



**National Institute for
Health Research**



*THE ROLE OF THE
CLINICAL RESEARCH NURSE
In their own words*

Celebrating the Clinical Research Nurse | 2016



WELCOME

To mark the first NIHR meeting, Celebrating Clinical Research Nurses, we spoke to nurses about their experience of working in this exciting space. After each annual meeting we have added more case studies to reflect the variety of roles our clinical research nurses undertake. Here are their stories, in their own words.

All speak of having started their research careers with an uninformed view of what a research role could bring them. All speak of their surprise at the autonomy of the role, the skills they have developed and the variety of work they undertake. All speak of working in great teams, the career opportunities that have opened for them and the importance of their relationships with the clinical research nursing community. All speak of the challenges they have faced and overcome in research. And all speak of their passion for research.

Most importantly they all speak of their crucial role in delivering high quality patient care. I felt inspired reading their stories. I know you will be too.

Dr Susan Hamer

Director of Nursing, Learning and Organisational Development,
National Institute for Health Research Clinical Research Network

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BUILDING LOCAL RESEARCH

Anne Suttling

Senior Research Nurse

Portsmouth Hospitals Trust

After qualifying as a nurse, I commenced a rotation programme for 18 months. I worked in surgery, medicine, Accident and Emergency, critical care and also coronary care – where I gained a permanent post. That's where my love is ... in coronary care and cardiology.

After seven years, I needed a change but still wanted to remain in cardiology. That's when the opportunity to set up a research study came up. **On the first day I was faced with an empty six – bedded bay, on an empty ward and told this was the available space to set up the clinic.** The study was a success and on the back of this, the PI got funding for a full – time research nurse, to run interventional studies.

I remember the first complex commercial portfolio study I set up. Before I recruited my first patient I did not sleep the night before. I took home the packaging for all the bloods and biomarkers and had it all out in my living room ... there was so much to get my head around. It did go ok – we became one of the top UK recruiters for the study.

Because research in the department was working well, more PIs wanted to come on board. **They could see research wasn't such a demanding workload for them because research nurses were organising what they had to do and carrying out the study management.**

I currently manage 17 staff in eight specialities. This brings its own challenges. A ward manager has one speciality on their ward and can see what is happening. In this role, you can't be in renal, gastro and surgery if problems arise ... So it's slightly more difficult to manage. But I am learning so much about other specialities.

I enjoy the patient contact and the patients really enjoy being in research. Patients have a hotline to consultants ... any problems or issues they call the research nurse.

I go to monthly meetings with the industry manager. If a company want 8 sites in the UK, they will send out expression of interest forms. If they get 20 back, they will do site selection visits.

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A clinical research nurse has a certain amount of autonomy ... **you have to be able to manage your own time, prioritise and pay attention to detail.** Data queries can drive you insane, but that is what research is about. It is all recruit, recruit, but, what is the point if the data is not correct? Part of being a research nurse is having the determination to meet targets. Follow ups don't necessarily count (as part of the target). You are under pressure to recruit but you still have to follow-up patients ... that is what I find difficult. You are perceived to be successful if your recruitment figures are high. Follow up and maintaining consent throughout the trial is just as important – this is when the majority of data is collected.

Our role is so diverse – it is not just recruiting patients. There are follow-ups, collecting data for the CRFs, maintaining site files, knowing about the agencies, regulatory bodies, protocols, consent and giving presentations to inform colleagues about what we do in research.

Cardiology were nominated in 3 or 4 categories at the Portsmouth Hospitals Research Conference and won a “Research Merit Award” ... this was in recognition of how we built up cardiology research over the last three years. In cardiology we are getting more PIs on board because they can see we are organised ... the PIs are understanding that they don't have to do all the work ... they have a team of experienced research nurses to co-ordinate their trials.

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CHANGING RESEARCH CULTURES

Alison Mortimer

Lead Nurse

NIHR Clinical Research Facility, Sheffield

I fell into research. I bumped into an old colleague on the stairs, she was working in research and had a job going. My first reaction was negative, as research was like a swear word and I hated anything to do with research in my training ... but I went away, did some reading and decided to apply. I was shocked when I actually got it. I had no idea what I was walking into.

I absolutely loved it. **It was so fast-paced, the workload was immense but the patient benefit was amazing** ... I could see positive outcomes, but it wasn't only that. I was working with the same patients for a year or longer and built up rapport with them, and they spoke to you about everything that was going on with them ... I loved it.

