

INVOLVE

South West

For supporters of health research in Devon, Somerset,
Cornwall & the Isles of Scilly

Pilot issue

2016

**“Research was
like a
lighthouse in a
confused sea.”**

**Study participant
Peter Stamp
shares his
positive
experience
In this edition**



Welcome



No amount of thanks will ever be enough for the incredible commitment and contribution patients and members of the public give to clinical research in this country.

In addition to the 600,000 people who participated in clinical trials supported by the National Institute for Health Research in England last year, thousands of volunteers supported health research in other ways. Tapping the perspective and experience of citizens adds value and positively shapes and informs research activity.

INVOLVE defines public involvement in clinical research as research being carried out with or by members of the public – as opposed to, about and for them. Examples of INVOLVE activity in support of research includes the public sharing their perspective or experience to inform the design of a research study, funding priorities; the wording of research-related information materials and contributing as members of project steering groups.

Crucially the perspective of ‘the public’ – patients, potential patients, caregivers, health and social care service users – can be different to the perspective of people with a professional role in health and social care services.

We are very fortunate to have citizens happy to give us their time and insight for the universal benefit of others and future generations. Our challenge is to ensure that we harness and engage with them

effectively so that they feel their involvement was worthwhile and rewarding.

In the South West there are excellent examples of how the public has positively contributed to research from reviewing a GP letter inviting patients to consider taking part in a clinical trial to ambassadors who attend community events and present talks to raise awareness about the opportunities to engage with health research.

This newsletter is a pilot edition produced by the Clinical Research Network for the South West Peninsula (Devon, Somerset, Cornwall and the Isles of Scilly) to see if patients and the public would like to know more about the opportunities to support and participate in clinical research.

This edition is the starting point for a conversation with patient and public representatives to determine what future newsletter content should be with contributed articles and case studies showcasing how patients and the public are improving and informing research work. Ongoing development of this newsletter will INVOLVE the target readership – the public – so that the content is relevant, topical, useful and inspirational.

Simon Denegri

*National Institute for Health Research
(NIHR) National Director for Public
Participation and Engagement in
Research and Chair of INVOLVE.*

Keeping you up to date with clinical research news in the South West & celebrating your contribution

This is our first e-magazine for patients and the public supporting clinical research in the South West of England.

We are one of 15 Clinical Research Networks in England, as part of the National Institute for Health Research, the clinical research arm of the NHS.

This e-magazine is for patients and members of the public who support clinical research in this region in a wide range of ways. Some readers may have taken part in a clinical research study or trial. Others may have given their time to help raise awareness about the benefits of research by sharing their own experience or helped research staff with their preparations for a study before it has opened for recruitment.

We are piloting this e-magazine to see if it is an effective way of keeping you informed about clinical research and forthcoming events and opportunities for you to get involved and continue to support clinical research in your area.

There is great Patient & Public Involvement and Engagement (PPIE) work going on and we would like to show case examples through features and contributed articles.

This edition is a starter for 10. We hope this communication will evolve and take shape with ideas and content from readers to ensure the news and features are topical, interesting and useful.

If you would like to get in touch about this magazine you are welcome to email me at wendyshaw1@nhs.net or call 01752 431944.

The content deadline for the second pilot edition of this magazine is 20 February 2017 for issue in March.

We will review after next April whether the e-magazine format could be extended to include printed hard copies (if there is evidenced demand) within the context of budget implications for the NHS, potential for sponsorship and the environmental benefits.

**Wendy Shaw, Communications Lead
Clinical Research Network for the South West Peninsula**

In the South West

➤ **208,177 people have taken part in NIHR-supported clinical research studies over the past decade.**

In 2015-16

➤ **21,302 people gave their time and support as participants in clinical health research studies.**

➤ **Our CRN supported 549 clinical studies (131 commercial and 418 non-commercial funded by the NIHR and charities).**

To get in touch with us: Call: 01392 403148 | Email: CRN.SWP@nhs.net



Taking part in a health research study gave me back my life – and it's better than before, says South West participant Peter Stamp.

Reflecting on his experience of taking part in a clinical research trial for Type 2 Diabetes patients who have had a 'coronary event,' Peter says he felt physically weak and pessimistic when he was offered the opportunity to join the study in 2012.

Looking back Peter says: "I was recovering from a heart attack and my diabetes was out of control. I could only walk 100 yards which ruled out being able to do my favourite two mile hike in the foreseeable future. My outlook was bleak.

