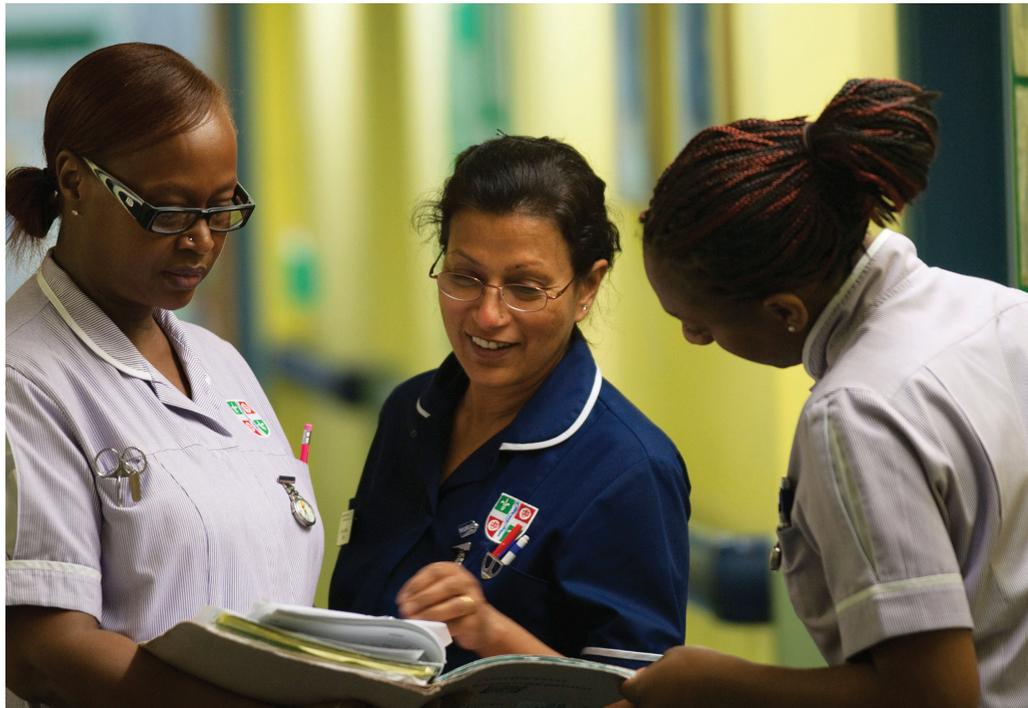




TIME FOR SOME ADVANCED THINKING?

THE BENEFITS OF SPECIALIST NURSES



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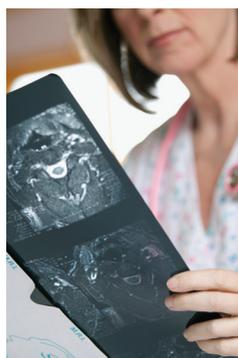
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FOREWORD

CLAIRE READ

Making a special case

This is an age of unrelenting pressures on the health service. Money is lacking and demographics are changing. Long term conditions are in the ascendant and care is becoming more complex and fragmented as a result.

With this long list of pressures, healthcare leaders could perhaps be forgiven for not focusing on specialist nurses in advanced practice. Not least since there has sometimes been a perception that these nurses – senior, highly expert, and with strong leadership abilities – are more of a problem than a solution. There has been talk of how costly they are, that they do not combat the real pressures being faced, that they move care closer to bursting-at-the-seams hospitals rather than away from it.

Yet the evidence points to quite the opposite. Research study after research study has shown that such nurses can lead to savings, to greater efficiencies, to better outcomes. They bridge gaps in the system, leading to a more seamless patient journey. They lead innovations. They help keep patients closer to home and out of hospital.

For this supplement, we have spoken to a range of individuals to explore these contributions. In the pages that follow, patients, researchers, academics, healthcare managers and those working in charities and patient support groups – as well as nurses themselves – share their perspectives on the difference specialist nurses can make. In so doing, the case is made that this is a workforce of which every healthcare leader should be aware – and in which they should consider investment.