For me research has the best mix of autonomy and teamwork. You manage your own caseload but good communication across the team is essential. I also love the element of surprise ... on one occasion I came in to find an email saying we needed to pull all of the patients on one of our trials off the drug immediately. **I love that fast-paced excitement, it makes you grateful for the rare moments you do get to sit down at your desk and answer a data query.**

I moved into the CLRN in 2009. **To me it felt like a completely new way of thinking** ... you were working across such a wide area and with acute and primary care organisations that weren't at all geared up for research. We had to be flexible so we could be responsive to the different needs of the Trusts. We also had to be sensitive to the internal politics, we were perceived as outsiders ... it took a lot of thought and time to ensure we didn't mess that up. But it was definitely rewarding.

In my role I have responsibilities for the Clinical Research Facility, research nurses within the trust and the CLRN. **After that first conversation on the stairs I would have laughed if you had said I would be in this position now.**

I think research is still a dirty word amongst nurses ... the most common reaction is 'why would you want to do that'. It's mainly misunderstanding of the role, **research used to be an easy role that people took when they are coming up to retirement.** Once that perception exists it is hard to change.

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My main passion is thinking about how we can unite clinical and research nursing.

One of my main struggles is getting buy in from matrons on the ward. A lot hate research because they feel keeping posts open while nurse go on research secondments depletes their staff. For ward matrons they have targets and certain expectations to make their ward high quality and forward thinking. They don't realise that we are feeding into that. I think some of the tensions arise because clinical nurses don't realise that patient welfare and good patient outcomes are as central to our work ... **we need to stop speaking our own research language, go back to our roots and speak the same language.**

After the Francis Report nurses developed the **6 Cs to guide nursing – Care, Communication, Compassion, Courage, Competency and Commitment.** If you think about what a research nurse does these are as essential to us as they are to clinical nurses. We should use this as a common language to unite us.

SUPPORTING SURGICAL TRIALS

Joyce Katebe

Clinical Trials Nurse

Surgery / Gastroenterology

I am a Surgical Clinical Trials Nurse and I trained and qualified in Zambia. My research started during post basic nursing training, during my BSc Nursing. Research was not part of the pre-registration nursing diploma/certificate then, but it was a requirement for the completion of the BSc Nursing.

After this, I became interested in research and was encouraged as I worked with my lecturers. I helped with data collection which I found very interesting and thought it was something I would like to do more of in the future.

I was fortunate to be involved in research for the **World Health Organization (WHO) on family planning in Zambia, and this inspired me to want to do more and helped me to develop my own questions about improving nursing practices to improve patient care.**

While working in a local teaching hospital, I helped come up with a proposal about teenage pregnancy and the provision of ante-natal clinics for them. It was noted that most of them were first seen in labour when they were admitted to give birth. This prompted me to ask about what services were available for these mothers. I thought I would use this project to help set up ante-natal clinics for teenagers.

Having moved to the UK and having spent time working in the NHS, I applied for a position at the Oxford University Hospitals. It was my first research nurse role and I worked with an enthusiastic professor who was very keen to involve nurses in his research. Very exciting! There were always new studies and each of the studies had different research questions to answer.

In my role, I was required to attend research meetings as well as having regular meetings with the principal investigators. I really got a buzz from these meetings as I felt really involved in trying to improve health of patients for the future.

I lived in Oxford during the week and went home to Bristol at the weekends. Family life was difficult because my family stayed behind in Bristol and could not relocate as the children felt settled in their schools in Bath and were not keen to move to Oxford.

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Many people when they hear the word 'Research' think having a career in research is beyond them, but in research I find that there are many opportunities to learn different things.



I applied for my current position in Bath to help set up a research unit in the department of General Surgery and Gastroenterology. I was the first research nurse recruited to work purely for the two units.

Initially, it was a challenge because I had to find my way around the system: With the help of the surgeons and colleagues from oncology clinical trials unit, I had to look for office space, desk and all the equipment needed. I had to ensure that everyone joining the unit had Good Clinical Practice training and I went around the wards meeting the different specialists and nurses to discuss the research we did in the unit and this was repeated as required.

It is important that I develop good working relations with non-research nurses because most of my patients are in their care. It also allows them opportunity to understand the research we are doing. I meet patients in pre-op assessment unit, wards and in outpatients. The majority of them are keen to participate in research, the phrase I hear a lot from patients is **"I am doing this because I want to give something back to the NHS and community at large"** and some say **"If no one did this years back, we would not have the treatment we have today."**

To hear these words from patients is very encouraging ... Many people when they hear the word 'Research' think having a career in research is beyond them, but in research I find that there are many opportunities to learn different things as well as witnessing how research is improving lives.

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DEVELOPING NURSES

Lisa Berry

Senior Research Nurse

NIHR Wellcome Trust Clinical Research Facility, Southampton

The desire to be a research nurse came from a passionate belief that healthcare needs to be evidence based. It combines all the things that I enjoy; law, ethics, clinical care and working in complete partnership with research participants.