"When the staff at Yeovil District Hospital in Somerset asked if I would like to join a clinical drug trial I felt I had nothing to lose in saying yes. At that time my situation felt hopeless. Being a study participant switched from a passive stance to an active one and the research was like a lighthouse in a confused sea. I thought the treatment might just work and even if it didn't it would still advance knowledge."



Peter's working life was in industrial electronics with extensive technical support and teaching experience in aviation, oil platforms and one space shuttle flight, so he understood how research and development achieved advances.

He was enrolled for the remaining two years of a four year clinical trial. His commitment involves injecting himself each morning which takes about 20 minutes; twice a week measuring his fasting glucose and keeping a patient diary. Every two or three months he attends a hospital outpatient clinic for monitoring.

Peter, who lives in Sturminster Newton, said he underestimated the positive benefits he would gain from research participation – giving a renewed sense of purpose and hope for a better quality of life.

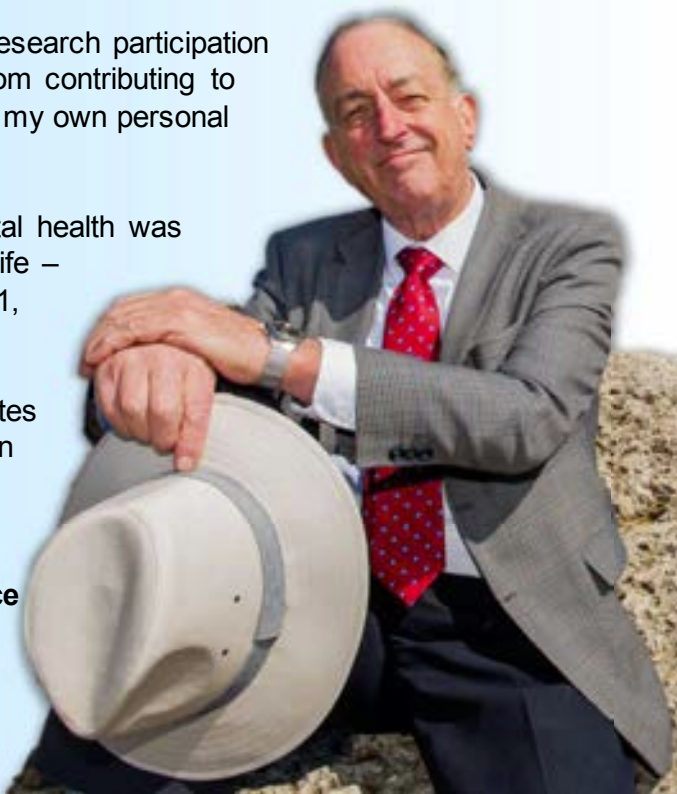
In 2010 Peter said “I had started to shut down areas of my life and disconnect because I didn't expect, with my family history, to live much longer. Six months into the trial in 2013 I was clocking up all these milestones. Week on week I could do something new. I was waiting for the sucker punch and wondering whether the improvement was sustainable.”

Paying tribute to the research nurse Clare Buckley at Yeovil District Hospital, Peter said: “In all the turmoil she was professional, focussed, constant, meticulous and diligent. Clare was my anchor. My mind set changed. This wasn't just about survival – this was recovery. So I began to re-connect with people and I rekindled my social life. I joined a creative writing club which is very enjoyable and took up hiking with my neighbour's dog!”

Summing up the personal benefits of research participation Peter added: “I feel a sense of pride from contributing to the health and wellbeing of others and my own personal journey.

“The recovery in my physical and mental health was unexpected. It has given me back my life – which is better than it was before. At 71, I feel like I am probably in better condition than I was aged 50 in terms of my stamina and strength. The diabetes is now well controlled, my heart function is normal; I am more active and my morale is high!”

Peter regularly shares his experience with health care professionals and the public at events to raise awareness the benefits of research.



A Cornwall GP has been highly commended for a national award celebrating excellence and innovation in clinical research



The National Institute for Health Research Clinical Research Network applauded Dr Nicholas Jacobsen from the Petroc Group practice in St Columb Major as a clinical research trailblazer when it announced winners of research awards run in partnership with the Royal College of General Practitioners.

These new awards recognise research active NHS GPs and general practices demonstrating excellence and innovation in delivering NIHR research. Dr Jacobsen has set up from scratch over the past 10 months a research ready team at the Petroc Group practice. Since October 2015 the team has conducted six clinical research studies into various health conditions and to date has recruited about 90 patients to take part in the research.

Patient perspective can improve the set up and delivery of clinical research in community settings. And a patient doesn't have to commit a great deal of their time to make a positive difference.