A note on titles

Specialist nurses have many titles. In this supplement we recognise the title “specialist nurse in advanced practice” to be most useful, because it accurately reflects the four main work domains identified by the Nursing and Midwifery Council (advanced clinical or professional practice, facilitating learning, leadership and management, and research practice). Where other titles are used in interviews for this supplement, for example “specialist nurse” or “clinical nurse specialist”, these should be understood as synonymous with our preferred term of “specialist nurse in advanced practice”. ●

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More trusts are looking to assess the true economic value of specialist nurses, moving beyond looking at costs alone. Page 6



LEADERSHIP

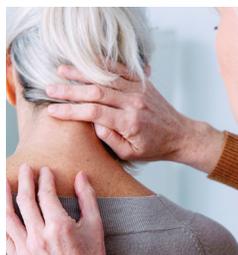
Specialist nurses in advanced practice say they have a view of the whole patient pathway and they can help drive a more multidisciplinary way of working. Page 7

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The day-to-day care of many patients with orthopaedic, rheumatological or musculoskeletal problems in Oldham is managed by a primary care-based team that consists solely of specialist nurses. They say that the fact that they can see patients often helps to get disease under control earlier, leading to improved outcomes. Page 8

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‘Brokering’ care by liaising with, educating and upskilling other professionals could be a key area where nurse specialists make a difference. Page 9



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Chronic pain sufferers passed fruitlessly round specialties appreciate a nurse who can take a holistic view. Page 10

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One man's diagnosis of prostate cancer at the age of just 50 brought him under the care of nurse specialists. He tells how he became an ardent advocate and fundraiser for specialist nursing. Page 11

THE VALUE OF SPECIALIST NURSES: THE CHIEF EXECUTIVE'S VIEW

“In talking to cancer patients and looking at cancer patient surveys, the one person those patients value over anybody else is the clinical nurse specialist. The person who holds it all together and integrates the care together is

the nurse specialist. These nurses save the time of doctors – many patients are more appropriately seen by nurse specialists.”

Sir Robert Naylor, chief executive, University College London Hospitals Foundation Trust

HOW SPECIALISTS CAN HELP YOU

Six reasons specialist nurses in advanced practice should be on your agenda

Be honest: are specialist nurses in advanced practice on your agenda? If you are a non-clinical member of the executive team, the odds are that the answer is no. They are likely displaced by the pressing need to deliver better care at lower cost, to work more efficiently with your partner organisations, to find ways to redesign services.

Yet experts say that the reality is that, if any of those issues are on your to do list, specialist nurses should be too. Members of this staff group:

- Have knowledge of, and insight into, the entire patient pathway
- Have high level expertise of the patient group for which they care
- Have additional qualifications meaning they can perform advanced tasks – this may include ordering and interpreting tests and investigations, conducting physical assessments, and prescribing medications
- Have considerable knowledge of the healthcare organisation in which they work, and of partner organisations

What that means is that specialist nurses in advanced practice are perfectly placed to help with all the pressing agendas on your to do list.

Care at reduced cost and increased efficiency

- Ensuring the best use of hospital and consultant time

Specialist nurses in advanced practice can help ensure that patients are only in hospital when they need to be. Take the example of patients with inflammatory bowel disease, who tend to have periods when they are generally well and then periods when the condition flares up. Explains Helen Terry, director of policy, public affairs and research at Crohn's and Colitis UK: "You could have an annual review or a six monthly clinic appointment but it might fall at a time when you're really well, and you're having to take



time out of work to attend clinic appointments when actually you don't need to be in the clinic. But you might then find it difficult to access that specialist support quickly at times when you really do need it. If you're flaring, the sooner you can get appropriate advice and moderations to treatment [the better]. And doing that does have huge implications in terms of ongoing healthcare costs but also in terms of the costs to individuals and their families." Specialist advanced practice nurses are also expert at reducing unscheduled care – intervening before an issue drives a patient to A&E.

- Freeing up the time of other members of staff
- "Clinical nurse specialists are doing work

that might otherwise be done by more expensive resources, and that can represent a real financial benefit," points out Jenny Ritchie-Campbell, director of services, strategy and innovation at Macmillan Cancer Support. Paul Trevatt agrees. "I think you cannot afford not to invest in the specialist nursing workforce," contends the strategic clinical network lead for NHS England. "A number of the roles that nurse specialists do were roles that were previously done by consultants and now they're doing it at a fraction of the cost."

- Driving innovation
- "Clinical nurse specialists come up with fantastic, innovative ideas about how they can mobilise different teams, different colleagues, different sets of finite resources



to actually deliver high quality patient outcomes,” says Chih Hoong Sin, director at research organisation and consultancy Office for Public Management (OPM). “They have a really keen eye on what makes a difference to their patients and then they’re able to behave in a way, and get others to behave in a way, which meets those needs.”

- Offering value for money

As Liz Darlison, respiratory nurse specialist says: “If you manage them effectively and nurture them, I think you get a lot of bang for your buck with specialist nurses.” Jill Firth, consultant nurse in rheumatology, adds: “There’s really, really strong, multi-centre, randomised control evidence that nurse-led care produces equivalent outcomes at lower cost.”

System leadership and service redesign

“Because specialist nurses in advanced practice really understand the patient pathway, understand patient need and how services are configured, they’re excellent people when it comes to things like service improvement and service redesign,” reports Alison Leary, professor of healthcare modelling at London South Bank University.