At times, healthcare can be paternalistic - patients come to us unwell and we do things to make them better. **Whereas in research the balance of power shifts considerably, we cannot achieve medical advances without help from patients** (research participants). We work with them to assess the efficacy and safety of novel therapies and there is no guarantee that participating in a research study will be of benefit to the participant. In research, the safety and wellbeing of our participants is at the centre of everything we do and the research nurse is crucial to supporting them through the whole process of taking part in research.

There are a specific set of skills that a research nurse needs. All the skills you learn on the ward are transferable and it is essential to have a good clinical grounding. You also need to pay attention to detail, understand the principles and importance of informed consent and be extremely organised. **You need to understand not only the science behind the protocol but what participation will entail for the patients/healthy volunteers taking part.**

Our nurses need to have the confidence to act as an advocate for the participant and must remain clinically relevant. We specialise in experimental medicine and provide care to healthy volunteers and patients with a wide range of disease and conditions. It is possible that a participant could become very unwell during a trial and therefore it is essential that research nurses remain sufficiently engaged with their clinical training to act appropriately and quickly.

Part of my role is to ensure that researchers are allocated appropriate levels of support and that the studies are set-up in a timely, safe and efficient manner and that we deliver an excellent standard of clinical and research care. Research nurses bring a study to life; they make a huge contribution to advancing healthcare and are a valuable asset for any research team.

I was a Health Care Assistant before qualifying as a nurse. **Although I am passionate about research nursing, this is not enough to build a career. I would not have progressed as quickly to the role of Senior Research Sister without support, mentoring and**

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We cannot achieve medical advances without help from patients.



developmental opportunities. Since I started in research in 2006 I have seen more career opportunities. More training has become available and there is a greater understanding of what clinical research nursing is. Even I didn't really know what research nursing was when I started!

We try to encourage our nurses to consider all their development options. We facilitate academic development as needed and also strive to provide career opportunities. A few of our band 6 and 7 nurses have been very fortunate in obtaining MRes funding. The NIHR funds the course fees, salary and also backfill for their position. **The NIHR fund one person to do a Masters degree in research, but really they are funding the development of two people because someone else can then act-up into a more senior role and is also developed.**

Our aim is to ensure that research is fully embedded within healthcare at this hospital. All research nurses now wear a dark grey uniform. This has given us a very visible identity and it is exciting to see how integrated into and dispersed around the hospital we are... suddenly people become very much aware of the research presence in every division.

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INFORMED CONSENT

Arshiya Pereira

Research Nurse

**Renal Transplant Department,
Central Manchester University Hospitals NHS Foundation Trust**

I was trained in India to become a nurse. My first placement was in renal dialysis. I was interested in learning more about renal because of its vast subject area; renal medicine, renal transplant, research, transplant clinic and dialysis.

The main aim was to get more knowledge and experience working in a specialised unit. After moving to the UK I worked on the renal ward and dialysis unit at Sunderland Royal Hospital.

I moved to Manchester as I wanted to gain more knowledge and experience of transplant. Initially working in the renal transplant clinic conducting follow up I became aware of research and I was curious about the research studies my patients had been recruited to. When a vacancy in Renal Transplant Research was advertised I applied.

I was a bit apprehensive in taking the role initially as I had heard many people say you lose your clinical skills and you do not get to take care of the patients as you would on the ward. I realise that those assumptions are inaccurate. I get to spend more time with the patients and I have discussions about the research. What we do in research today may change the way we practice medicine in the future.

Every day is different in renal research. We work with two different types of donors, live donor transplant and cadaveric donors. With live donor transplant we know when they are coming to us. With cadaveric donors we don't know when we are going to get the kidney ... so I have to organise myself on the day itself. **Recruitment always takes priority. The first thing I do each day is check if there are any transplant operations and if there are, I see if the patients are eligible for my study, and recruit them if they are happy to take part.**

At times I have found it difficult to get the Principal Investigator (PI) to consent the patients because they were either in surgery or clinic. I began to wonder whether it would be possible for me to conduct informed consent? At the same time, the Trust was undertaking a scoping exercise to assess the need for clinical staff who were not doctors to take informed consent and developed policies and procedures to support us to take on this role. This is a wonderful opportunity for clinical staff who were not doctors to extend their role. Initially the role was

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delegated by the Principal Investigator who had to justify the need for a clinical research nurse to take the informed consent for a specific study. **A half day training programme was developed to gain more in depth knowledge of informed consent and group activities to explore the issues and processes involved. My competency in obtaining informed consent was assessed by the PI. I passed ... I felt really proud of myself.**

To take consent I screen the patients' eligibility and send information sheets two weeks prior to clinic visit, so they have time to read the information and speak to family. I also consult with the respective surgeon to see whether they are happy for their patient to be approached for the particular study. When the patient comes to clinic I discuss the study and if they are happy to take part, I make sure they are fully aware of what the study involves. **In total, I have taken 20 informed consents so far, which has enabled the team to recruit to time and target.**

I have now been working in research for over five years. **I feel that due to the skills and expertise gained in particular informed consent my leadership qualities have improved significantly.** I ensure the patient feels valued, they are followed closely from their pre-transplant appointment to their aftercare and they always remember me for the care I provide for them.