Pat Walton (pictured) generously gave three hours of her time to read, review and suggest changes to the wording of a letter drafted by her local GP to potential participants for recruitment to a health research study being conducted at the practice. This came about because Pat supports the work of the Patient Participation Group at the Petroc Group Practice in St Columb Major where she lives.

Pat says: "The gist of the changes I suggested to the wording of the letter was to make the opportunity of taking part in a research study relevant to the individual patient and for the explanation of the study to be easy to understand and interesting. I hope my fresh pair of eyes made constructive suggestions to improve the content and the appeal of the correspondence which might encourage more patients to consider taking part in the research."

Patient insight



Being on the front foot with study walkthroughs

An RD&E hospital research team discovered issues they would not otherwise have anticipated on paper from a pro-active study walk through as part of their set up preparations.

They recently carried out this exercise – a rehearsal of every step in the process of actively running a study – before running the renal clinical trial STOP.

Issues which came to light from the walk through included:

The length of time the nurse needed to leave the patient alone whilst visiting pharmacy/collecting expenses during the visit was longer than expected.

SOLUTION: Refreshments will now be ordered for patients as well as ensuring adequate clinical cover.

Wound photographs needed to be taken during the appointment but there was no strict guidance on the angle, number of photographs and patient consent for their use.

ACTION: Study sponsor will be asked for guidance/clarification before the study delivery starts.

RD&E Research Nurse Specialist Maxine Hough said, “I would definitely do a study walkthrough before any trial now as it was so helpful. I think this activity will make us much more slick when performing our visits.”

Research delivery teams across the South West are being encouraged to identify appropriate studies which would benefit from a pro-active study walkthrough to pre-empt any issues or practical logistics before a study starts which may not get picked up and addressed by reviewing the arrangements on paper. Feedback to date suggests benefits for improving patient participant and staff experience.

Free online learning about clinical research

‘Improving healthcare through clinical research’ is a MOOC or Massive Open Online Course available to anyone worldwide and free to follow.

The course has been prepared by the National Institute of Health Research Clinical Research Network (NIHR CRN) working in conjunction with Leeds University to help people from all backgrounds to understand more about clinical research; how it is undertaken and the impact of it.

Running over a four week period, the online course allows learners to understand more about research discovery in their own time and within their own environment, making learning about research accessible to everyone and anyone across the globe.

Free registration for the MOOC [here](#)

SW ambulance service number 1 nationally

South Western Ambulance Service NHS Foundation Trust is the top ambulance service in England for running the most clinical research studies to inform and improve patient care and treatments in the future.

One hundred per cent of all the NHS Trusts in England are offering the opportunity to participate in health research to patients according to a league table published today by NIHR Clinical Research Network (CRN).

The 2015/16 NIHR Research Activity League Table shows all NHS Trusts in England are delivering clinical research, providing thousands more patients access to better

treatments and care. Promoting, conducting and using clinical research to improve treatments for patients is part of the NHS England Constitution.

For the second consecutive year running South Western Ambulance Service NHS Foundation Trust (SWASFT) is the most research active ambulance service in England out of 10 ambulance services.

“Taking part in clinical research not only provides my patients with additional treatment options but also gives me a better understanding to manage their condition.”



Pictured: Mary Jean-Tucker, Paramedic

SWASFT has achieved an unprecedented increase in the number of clinical research studies its frontline emergency crews are offering their patients. In 2015/16 SWASFT recruited 2,341 people to eight research studies compared with 386 participants enrolled to four studies in 2013/14.

SWASFT Chief Executive Officer Ken Wenman said: We are delighted to be the top ambulance service in England for running the most clinical research studies.

“This is extremely challenging when taking our geography into account. The Trust’s workforce operates from over 100 sites across an area spanning one fifth of England.”

“By participating in research initiatives we can directly help patients to receive even higher standards of clinical care.

Our research and development team continue to work incredibly hard embedding a research culture across the organisation and has already made incredible progress.”

Ken Wenman

Plymouth-based paramedic Mary-Jean Tucker (pictured) is one of over 500 paramedics SWASFT trained to be research active.

She said: “My main priority is my patients and providing the best possible care for them. Taking part in clinical research not only provides my patients with additional treatment options but also gives me a better understanding to manage their condition.

“Clinical research is an important step in discovering new and more effective treatments, improving our knowledge and patient care now and in the future.”

Matching volunteers with dementia research

People living with dementia, their carers, and healthy volunteers in the South West can self-register their interest in taking part in dementia research studies.