Bringing care closer to home and reducing the burden of long term conditions

- Helping patients to help themselves

“I would say specialist advanced practice nurses are the key to self management in long term conditions,” contends Professor Leary. “They help patients understand when they should contact acute services – when

it’s appropriate to do so for that patient – but they also educate and empower patients to manage their own disease.”

- Making the right interventions and referrals at the right time

“The key thing about a lot of really specialist nursing is that it’s primarily caring for patients who have long term conditions and who really need to be able to support their self care in the long term – which reduces the burden on all health services,” says Ms Firth. “Patients who we identify are not coping well and have lower levels of self-efficacy we can refer to a self management programme and to other resources.”

Seamless, integrated, multidisciplinary care

- Brokering care between healthcare professionals and other organisations

“Specialist nurses are pivotal to filling in the cracks in your service, and making sure that the patient gets the best outcome,” argues Sue Oliver, a nurse consultant in rheumatology. “They provide continuity of care, the value of which is often underestimated by healthcare organisations but which is highly valued by the patient.”

- Caring for a patient at any point on their journey

‘Nurse specialists do some roles previously done by consultants at a fraction of the cost’

“Our work stretches over the whole of the patient pathway,” emphasises Julia Taylor, consultant nurse urology, Salford Royal Foundation Trust. “For cancer, that increasingly includes focusing on survivorship because there are many more people are surviving the disease.”

- Driving multidisciplinary care

Says Chih Hoong Sin: “I am constantly impressed by how clinical nurse specialists build partnerships and alliances across different professional groups – with social care, with community services, with GPs and so on, and that’s all with an eye on a patient. That is very impressive.”

Treating the person, not the condition

- Delivering holistic, whole person care

“As nurses we do look broadly at our patients,” says Ms Darlison.

“We do see the holistic impact of ill health. My surgical colleagues, I want them to focus purely on the surgical techniques but my expertise is more about the impact of that on the patient and putting it into the context of life.”

- Breaking down the barriers between physical and mental healthcare

“Where people need psychological care as well as physical care, that’s where specialist nursing in advanced practice excels,” argues Professor Leary.

Excellent patient care and experience

- Responding to patients’ needs

“We use nurse specialists at all sorts of different levels within our department now, and they provide almost the glue in the middle – a person who can pick up concerns and action problems but can also provide a supportive, health promoter type role,” explains Isobel Mason, nurse consultant in gastroenterology at Royal Free London Foundation Trust.

- Offering accessible support and expertise

“I think patients ask different questions and speak to nurses in a different way than they do to doctors,” adds Ms Mason. “So where they won’t want to bother a doctor, for example, or they will feel that a hospital consultant is two steps away from them, they can pick up the phone and speak to a specialist nurse and probably express different things. Certainly with inflammatory bowel disease patients, we know they absolutely want and need a doctor when they’re needing expert medical attention. But the rest of the time, when they’re making decisions that relate to their health and how they’re living in the world with their illness, actually they find it much easier having those conversations with nurses.” ●

ANALYSIS

TIME TO THINK AGAIN?

The five things you thought you knew about specialist nurses in advanced practice – and the evidence which suggests you were wrong

Alison Leary is used to hearing myths about specialist nurses in advanced practice. For 15 years, she worked in the role herself as a clinical nurse specialist in oncology. Today she is professor of healthcare modelling at London South Bank University. Her major focus? Researching the work done by this expert group, and finding ways to prove the impact and value it has. Below, five of the most common misperceptions she says she comes across – and her response to each.

1 Specialist nurses in advanced practice cost a lot of money and don't give much value in return.

"There's a perception that these nurses are expensive, but actually they're a very good return on investment and there are lots of studies now which show that," argues Professor Leary.

"Together with colleagues, I have looked at the work of 12,000 specialist nurses in advanced practice, around 50m hours of work, and they're a cost effective, high quality option in terms of delivering care.

"Their expertise is such that they are very good at proactive case management. They

are able to see problems before they really arise, which I think is why they're very good at avoiding unnecessary admissions. Patients have a key professional who can case manage their care, and provide solutions to things like A&E admission or presentation."

Professor Leary also disputes the notion that for the specialist nursing workforce to have more of an impact, large amounts of additional money will be required. "Just with small investments in education and small investments in administrative support, we could grow and develop this workforce. And it would be a solution rather than a cost and a problem."

2 Since most are based in acute care, they only really benefit that sector.

"Because specialist nurses in advanced practice are based in the hospital, there's a myth that they're not serving the community," reports Professor Leary.

"Yet they're often utilised by GPs, community nurses, district nurse teams as experts in managing patients with a specific condition. They are an accessible, expert

resource. Most specialist nurses in advanced practice, even if they're based in the acute sector, practise in the community. For instance, 30 per cent of a specialist nurse in advanced practice's work is generally done over the phone. So that's supporting patients in the community and supporting community practitioners of all types to manage increasingly complex care needs."