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TRAINING

Ruth Hulbert

Lead Nurse

Kent and Medway Comprehensive Local Research Network

I came into the NIHR from the pharmaceutical industry, working with GSK and then Pfizer, I was used to an environment where money was no object and it wasn't necessary to get people on board with the idea of research. The need to influence the right people in order to get research done was completely new to me.

Clinical research nursing is definitely not for the fainthearted. Most people get into nursing for the patient contact. You still have that ... but you also get other experiences like handling data, project managing and making direct approaches to very senior managers and consultants. You have to be proactive which can be difficult ... the patients don't come to you, you have to go out and find them.

When I began in the Cancer Research Network my personal worry was about approaching patients to join a study. It is an unusual position for a nurse, **you are asking them to help you.** The first patient I recruited was a lung cancer patient for an observational trial ... he was very receptive which gave me the confidence going forward.

Clinical Research Nursing comes with **a lot of autonomy**, you don't get that freedom in other areas of nursing.

Nurses are in a much better position now in clinical research as there is **a much clearer career structure.** Most nurses come into our CLRN as a Band 5 with some nursing experience. Our goal is to develop them, and within a year to 18 months, most become Band 6s.

Training is passion of mine. I think there is a lot of satisfaction to be gained in **passing on your knowledge and skills** to people who are new and inexperienced. It is great when you see people growing and becoming a more confident and competent version of themselves.

I am one of the Network's Good Clinical Practice facilitators. At the last facilitators meeting it was announced that we had now trained 30,000 people across the network, **to be even a small part of that it great.**

I was twice involved in developing new networks in Kent and Medway; the Cancer Research Network and then the CLRN. There was very little research activity at the time ... but

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awareness of research is definitely starting to change ... a major culture shift but there are still areas within our CLRN where there is no research activity. In the early days there was a mixture of lack of knowledge and lack of interest in research, but most of all the clinical staff didn't realise we were there as a resource for them to handle the more time consuming aspects of starting up a trial ... that has changed.

My hope is that within my lifetime **research will be embedded into the NHS** in Kent to such an extent that the public can go to their doctor and ask what clinical trials are available for them and their doctor will know.

Wherever my career takes me from here, I know that I want to stay within research I have developed a passion for it.

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RESEARCH MANAGEMENT

Debbie Beirne

Nurse Consultant

Cancer Research UK, Leeds

I loved research from the start ... I loved the autonomy, responsibility, the degree of change, the degree of learning.

When new nurses start with me I tell them that they will probably feel like a fish out of water for six months ... I explain it is a very dynamic and interesting environment, not suitable for anyone who likes things to stay the same.

Adapting to change is probably the most important thing. With research we don't want things to stay still, we want them to move forward and nurses have to be able to move with that.

A big misconception is that research nurses float around with a clipboard, drink tea and work very standard hours ... none of that is true. I don't think that there is the appreciation that **we are actually delivering care**, not just writing protocols for others.

I have several parts to my role – my day-to-day operational role, a translational development role, a role within my trust as a **research expert for other departments**, and my Cancer Research UK role in engaging with the public at events.

I work with some of our clinician scientists to deliver their protocols. I help them look at what they are currently doing in the labs and how that could translate into patient care. As a result, **I have some co-investigator roles on a few grants.**

I have seen huge changes in almost every aspect of research since 1999, except for **the fundamental of how we care for the patient** ... Research Governance has changed, the way we structure and deliver clinical research has changed, the way we inform people has changed.

Clinical trials are much more complex than they were ten years ago, and so **the role of a research nurse is much more complex too.**

Obviously medical science wants to engage with the public and keep them aware of advances

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but when a newspaper runs a 'magic bullet' headline it impacts the work I do. I frequently get calls from patients who don't realise that the headline doesn't relate to their situation or refers to something in a lab which could take us 18 months to translate ... **I think we have a duty to give people hope but make sure it is a realistic hope.**

Research allows you a degree of personal and professional development in a more flexible framework than traditional nursing. There are lots of different avenues; Network managers and lead nurses, Trust and R&D lead nurses and new roles are always coming up. As recently as five years ago **if you wanted to move beyond a Band 7 you had to leave nursing, now I am a Band 8b and still a nurse.**

We need to move away from the idea that as a research nurse you are just picking up the trial and delivering it. **Research nurses can now have a role that is much broader** ... you can be involved in writing the protocol, be a patient voice with scientists, change the research culture within the wider trust.