A national Join Dementia Research online and telephone service matches registered volunteers with researchers recruiting participants to clinical research studies.

In the past there has been difficulty knowing how and where you can get involved in clinical research with less than 5% of people with dementia take part in studies. It's important that everyone should be able to find out about research that is happening near to where they live and get the opportunity to be part of that research. Current research studies being conducted in the South West range from clinical trials of new treatments to surveys identifying ways to improve the quality of life of people with dementia.

Join Dementia Research is funded by the Department of Health and provided by a partnership between the National Institute for Health Research (NIHR), Alzheimer's Research UK, Alzheimer's Society and Alzheimer Scotland.

Registration couldn't be easier

Registration is welcome by people diagnosed with dementia, carers and healthy members of the public aged 18 years or over. You can register by calling the helplines of Alzheimer's Research UK 0300 111 5 111 and Alzheimer's Society 0300 222 1122.

The joindementiaresearch.nihr.ac.uk website offers a secure and easy way to register.

By signing up to the service, you give permission for researchers to contact you with details of studies in their area that match your profile. You can then decide if you would like to participate in those studies on a case-by-case basis. **By registering, you do not have to agree to take part in any studies and can opt-out at any time.**

Why dementia research matters

Dementia is increasingly touching more of us and research gives hope. Dementia affects over 850,000 people in the UK, with 25 million of the UK population having a close friend or family member affected. In England there were 316,864 patients on GP dementia registers in 2013 and 16,786 of these patients were in the South West Peninsula.

The prevalence of dementia in the South West Peninsula (Devon, Cornwall & Somerset) is 0.74% of the population compared with 0.57% nationally.

Thank you to the dementia research participants in Exeter and East Devon featured in a new film we are producing to promote Join Dementia Research.

The film will be available early in 2017 for staff and lay public presentations at public events.

- **Jan and Alan** - As a patient participant in dementia clinical research, Jan explains why her family are her motivation for taking part and sharing her experience to inform advances in treatment which may not benefit her personally.
- **Ines** - As a healthy volunteer who has taken part in a dementia clinical research study, Ines shares her motivation for participation and her admiration for people who give their time to research to benefit others.
- **Isabel & Bob** - As healthy volunteers both participating in dementia clinical research studies, Isabel and Bob share why they believe it is so important to do what they can to help find answers which may improve care and treatment of people with this condition in the future.

Patient story

Graham Leslie says he had ‘nothing to lose’ and there was potentially so much to gain from taking part in a clinical drug trial in the South West.

Graham, who was diagnosed with Alzheimer’s in his late fifties, was acutely aware of the importance of research into dementia as the former owner of a care home in Cornwall where he looked after people with the condition.

Describing himself as an optimist Graham, said when he was approached about participating in a research study: “I had nothing to lose and believe I could give something positive back by sharing my experience of this condition. How else can we expect to improve treatments and quality of life of people with dementia and their carers if we do not play our part in research to find more answers? There is so much to be gained from research.”

Graham said his commitment involves taking a tablet daily for two years and having blood samples taken by a research nurse in his St Neot home every three months.

Cornwall Partnership Foundation Trust lead research nurse Sharon Hudson said: “Graham is one of 15 patients we aim to recruit to this national study in Cornwall which aims to evaluate any impact of the drug and assess its safety and patient tolerance of it. This study is a very good example of research participation with relatively little disruption to the daily lives of patients and it doesn’t have to involve travel to hospital. We are immensely grateful to patients like Graham who recognise that medical advances can only be achieved with health research.”



THE POWER OF PICTURES

A North Devon teenager came up with the idea of using a comic strip to tell his own experience of participation in clinical research for a national NHS awareness campaign.

The National Institute for Health Research 'Our stories' campaign features real patient experience of taking part in clinical research studies to raise awareness and encourage more people to consider participating. The stories are shared with the media, specialist health charities and support groups and on the NIHR website

Fourteen-year-old Ryan Fryer has taken part in a drug clinical research study, which is comparing the effectiveness of drug treatments for a renal condition called Nephrotic Syndrome, for the past three years.

Each year one child in every 50,000 is diagnosed with this condition which

affects more boys than girls.

Ryan's mum Ann-Marie says: "There was no reason for Ryan not to take part in this research. The only way we are going to make the treatments better is by finding out the answers in this way.

"We have a much better understanding ourselves of Ryan's condition and what to do if his symptoms get worse. It has been reassuring having regular check-ups and knowing Amanda, the research nurse from North Devon hospital, is at the end of the phone if we have any worries. It is great when Ryan feels good and can play football. He loves nothing more than playing football and scoring goals!"

