medical Statistics Unit, the Clinical Research Network SWP Core Team and Research Participant Tony Patrick for contributing to the success of this event.

DEMENTIA:

The Alzheimer's Society has committed almost £2 million to the University of Exeter for research to improve both quality of life for people with dementia, and care in advanced dementia.

The research grant will fund a second phase of a large-scale national study entitled Improving the Experience of Dementia and Enhancing an Active Life (IDEAL). Running since 2014, it aims to understand how to help people to live well with dementia by taking into account the experiences of people with dementia and their carers over six years. Expansion of the study includes adding the experiences of people from black and minority ethnic backgrounds and people in the advanced stages of dementia.

HONOUR:

World-leading expert diabetes expert Professor Andrew Hattersley has been awarded the CBE in the Queen's birthday honours for his work revolutionising diagnosis and treatment of diabetes.

Andrew is a Professor of Molecular Medicine at the University and a diabetes consultant at the Royal Devon & Exeter NHS Foundation Trust. He has won international awards for his work in combining genetic diagnosis with clinical treatment to make a real difference for patients with genetic sub types of diabetes across the world.

MS:

A research team from Plymouth University and Plymouth Hospitals NHS Trust was awarded second place prize for their poster giving an overview of their work on the Balance Right in Multiple Sclerosis (BRiMS) study at the international Annual Rehabilitation in MS Conference in Barcelona.

MENTAL HEALTH:

A large research study from the Universities of Exeter and Plymouth has revealed that older people are not being referred for mental health support nearly as frequently as their younger counterparts despite achieving better outcomes when they are referred.

The study, published in the British Journal of General Practice, analysed over 80,000 mental health treatments in South West England. It was conducted as part of the South West of England Improving Access to Psychological Therapies (IAPT) Evaluation Project commissioned by the then SW Strategic Health Authority with additional contributions from the NIHR Collaboration for Leadership in Applied Health Research and Care South West Peninsula (NIHR PenCLAHRC).

Professor Richard Byng at Plymouth University Peninsula Schools of Medicine and Dentistry, a lead author of this study, said: "What we found striking was the fact that, although older people would benefit the most from 'talking therapy' they were least likely to be referred to it - despite the fact that GPs are the most frequent referrers to these types of services, and this age group is more likely than any other to have regular contact with their GP. We would suggest that GPs should do more to discuss mental health problems with their older patients and increase awareness of the different therapy options that are available."

Co-author Professor William Henley, of the University of Exeter Medical School, said: "This research is an important step towards improving mental health services for older people, who have a right to high-quality treatment. This research enables us to explore what barriers to treatment remain by analysing data that is routinely collected during consultations, ultimately making a positive impact on people's lives."

NEURODEGENERATION:

Dr Camille Carroll has been appointed NIHR CRN National Specialty Lead for Neurodegeneration – a clinical ambassador for this specialty.

In this role she will provide national leadership across commercial and non-commercial clinical studies in neurodegeneration, which includes Parkinson's disease, motor neurone disease and Huntington's disease; as well as develop relationships with a variety of groups including the public sector, charities and life-science funding organisations and maintain oversight of the specialty's research portfolio.

Dr Carroll, who is also the Clinical Research sub-specialty lead for Parkinson's Disease for the CRN SWP and Research Fellow in Clinical Neuroscience at Plymouth University Peninsula Schools of Medicine and Dentistry, and consultant neurologist, will hold the national role until March 2020.



DIGITAL:

All CRN staff can access the eduroam wifi network, where it is available, as part of the NIHR-wide Accelerating Digital Programme.

eduroam (education roaming) is a secure wireless network service that allows staff to access wireless networks when at or near participating eduroam institutions. It is available to all NIHR staff with a valid NIHR email address.

eduroam is particularly convenient for smartphone and tablet users. Once you have set up access on your device you can log in automatically wherever the eduroam network is available. Most eduroam locations in the UK can be found on this interactive map of participating sites, but as a general rule these are in and around academic institutions, including university hospitals.

Not all CRN staff will be able to access the eduroam network from their primary base. However, those who travel in their role will be able to access it where it is available, once they have gone through the certificate process. For assistance contact Hub Support by following the link at the bottom of the Hub homepage or call 020 7333 5060.

PRIMARY CARE:

Congratulations to Oak Tree Surgery in Liskeard for recruiting the first global patient onto the ORION 3 cardiovascular study.

NURSING:

A research active nurse at the Royal Cornwall Hospital was shortlisted as a contender for the 2017 RCNi Nurse Awards category Bank Nurse of the Year.

Kim Arnell has worked at RCHT for 12 years. Between 2010 and 2013, Kim was seconded to work on a Department of Health research project called the Building Blocks trial; a study to evaluate the Family Nurse Partnership Programme which was a voluntary home visiting programme for teenage single mums. In 2015 Kim was asked to support a chronic heart failure study called REACH-HF.