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PATIENT AND PUBLIC INVOLVEMENT

Maggie Peat

Lead Research Nurse

**Harrogate and District Foundation Trust and Patient and Public Involvement Lead
North and East Yorkshire and Lincolnshire Comprehensive Local Research Network**

I was working as a nurse giving chemotherapy ... it was just at the start of the cancer research networks ... to be honest I didn't really have much idea about what research networks might do, it just sounded like a really interesting job.

When I started there was a lot of feeling your way ... there wasn't a lot of guidance around. There is a lot more now ... **we mentor people.**

We recognised fairly early on that most student nurses didn't really know anything about research ... I wanted to show them that it wasn't just about systematic reviews and all the really dull stuff but about actually recruiting patients into studies and the really **exciting stuff of being at the sharp end of research** ... student nurses absolutely loved it.

Some of the Patient and Public Involvement work has been about raising awareness because **patients and the public have all sorts of good ideas** that we don't think of, like putting information up on screens in patient waiting areas. Everybody is doing that now ... but none of us had thought of that because we didn't wait in the waiting areas.

Accessibility to information is really important – the people who need properly accessible information the most, are the people who are least likely to ask because they don't want to look stupid or think that they are going to be judged.

It's a simple thing that after taking consent to say to the person "right I want to be really sure that you understand what you are taking on. So can you say to me, what you might say to your wife when you get home?" It is simple but nurses are not taught how to do that. **It is important that we have tools to measure understanding.**

The power imbalance between a nurse and a patient is less than between a consultant and patient ... it makes it easier for a patient to say no to taking part in a study. It is important, that people can say no to a trial.

Patients understand the incremental process of research...one of the things they say is "all the stuff I have benefited from has come from someone else doing a study." **Often**

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I wanted to show them that it wasn't just about systematic reviews and all the really dull stuff...



patients will take part in research because it is for the greater good or sometimes it is a positive thing to come out of something bad that has happened to them.

I think people are sometimes terrified of signing up for Patient and Public Involvement, thinking that they may have to do more than they want to do. So all our stuff is about saying to people, you can be involved as much as you want to be, you can do the occasional information sheet, you can look at a questionnaire and comment on it or you can come and be part of a steering group. **People and patients can be involved in research as much or as little as they like.**

It's about the meeting **being accessible**. Participants shouldn't be using jargon. They shouldn't be using abbreviations ... everybody should be talking in a way that everyone else can understand. Even the act of trying to make taking part in research accessible makes a difference.

NIHR has made it easier for consultants to take a study on, partly because of the nursing infrastructure. Nurses and support staff can work with consultants and **we are here to stay**.

If you are interested in research nursing just do it ... it suits most people. **We have not had anyone work here that doesn't love doing research.**

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INFORMING THE PUBLIC

Karen Doyle

Senior Nurse

Cancer Research UK

When I started, research nursing was on the fringe of nursing ... at the time we were told 'you look after the doctors that is your role'. That old fashioned view of nursing was still there.

I started in clinical research nursing because I wanted to be using all of the knowledge that I had gathered in my career. There were nurse specialist posts but **I wanted something more intriguing, more complex.**

I didn't want to do nurse management because it would take me away from patients ... **I always wanted to be patient centred.**

Research nursing offered all of that. I loved the fact that research nurses were involved in the science.

There were a lot of cancer patients with horrible side effects from the treatments available at the time ... **I wanted to be part of something that was not just accepting what we had** because there was room for improvement. I wanted to be with the team that was making things better for these patients.

Initially we were given early phase work ... toxicity, safety of the drug or treatment ... so lots of additional testing. I loved the intensity and **you got to know patients really well**, I loved that in-depth interaction.

Medical teams sometimes want to get their patients into trials for compassionate, for misguided reasons. Sometimes you will get medical teams saying "But we have no other treatment to give them." **You have to be strong** – a clinical trial is not a treatment option and I think people forget that. We have to make sure that it is the right thing for the patient ... that is what we are there for.

When deciding if a trial is the right thing for a patient it is not only the science that matters. Sometimes it is the simple questions that matter for patients. Can you take tablets? Will you be able to cope with travelling to the trial?

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We are the practical voice that makes the trial work...



Those questions are missed if you haven't got a nurse ... **we are the practical voice that makes the trial work.**

I have developed my research nursing role to include informing members of the public about research ... I love talking in the community because that is where the information is needed. We are getting out into the communities with the right messages – myth busting about clinical trials. Public understanding is better than it was but it has a long way to go.