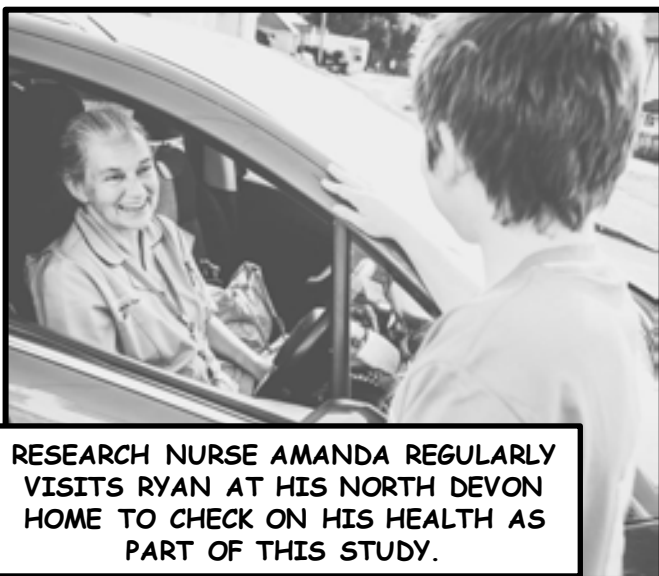


TEENAGER RYAN FRYER HAS A KIDNEY CONDITION.



WHEN FEELING UNWELL HIS JOINTS SWELL AND BECOME PAINFUL AND HE HAS LOW ENERGY.

RYAN HAS TAKEN PART IN A CLINICAL RESEARCH STUDY LOOKING AT DIFFERENT DRUG TREATMENTS TO MANAGE HIS SYMPTOMS.



RESEARCH NURSE AMANDA REGULARLY VISITS RYAN AT HIS NORTH DEVON HOME TO CHECK ON HIS HEALTH AS PART OF THIS STUDY.



HIS MUM ANN-MARIE SAYS THE ONLY WAY TREATMENTS WILL GET BETTER IS IF WE SUPPORT RESEARCH TO FIND THE ANSWERS.



RYAN KNOWS MORE ABOUT HIS CONDITION AND HOW TO LOOK AFTER HIMSELF BETTER. WHEN HE FEELS WELL HE LOVES NOTHING MORE THAN PLAYING FOOTBALL AND SCORING *GOALS!*

We would love to hear from you

The Clinical Research Network for the South West Peninsula (CRN: SWP) brings together a diverse range of partner organisations to deliver health research. These include NHS acute hospital trusts, mental health trusts and GP practices in primary care.

Partner organisations have Patient & Public Involvement and Engagement leads as the point of contact for anyone who would like to support health research in some way. You are welcome to get in touch with them to find out about PPIE opportunities and what you might be able to do. Here are the local contact details:

Cornwall & Isles of Scilly			
Royal Cornwall Hospitals NHS Trust	Amanda Datson	a.datson@cornwall.nhs.uk	01872 255177 or 255131
Cornwall Partnership NHS Foundation Trust	Emma O'Shaughnessy	e.oshaughnessy@nhs.net	01209 318366
Devon			
Plymouth Livewell South West	Rena Truscott	Rena.truscott@nhs.net	01752 434498
Plymouth Hospitals NHS Trust	Sarah-Jane Sharman	Sarah-jane.sharman@nhs.net	01752 432447
Torbay & South NHS Foundation Trust	Cheryl Weekes	Cherylweekes@nhs.net	01803 656635
	Chris Dixon	chris.dixon2@nhs.net	01803 656635
Northern Devon Healthcare NHS Trust	Sally Tetersell	Sally.tetersell@nhs.net	01271 311867
Royal Devon & Exeter NHS Foundation Trust	Stephanie Estcourt	Stephanie.estcourt@nhs.net	01392 406901
Somerset			
Taunton & Somerset NHS Foundation Trust	Laura Davis	Laura.davis@tst.nhs	01823 333444
	Catherine Thompson	Catherine.Thompson@tst.nhs.uk	01823 333444
Yeovil District Hospital NHS Foundation Trust	Jo Rendall	Joanne.rendall@ydh.nhs.uk	01935 384297
Somerset Partnership NHS Foundation Trust	Carinna Vickers	Carinna.Vickers@sompar.nhs.uk	07824 452211

Regional overview: Clinical Research Network SW Peninsula

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