3 They're just assistants to the medical staff. They don't really do anything independently.

"Specialist nurses in advanced practice are usually independently practising as part of a collaborative multidisciplinary team," explains Professor Leary. "They are not some kind of assistant to the medical staff."

4 A specialist nurse in advanced practice has, at best, knowledge equal to that of a junior doctor.

"Specialist nurses in advanced practice generally have many years of experience, not only in technical aspects of care but also in case management," says Professor Leary. "They are able to be strategic leads because they understand the disease trajectory and the associated parts of that disease process. These are experienced practitioners who are able to release consultant time."

5 They're a nice to have, not a need to have.

"The changes to the health service in the last 10 years mean that actually these people are now pivotal to running services in long term conditions," argues Professor Leary. "These are not people who are a nice extra. They're responsible for managing very complex caseloads of patients with multiple co-morbidities.

"Specialist nursing in advanced practice is not just about sitting around and having a cup of tea and a chat. It requires real expertise." ●



EFFICIENCY

MEANINGFUL EFFICIENCIES

Simplistic focus on costs can ignore the benefits of nurse-led innovation

A growing number of organisations are seeing the economic case for specialist nurses in advanced practice. The Multiple Sclerosis Trust is so convinced it has published a whole report about it.

Amy Bowen, director of service development at the MS charity, puts it very simply: “We think that there is a very strong economic case for specialist nurses.”

The organisation’s report, *Defining the value of MS specialist nurses*, explores how this workforce is leading to savings for the healthcare economy.

The MS Trust is far from the only organisation collecting such evidence. Indeed, its report cites research from other specialties – the study which showed that rheumatology nurses saved £175,168 per nurse by freeing up consultant time; the University of York study which showed that cardiac specialist nurses achieved an average 35 per cent reduction in all cause hospital admissions; the data showing having a specialist Parkinson’s nurse can reduce hospital admissions by 50 per cent.

In short, the figures are not lacking. Study after study has provided strong evidence of the financial case for specialist nurses. What the figures are, though, is specialty-specific. There is as yet no overarching understanding of the country’s specialist nursing workforce and much of the research is associated with charities or patient groups in a particular area. Ms Bowen recognises that may undermine its impact: unnecessarily, she feels.

“Working in a charity, it can be perceived that: oh, well, of course you would say that ... [and you] will be advocating for the very platinum model that you can get for your community,” she says. “What we believe, and what we’re collecting evidence to hopefully demonstrate, is that it is a very wise investment of scarce resources.

“In services where there are nurse-led components, or there’s a model where the



follow-up is shared between the consultant and the nurse, obviously there’s the potential for savings there and the avoidance of... emergency admissions,” explains Ms Bowen.

“We know, for example, that the biggest drivers of emergency admissions for MS are not uncommon ones – urinary tract infections, falls, and respiratory problems. And all of those are amenable to reduction through proactive models of care.”

Chih Hoong Sin has long been exploring ways to quantify the value of specialist nurses. He began in 2010, when the director at independent research organisation and consultant OPM (Office for Public Management) starting exploring the return on investment of “high impact actions” – eight measures which a public consultation of nurses and midwives suggested could save money and improve care.

“Around that time, after the general election, public services were being seriously squeezed and regardless of all the talk of ring fencing NHS spending, in real terms it actually went down,” he remembers.

“Specialist nursing posts were not being filled and what was very disturbing to me...

was I felt that disembodied experts were running the pound signs somewhere without necessarily understanding what it means to be delivering certain types of nursing services on the ground.”

It led him to develop a programme to help nurses “run the numbers on the costs and benefits of nurse-led services and innovations”. It became accredited by the Institute of Leadership and Management and, early on, identified savings from three nurse-led innovations – including a clinical nurse specialist project which avoided admissions for heart failure patients.

“These services had very, very tangible financial and economic benefits that actually could save the NHS a huge amount of money. So the argument... was that nurses, including clinical nurse specialists, are the solution not the problem. And actually, if you cut them, you are removing that ability to generate efficiencies that are meaningful, that actually uphold the quality of care.” ●

VIEWS ON THE VALUE OF SPECIALIST NURSES IN ADVANCED PRACTICE:

GETTING THE RIGHT CARE, EFFICIENTLY

“Specialist nurses make sure that the patient gets the right outcome – they listen to the patient, identify a problem solving approach, and then make sure that approach happens. And they do it with a high level of expertise and knowledge, and a real ability to cross boundaries. And in essence, the greatest value for any of the work we do within the NHS is ensuring the patient gets the right outcome as fast and as efficiently as possible and feels supported.”