I have discovered that in addition to being face to face with the patient making the difference, I can also become the person (as a trainer) who will influence the nurses who are face-to-face ... I can benefit many more patients through training than I could with nursing alone. **I get a lot of reward from influencing other nurses.** It is not management to me ... management was taking you away from patients.

Research nurse leaders should be proud. We have taken the role of nurses in research from setting out someone's lunch to a **dynamic career.**

We have got national research nurse networks, we have got training and we have got the support of the NIHR. The change really is dramatic.

I don't know of any other type of nursing where it has **improved as much and got more respect over time.** You are really working as a specialist team member ... that is the way it should be.

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NETWORKING

Claire Merritt

Lead Research Nurse Manager

Dementias & Neurodegenerative Diseases Research Network, Oxford

I caught the research bug in my first research post about 10 years ago. A consultant colleague had a grant to do a pilot study and asked me if I would be interested in working as a research nurse on their research study.

I was the only research nurse and was responsible for recruitment and study delivery and very quickly learnt about how challenging it was identifying patients and accessing patients for research. Rightly, there are people who want to protect patients, but it's about persuading them that research is a good idea. Encouraging them to introduce the idea to a patient can be hard. People think there is a large cohort of people out there for trials. In reality, the numbers are much lower than you expect them to be.

What we have done for the last seven years within DeNDRoN is about trying to facilitate a culture change within the Trusts and make research part of everyday thinking. We've introduced what we call link workers into teams. **Each of the community mental health teams has an honorary research worker linked to it.** This has been successful as they develop an understanding of what that teams needs and wants and how they work.

As well as building up a team it's about building up an infrastructure to support research to happen. During the time I have been working with DeNDRoN the portfolio of research studies within Trusts has grown, as has the complexity of studies we are able to support. **The key message is that research becomes embedded in patient pathways so it becomes everyone's business and not just ours.**

Our job is about helping to facilitate research to happen. Partly, that's just continuously giving that message that research is an important activity. We've had a degree of success, but I think we still have a way to go to persuade all clinicians that research is their business. Some clinicians have bought into this concept well, some still argue they do not have the time to do research and some say they find research is something scary. **However, research is about empowering patients and their caregivers and the general population to help.**

You get a very interesting range of people who are keen to take part in research.

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Working with patients is what nurses do best...



Some people want be able to access something that may make a difference to their relatives or themselves. Others have altruistic motives and want to help, because it will help others rather than help themselves. On the other hand some people don't really understand what we mean by research, or feel it's too scary or risky or too much of a burden. So education is important.

We must always remember we work with people in crisis and sometimes it is not the right time for them to consider research.

Working with patients is what nurses do best. So for most research nurses the contact with patients bit deals with itself. There is though a lot to learn and it's all the other stuff around research you have to work hard at. As a lead nurse most of my job is about providing clinical leadership to staff, making sure that things happen and supporting workforce development. Key to what I do is making sure we have the right people with the right training in order for us to do research that can go on to make a difference to people in the future. Everything we do is about forward thinking, **you always have to be thinking about the future.**

Toward the end of a long career in mental health nursing I am really pleased to have found myself following a career in research. I am quite passionate about working in research. **You have to believe in research to make this job a success.**

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PATIENT CARE

Kathryn Kennedy

Trainee Advanced Clinical Research Nurse Practitioner

Manchester Clinical Research Facility

When I worked as a clinical nurse we did not have that much interaction with the research nurses who came onto the ward, even though most of the children were on trial drugs with a protocol I don't think I really understood what that meant.

Because I was nosy and interested I got to know more about the research side of things.

When I started in clinical research nursing the studies were lower intensity to what we have now, generally well children in an out-patient setting. At first it **felt like a little bit of step back on the clinical side** but that gave me the opportunity to really develop my research knowledge.

The team is now dealing in phase 1, phase 2 trials now in children who have no other treatment options, sometimes quite unwell, so **we are in the heart of clinical nursing on a daily basis.**

The role of the research nurse is critical to keeping families motivated to stay on the trial ... we spend a lot of time ensuring that their journey through the trial is a positive experience.

I think the perception of losing the clinical part of the nursing role perhaps puts some people off ... friends have expressed that they would not consider research because they see it as a **very academic, very administrative based role. That could not be further from the truth.**

We don't cut corners with informed consent ... parents (need) to understand at a level **where they are able to put their emotions to one side and make a decision based on the knowledge we have given them.**

Some of our children come from Europe and can be re located in this country for up to 6 months with their family. The research nurse is very much responsible for that relocation, as the liaison with hospital services or sponsors, ensuring bank accounts are in place, other children are getting educated.