Sue Oliver, consultant nurse in rheumatology

LEADERSHIP

DIFFERENT ANGLE

Specialist nurses argue they can provide a more complete view of care

A few years ago, Sarah Ryan and her colleagues decided to conduct a study of the impact her nurse consultant role was having within Staffordshire and Stoke on Trent Partnership Trust.

“It was a qualitative project, and my colleague was interviewing people within the organisation who had had contact with me,” explains Ms Ryan. “And I just remember one of the managers saying that my role had taken the pain service ‘to a more strategic level.’”

It is a point which speaks to the position of specialist nurse as system leader.

Another example is Isobel Mason. A nurse consultant in gastroenterology at Royal Free London Foundation Trust for five years, she has for the past 18 months also been the lead for the department. That means that as well as supporting and developing her nursing colleagues, she makes strategic decisions relating to the service and to all members of the team.

“I think having a nurse consultant as the service lead means that things just get seen from a slightly different angle,” she suggests. “So, for instance, our trust has just merged with two other hospitals, but the decisions about what our department’s services look like to patients definitely have a much more holistic view.”

She stresses that her medical consultant colleagues very much see her as a peer – “they’re really excellent, I just get seen as one of them” – but she also thinks that having a nurse in charge means others feel more able to make a contribution.

“Where before medical consultant voices were the main ones in terms of decision making for the services, I think everybody in the department now feels they have a stronger voice because I come from a different place. I think it very definitely gives a different tilt to how the department works.”

Much of that work is now done by nurse specialists. They each have their own areas of focus: some specialise in inflammatory bowel disease, others run the nutrition team, some perform endoscopies.

“They’re all areas of nursing development I have identified over the years and, as nurses have come in, they’ve continued to develop their services in different ways. They’re often providing very different roles – they’re not all doing the same thing, but have all found areas of care where nursing really brings extra value.”

According to Alison Leary, professor of healthcare modelling London South Bank University, too few organisations are capitalising on the potential of nurses to

SPECIALIST NURSES AS LEADERS: THE CUCKOO LANE SURGERY

Cuckoo Lane Surgery is a nurse-led GP practice. Based in West London, the nurses who see patients are authorised to do everything GPs can do – with the exception of certifying deaths or signing sick notes. “I think the patients within the practice like it,” says Helen Ward, a nurse practitioner at the surgery who is also a principal lecturer in advanced nursing and prescribing at South Bank University. “I think the patients feel nurses are easier to talk to. We take the time to talk to them, explain to them, give the rationale for treatments, make sure we go through medications with them, make sure they’re taking the medications properly. I think listening to patients is probably one of the things nurses are best at.”

successfully lead services. This is, she suggests, a waste of the unique knowledge these individuals have.

“Specialist nurses in advanced practice understand their service and see it from end to end from a patient’s point of view,” she points out. So whereas your surgeon will see the surgical part of the pathway, the specialist nurses will see from diagnosis to treatment and beyond.

“So they understand where it doesn’t work well and where it does work well. And that is rarely exploited in the organisations they’re working for.”

At The Royal Free, there is currently only one other nurse service lead in addition to Ms Mason. “But I know that the leaders here are really keen that we try and use more non-medics to lead services,” she says. “Because it does bring a different view. And it’s really important that we say, actually, clinical leads don’t need to be doctors.” ●

SPECIALIST NURSES IN ADVANCED PRACTICE AS LEADERS: MESOTHELIOMA UK

When Liz Darlison first set up Mesothelioma UK, she was a third of its staff. The respiratory nurse specialist was joined by a part time secretary and a one day a week bookkeeper. A decade later, she leads an organisation which is now a charitable trust employing 11 specialist nurses. Together, they offer expert care for patients diagnosed with the condition, an incurable cancer caused by exposure to asbestos which brings with it a heavy

symptom burden and a very short life expectancy. The nurses are placed strategically across the country, with the aim of ensuring that each region has access to their expertise. “You can’t expect to have mesothelioma experts in every NHS hospital up and down the country,” says Ms Darlison. “There isn’t the incidence. So we’ve developed a bespoke approach to upskilling or providing expertise and support at a local level.”

SERVICE REDESIGN

HELP THEM TO HELP THEMSELVES

How nurse led specialist care in Oldham is encouraging self management

If you live in Oldham and have a suspected orthopaedic, rheumatological or musculoskeletal problem, you will be referred to see a consultant at Pennine MSK Partnership. And if the consultant diagnoses an issue, he or she will refer you straight to a team of colleagues in the primary care-based organisation: a team which consists solely of specialist nurses.