A lot of biotech companies are new companies ... it might only be their third or fourth clinical

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Because I was nosy and interested I got to know more about the research side of things...



trial. **Our expertise is essential in ensuring that the study runs smoothly.** It is not reasonable to involve parents in that process if these things have not been thought through.

We are invited earlier now to go to (sponsor and management) meetings because they are recognising our expertise. **We are the ones who understand how to get things right from the very beginning.**

I am a **trainee advanced practitioner** due to qualify in September. It is really exciting to be the first. This is a brand new role to research; able to recruit children to clinical trials, deal with physical examinations, prescribe and see patients without the support of a medic.

As an advanced practitioner we can provide support for PIs ... hopefully this will ease some of that pressure so that trials that we wouldn't perhaps have been able to do, because there wasn't the medical support, get done.

I wasn't sure that research nursing was somewhere I would stay forever. I wanted the research knowledge and experience but knew that my heart would be in clinical nursing. **This new opportunity coming along has allowed me to be even more clinical in research nursing.**

My new role has generated interest from other nurses that did not know that this kind of role would be possible in research.

You get to make a difference in a very different way. I still get to look after sick children ... which is what I always liked about nursing. **But now there is a deeper level to this in that I can potentially benefit other children and their families that I will never meet by doing a good job (in research).** In the future if I were to go to work on a ward I might see that drug given as a standard.

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SUPPORTING PRIMARY CARE

Julia Rooney

NIHR Primary Care Research Nurse

Kent, Surrey and Sussex Clinical Research Network

I used to manage the cardiac care unit at Brighton for many years ... I also had a period in the Middle East working in a heart centre. When I came back I worked for the heart network in Sussex where I also worked within primary care which was great experience as it is very different from secondary care.

I am now a research nurse working in **primary care**, coordinating and running studies in practices where there isn't capacity to carry out research. I started in this post six months ago and I have found it to be a very fulfilling job for many reasons ... It is so **rewarding what you get back from patients** who want to be involved in research for the greater good.

In nursing you cannot move forward without research and we are an evidenced based profession, for example we wouldn't have made the advances we have in the treatment of heart attack patients without research.

The **autonomy** you get within this role and the one-to-one patient contact you have ... the whole process is extremely worthwhile. I cannot recommend the role highly enough.

I was looking for a something that would get me more contact with patients and a new challenge ... it allows me to utilise my clinical background and experience within research and means I can make a difference that way.

I was apprehensive recruiting my first patient despite years of experience in nursing. I am a bit of a perfectionist and wanted to get it right ... taking the informed consent, making sure the patients understood what they were entering into ... once you start it becomes very natural.

In my previous position I was moving further away from patients and then this opportunity came up ... **everyone who asks about my job I say 'I love it!** There isn't anything I don't like about it'. People are probably getting a bit bored of me talking about it now!

I underestimated the job in the beginning ... I knew it was something I wanted to do but I underestimated how much I would love it and how much of a difference I could make to patients' lives ... this **will change lives for future generations.**

You actually **get time with a patient.** In that hour or so you can hear other concerns they

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I underestimated the job in the beginning – I knew it was something I wanted to do but I underestimated how much I would love it...



have and you can talk to them and advise them ... you get the opportunity to discuss issues that may be of concern to the patient.

As a nurse you always are an **advocate for patients** ... you make sure they are the priority in the research.

My working days vary so much, for example for one study I arrive in clinic, order a courier to collect the bloods, get the clinic room ready and all of the paperwork. Then you consent the patient and run the study. I might have to then go to another clinic in another practice to complete paperwork or run a shorter clinic ... **I genuinely don't have two days the same.**

If you have the clinical background **just do clinical research** ... until you are doing the job you cannot be sure how fantastic it is.

The studies I am involved in will change lives ... you cannot put a price on that.

When I first started in this role I worked with another research nurse ... she was an excellent role model.

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SUPPORTING PRIMARY CARE

Susan Read

NIHR Primary Care Research Nurse

West Midlands Local Clinical Research Network

Five years ago the Midlands Research Practices Consortium (MidRec) secured funding to recruit some half-time research nurse posts based in local GP research active practices.

I've always been interested in research and was working in a very busy GP surgery at the time, seeing patients every 5-10 minutes, with no quality time available to spend with my patients. I thought this job would give me the opportunity to spend more satisfactory time with patients while becoming involved in gathering accurate information to provide evidence based medicine.

I was the first nurse appointed and now part of a successful team of six nurses, based in our own individual surgeries, overseen by a Lead Research Nurse. Before we started running research studies in our nominated surgeries our **Lead Nurse manager ensured that we underwent a programme of mandatory training so we had an understanding of what was required to safely be involved in research.**

Gradually the studies came in and **I remember being asked by Professor McManus how many studies we were running and I said we were currently running about 20 studies ... he was surprised ... I think that opened the GPs' eyes and they realised the opportunity they had with the support of the nurses.**

Many studies are observational where you are looking and extracting data ... We also look at feasibility of studies, so we are contacted by a study manager and asked to find out the number of patients we have ... so we can go back to the study team and say these are the numbers for this head of population which we think you will be able to access at these surgeries.