“Our patients are seen within the service and diagnosed by a consultant rheumatologist,” explains Jill Firth, a consultant nurse in rheumatology who’s worked for the organisation since 2010. “But their actual care on a day-to-day basis is then managed by a team of specialist nurses. So we will see those patients very regularly to help them control their disease activity, to prescribe for them, to administer medications and joint injections and so on.”

The figures show waiting times to see a rheumatologist have been cut from 45 days to 19. But it goes beyond that, to better outcomes. “Patients are able to be seen much more regularly than they were previously. Being able to see patients more often helps us to really be able to get their disease under control early,” explains Ms Firth.

“And if we get their disease under control early, then it leads to improved outcomes in terms of the progression of the disease, but also their quality of life. There’s a lot of evidence out there to say that the earlier we treat people with rheumatoid arthritis, for instance, the better they will do in terms of their long term outcomes.”

Around 100 miles south, in Birmingham, specialist nurses are also helping keep patients out of hospital. Dawn Homer is a rheumatology nurse consultant for the community rheumatology service at Vitality Partnership. The organisation is a GP “super practice”, with hospital avoidance and care closer to home among its key aims.

“The big agenda of the partnership is to bring long term conditions out into a

primary care setting, to keep people out of A&E, and to engage with those recidivist patients who don’t attend and who get very poor health outcomes,” explains Ms Homer.

She sees rheumatology patients at their local GP practice, managing their post-diagnosis care. “We free up the consultant rheumatologist from follow-up work and free them up to predominantly see new

‘Being able to see patients more often helps us to get their disease under control early’

patients. The patient is entirely managed by the nurse, and we only bring the patient back before the doctor if there’s a new medical condition, or where we’re getting to a point where we’re looking at the use of high cost drugs.”

Carmel Jones, rheumatology lead nurse and service manager at Lancashire Care

Foundation Trust, says bringing specialist nurses into the field has cut patients’ dependence on hospital care.

“My first job when I qualified as a nurse, in 1994, was on a general medical and rheumatology ward. Half the ward was rheumatology beds, and they were always full of older people who had chronic disease, chronic disability, lots of pain. They were very dependent – no self management to be seen,” remembers Ms Jones.

“Obviously we’ve had massive changes in drug treatment since then, but I would argue that the unique role of the rheumatology specialist nurse is helping people to help themselves. [We’re] encouraging self management, education, supporting patients to be healthier, to manage their flares, to understand their own warning signs and to come back to us when they need us, but preventing that whole cycle of hospital dependency – in and out of hospital, with flares, with pain, with disability, with not coping at home. It’s preventing all of those people going to hospital.” ●

SPECIALIST NURSES SUPPORTING SELF MANAGEMENT

The National Rheumatoid Arthritis Society runs a six week self management programme for patients with the condition. The society’s chief executive and founder, Ailsa Bosworth, says specialist nurses are key to its success.

“By and large, the healthcare professional providing the training is a nurse specialist, who covers things like medication, pain management, flare management and so on. We definitely see the nurse in that role of helping to educate and enabling self management, so anything we can do to support the nurse in that role we will.”

VIEWS ON THE VALUE OF SPECIALIST NURSES IN ADVANCED PRACTICE: LONG TERM CONDITIONS

“Specialist nurses are really expert at symptom management. More and more people are being diagnosed with long term conditions, and if we can help those people manage their symptoms, they won’t be going to A&E with them. They will have the confidence to manage, to increase their quality of life, to remain in the workforce and remain socially active – which reduces mental health problems as well.”

Sarah Ryan, nurse consultant

WORKFORCE

BROKERS CAN FIX IT

‘Brokering’ care by coordinating other professionals is a key part of the specialist role

When Ailsa Bosworth was first diagnosed with rheumatoid arthritis, specialist nurses did not exist. “It was just a rheumatologist, and a physio if you were lucky,” remembers Ms Bosworth, the founder and chief executive of patient support group NRAS (National Rheumatoid Arthritis Society). “It was only in 2000 that I started experiencing the specialist nurse. And it was a massive change.”

Part of the reason it was so different, she says, is that it was part of opening up greater access to a true multidisciplinary team. “It came as a nice surprise to me to find that there was a nurse who could actually talk through issues that were concerning you and that there was this MDT that I could access as needed.”

It is an experience which underscores the huge role specialist nurses in advanced practice play in “brokering” care. According to Amy Bowen, director of service development at The MS Trust and a nurse by background, this expert group plays a critical role in “liaising with, educating and upskilling other health professionals and brokering and planning care – contributing to multidisciplinary care conferences both within the secondary care context and within the primary care context.”

She argues they do not just increase integration in healthcare, however. “There’s also a huge amount of brokering social care support and referrals. So, for example... very many people with MS also have significant bladder problems, so being plugged into continence services is really important. And the nurses play a pivotal role in ensuring patients are plugged into continence services, in brokering all of those services.”