The medical knowledge nurses have, comes in useful when running feasibility studies ... we can search effectively for eligible patients. There has been discussion whether nurses are expensive ... but we significantly help the GPs.

I remember my first patient recruited to a study. I was absolutely thrilled because patients were willing to participate in the study where we were doing near patient

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We have this supportive network of research nurses which makes a powerful effective team.



testing and baseline health measurements with immediate feedback of results which we then had time to discuss. If necessary the patients could be referred back to their GP for any concerns that were highlighted.

The patient contact, the communication pathway that opened up in the last five years with the team has given me job satisfaction. We really feel included more so now than ever before. **What pleases me the most is that although we are autonomous within our own environment there are five other host nurses ... We have this supportive network of research nurses which makes a powerful effective team.** We have opened up effective pathways between the university, study teams and other professionals ... if they need help or an answer to a query we can normally provide the information quickly and efficiently because we have close contact with the GPs.

If someone is considering a career in research I would say come and join me for a day and see things first hand ... Many of the host nurses have come from a Practice nurse background and have a wide range of knowledge because you can in any given day look after babies, give travel jobs, look after women's health to caring for a patients with a chronic condition ... over the years our training has covered an enormous remit.

You learn a lot from problems, you have to be pragmatic and always look for solutions. **When they set up this scheme, we were a pilot study - would it work? So already we were in a research study in our own right and it was important that we pull together as a team and pass on what we have learnt** ... The success of the Pilot enabled funding to continue and currently the NIHR fund us through their networks even after MidRec itself came to an end.

Patients deserve the opportunity to be involved in research.

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BUILDING SOCIAL MEDIA NETWORKS

Nathaniel Mills

Research Nurse Manager

Clinical Research Network: Yorkshire and Humber

My research career started in 2007. I was working in a large teaching hospital, part-time research and part-time primary care.

When I started there was some negativity around working in research from colleagues who thought it was not real nursing ... they thought it wasn't direct patient care. But for me it was something I felt I could do to make a difference. The whole notion of improving health and wellbeing through research appeals to me. I joined the NIHR Clinical Research Facility in Sheffield when it was a relatively new facility and I was in one of the first cohorts of research nurses. As a novice to clinical research you think 'what's it all about?' but with experience and as time goes on, you physically see a **patient's symptoms improving. That gave me a great deal of job satisfaction. In some cases the patient you see at the beginning of a trial is different to the same patient at the end of the trial. This is not just because they have had an trial intervention but because you, the nurse and the research team have given them the support and care that comes with trial participation.**

Last September the NIHR Coordinating Centre began to consider social media as a tool to support research staff and utilise established tools. As a result, I became involved in the work of the NIHR Clinical Research Network Nurses Strategy Board. I met up with Fiona O'Neill, a few colleagues and Teresa Chinn from '@WeNurses' to start up a clinical research nursing network on twitter. Teresa was inspiring in the sense that she's a nurse working on her own and used social media to connect with other nurses. She now has a community of over 10,000 active and innovative followers.

So we developed a social media strategy (#crnurse) with the aim of connecting the clinical research nursing community - especially reaching out to those nurses working in silos, something which is common in clinical research. We advertised this through the Clinical Research Network newsletter, and widely on Twitter we have regular 'tweet chat' debates and anyone who has anything to say about clinical research can participate - this has

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I am passionate about twitter because it pulls together these groups of people who have common themes and needs...



led to an active and vibrant community on social media. Sometimes I get the odd negative responses such as 'I don't want to do this in my own time' or 'what's the point?' and that's the beauty of it, you don't have to, you can participate as much or as little as you like, the conversation is always going on.

Since its launch we have achieved a lot. We have a community of nurses and international nurses from the USA, Australia, South America and North Africa. We promote good practice and social media brings the learning to the community ... it's free, cheap and easy. People who link in to our network can find out which Trusts are running trials. Problems can be shared rather than dealing with them by yourself, because it is highly likely someone will have already encountered the problem. So I would encourage nurses to get out there and start networking through social media, it can help make the life of clinical research nurses much easier!

I think the future is whatever you want it to be in terms of social media. **If we do it right we can respond to what the nursing community wants. I am passionate about twitter because it pulls together these groups of people who have common themes and needs.** Of course we have to consider what we say on a public forum, but we are all professional nurses and we are accountable for our actions.

Follow me @natwm10 or @resnurse