Ask Sarah Ryan about this aspect of her role and the response acknowledges that it can seem like a simple task – one anyone could do. “It can sound a very basic role, can’t it, coordinator,” reflects the nurse consultant in rheumatology. “Because you



Specialists can draw together multidisciplinary care for arthritis

can do it at a very basic level – we all coordinate our lives every day to fit everything in, for example.

“But the key with specialist nurses is that they will have leadership skills and clinical experience: they’ll know who to speak to within an organisation, they will understand all the strategic levels of an organisation.

“[In my role] it might be that we’re liaising with consultants about whether a patient needs a neurological opinion or an orthopaedic opinion, and doing a lot of that coordination to try and make the patient’s journey streamlined and effective for them. You need to know the people and how

systems work to guide patients through that complexity – patients can find it bewildering.

“So it’s explanation of the journey, and guiding patients through it, and keeping a tab on referrals: so you might refer a patient for respiratory function tests and you’re waiting for them to come back to guide the next stage [of the patient journey] but in the meantime you’re liaising [to get the test results] and advising the patient why the tests are appropriate to do, and what you’re hoping to determine from the results.”

Paul Trevatt – a former clinical nurse specialist in cancer who now works at NHS England as a strategic clinical network lead – contends that the value of this cannot be underestimated.

“The clinical nurse specialist brings clinical expertise and the ability to deal with complex situations – that might be complex symptomatology, symptom management; it could be complex psychological or emotional support around a diagnosis,” explains Mr Trevatt, whose research work helped to map the English cancer clinical nurse specialist workforce. “They have an ability to interface with a patient at any given time and say: this is where you are, and this is where you’re going.” ●

VIEWS ON THE VALUE OF SPECIALIST NURSES: CARE INTEGRATION

“If you want care to be properly integrated, there needs to be expertise and specialist knowledge in the system that people can access. To drain the system of that is to introduce a risk – a financial risk, and a clinical risk.”

Amy Bowen, director of service development, The MS Trust

SERVICE IMPROVEMENT

THE WHOLE OF ME

Chronic pain sufferers have responded positively to a holistic approach

Sarah Ryan says she has heard it countless times in the 15 years she has run the rheumatology pain clinic. “Patients often say to me, oh, you’re interested in the whole of me. You’re not just wanting to separate me as a patient with a knee problem, or a lower limb patient – you’re wanting to know how it affects me on a day-to-day basis.”

Ms Ryan is a nurse consultant, and runs the Staffordshire and Stoke on Trent Partnership Trust pain clinic with a fellow nurse. It was established to meet the needs of patients with chronic pain, traditionally poorly served by local services.

“There wasn’t really a recognised or designated facility where those patients could get extra education, support, advice, guidance, self management to help them with their symptoms,” she explains.

“Often they were passed from pillar to post, going round a number of specialties, being told that there was nothing additional that could be offered medicine-wise but then not getting advice on how to manage their symptoms.”

It left the patients despondent and more in need than before. Meanwhile organisations in the local health economy were left counting the cost of numerous appointments which had not really addressed the individual’s problem.

It was a situation the local team agreed a specialist nurse was uniquely qualified to address. And so, in 2000, Ms Ryan was



appointed to her nurse consultant post to set up the clinic. A research study a few years later demonstrated the impact.

“We found that in terms of the emotional distress of pain, and the physical symptoms of pain, it was providing a service not only for the patients but was reducing the cost to the health economy. We found it reduced GP attendance for pain symptoms, and reduced patients going around to multiple specialities.”

It is a success which Ms Ryan believes is down to the distinct approach she and her nursing colleague bring. “We try to move medicine into the patient experience and

what’s important from the patient perspective – what’s their main aim in wanting to try and manage these symptoms?” she says.

“We’re listening to what’s happening with the patient; taking a full history. The main aim is how can we optimise the physical, psychological and social function when somebody is living with pain? How can we equip somebody with the skills to optimise that?”

“For some patients, it might be that they’re at a stage where they’re too emotionally distressed to move on, but we can identify that emotional distress and put a plan in of how we might manage that, whether with drug therapy or talking therapy or a combination of the two.”

In other words, taking the holistic approach which is commonly acknowledged to be precisely what health services should be aiming for.

Dawn Homer is also a nurse consultant in rheumatology, and shares the view that the holistic approach is a key strength of the role. She runs a community rheumatology service for Vitality Partnership – a GP “super practice” operating across Sandwell and Birmingham.

“Working in the community, what I’ve discovered is that you can actually do more for the patient by sorting out their social issues; addressing the chaos that is going on at home,” she says. “And I’m not saying resolve it for them, what I’m saying is empowering them to be able to sort out their own issues by holding their hand and never actually letting that hand go on the journey.”

“The only time I lose a patient’s hand is if they move away or they die,” she points out. “It’s safety netting – specialist nurses stop admissions into hospital. We really, really do a lot of advocacy work which stops the patient ending up in a worse position health-wise.” ●

THE VALUE OF SPECIALIST NURSES IN ADVANCED PRACTICE: SPOTTING AND RESOLVING PROBLEMS

“Clinical nurse specialists have the ability to escalate matters quickly if there is a problem. So, for example, a patient may ring up and say I’ve had this symptom, I’m not sure if it’s just me being worried or if it’s something I need to be concerned about. And what the clinical nurse specialist will then do is a risk

assessment, making a clinical decision based on their expertise [and] will reassure, treat or refer appropriately within the multidisciplinary team.”

Paul Trevatt, strategic clinical network lead for cardiac and vascular, stroke, diabetes, renal, and end of life, NHS England

PATIENT EXPERIENCE

‘A GOOD LEADER PICKS YOU UP’

How a cancer patient ended up riding to Marseilles to help expand specialist nursing

Simon Lord had a very specific image of how cancer diagnoses are delivered. It was one forged by years of exposure to films in which a stern, white-coated medic sees a worried patient to pass on the information. “In the films, classically, you go in to see the doctor,” says Mr Lord. “And he says: ‘Sorry, I’ve got some bad news for you.’”

So when the retail manager received his own diagnosis of cancer, he was surprised there was no doctor giving the bad news. Instead, it was broken by a nurse. “And if I ever get another cancer diagnosis – God forbid – I would want it to be given to me in that fashion; by somebody who was ready to talk about how the support mechanism was going to intertwine with the rest of the diagnostics and treatment.”

Mr Lord was diagnosed with prostate cancer in July 2010 at the age of just 50. “Eighty per cent of men diagnosed are 65 and over. So I was still 15 years younger than the majority of men diagnosed with the condition,” he explains.

He says that the nurse specialists who cared for him at Guy’s Hospital recognised this might mean he had different needs. It was an early example of the way these nurses



offered him holistic, person-centred, care he says. Another was they gave him information about the procedure he opted to have to treat his cancer.

“Rather than just give you a whole load of leaflets – which inevitably leads to more questions than answers which you never have an opportunity to ask because you’re too focused on other things – the nurses ran a half day seminar for all the men who were undergoing robotic prostatectomy and for their partners,” Mr Lord explains.

“I thought that was an excellent start, because someone had looked at it from the other side of the table, and said: ‘If I were a patient, what would be best for me?’ Because it was a group setting, it was far less intimidating and formal. And it was also really efficient from their point of view, because rather than giving the information to one patient at a time, they were speaking to a group.”

He firmly believe that this sort of expert input leaves patients better equipped to deal with the full impact of their condition – and less likely to need unscheduled care.

“A well resourced clinical nursing function will prevent readmissions – it’s as simple as that,” he argues. “Because they

THE VALUE OF SPECIALIST NURSES: CANCER CARE

For each of the past four years, the National Cancer Patient Experience survey has explored patients’ opinions on the cancer care they have received. The variable most strongly associated with a positive patient experience? The presence of a clinical nurse specialist.

leave people feeling better and more knowledgeable about their situation, those people are less of a burden on other aspects of the health service.

“They’re probably going to get back to work sooner, they’re probably going to be at their GP surgery less frequently. That has to be a benefit.”

It’s a benefit of which he’s so convinced that, last spring, Mr Lord cycled from Guy’s Hospital to Marseilles to raise money for the Urology Foundation.

A small charity, the foundation had previously only supported the training of doctors in the specialty. But, following a meeting between staff there and Mr Lord and his clinical nurse specialist, it extended financial backing to nurses.

Four and a half years after his diagnosis, Mr Lord is still struck by the skill of the nurse specialists: “They need to lead a patient who really doesn’t want to be there down a route they haven’t been down before to an end point that they may well think isn’t possible at the start point,” he observes. “That needs leadership skills.”

“Particularly at the outset, it’s quite easy to collapse in a heap and decide the whole thing is far too difficult. But a good leader will actually be able to pick someone up and say: ‘We’ll help you with it, we think you can do it, and these are the things we’re going to give you and show you that will get you there.’” ●

THE VALUE OF SPECIALIST NURSES IN ADVANCED PRACTICE: PATIENT EXPERIENCE

In Scotland, Crohn’s and Colitis UK surveyed patients with inflammatory bowel disease, comparing patients who did and did not have access to a specialist nurse. Those who did have access were more likely to have an annual review of their care, more likely to contact their nurse rather than their GP in the event of a flare up, more likely to follow self management guidelines, and more than twice as likely to be satisfied with the level of care they were receiving.