

A Place for Care

Variation and value in patient pathways

Professor Matthew Cripps / Baroness Brinton / David Barker



Based on the round-table discussion *Thinking Outside the Box: Patient Empowerment and Commissioning for Value in Chronic Care* and produced in association with

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How patient support programmes put patients at the centre

Philip Schwab, director of government affairs at AbbVie UK, argues that chronic conditions require a holistic approach



Our hospital care co-ordinates with the Carter Review and NHS mandates, which recommend that care moves closer to home

The World Health Organisation tells us that up to 50 per cent of people in the developed world who live with chronic conditions do not take their medication as prescribed. In a recent UK survey on the true cost of medication, two-thirds of people said this was because they “forgot”; a further 20 per cent say they no longer felt ill. Whatever the real-world behavioural reason, this is adversely impacting patient outcomes, creating waste and putting even more pressure on the NHS.

Chronic conditions are becoming more prevalent, and there is a growing need for patient-centric solutions that enable patients to get back to being people and living their lives to the full. At AbbVie, we realise that it has never been more important to explore new ways of delivering services, as care quality and patient experience are examined in the light of constrained budgets.

It is a stark fact that the NHS is at capacity. In response, industry must assume a responsibility to move beyond just the manufacture and supply of medicines. My AbbVie colleagues and I take this responsibility very seriously. We agree that the best way to be a responsible health and care partner with the NHS is to recognise that a holistic approach with the patient at the centre is needed. This will be key to achieving successful outcomes for people living with chronic illnesses. This shared vision was the impetus for the foundation of patient support programmes.

Our patient support programme, AbbVie Care, aims to evolve the traditional patient support programme into one that offers flexible, out-of-hospital solutions tailored to the needs of both the individual patient and to the local health economy, enabling improved

patient outcomes. Our programme is centred on improving patient experience through technology, patient-centric services, and supply-chain solutions.

Our hospital care co-ordinates with the recommendations in the Carter Review and NHS mandates to move care out of the hospital and closer to home. Our patient support programme aims to:

- Co-ordinate seamless home care and nurse support at home, joining up hospital and community services with the requisite accountability and governance to ensure quality outcomes.
- Provide digital educational information and tools tailored to the patient’s needs.
- Create a reliable supply chain, ensuring that patients get the right medicine at the right time, supporting medicines optimisation.

We are committed to measuring the real-world impact of our programmes in terms of making a remarkable impact on patient outcomes, along with quantifying the positive improvement in NHS health-care efficiencies.

It is contributing to a holistic solution and partnering with the NHS that I am truly passionate about, because it requires us to work collaboratively and put the person at the centre of their care. It looks at the individual’s needs while relieving pressures on the health and care system and contributing to the longer-term sustainability of the NHS in a way that can be measured. The impact should resonate with industry, patients, HCPs and payers alike.

There’s still a great deal of diversity, from our standpoint, in how health-care economies view hospital-based treatment or home-based treatment, for a variety of reasons. That’s one of the things we are interested in exploring, to understand how that kind of variation can be viewed and what sorts of incentives are working for or against the optimisation of care. In doing so we hope to discover how the optimal patient experience can be provided, how we can help support the patient in understanding their condition and getting the most out of that treatment, both for themselves but also for the system; because the system, too, invests in the diagnosis and the treatment of each individual.

Better outcomes and value for chronic care

As national director for NHS RightCare, Professor Matthew Cripps is helping to transform pathways of care to create better outcomes and better value



RightCare is a proven approach that delivers better patient outcomes and frees up funds for further innovation. Our ambition is for RightCare to become the “business as usual” way of carrying out evidence-based, clinically engaged change. NHS RightCare works with local health economies (LHEs) to make the best use of resources for better value – for patients, the population and the taxpayer. It helps LHEs understand how they are doing, by identifying variation with demographically similar populations, and gets them talking about population health care, rather than organisations. By identifying priority programmes that offer the best opportunities to improve health care for populations, LHEs can then make sustainable change to care pathways. The impact of optimising care pathways becomes powerfully evident when looking at an individual case.

Janet is a theoretical (but typical) patient of 85 years old, who suffers one of the 2,154 serious falls, per 100,000 population, that occur in the average Clinical Commissioning Group each year. In the current standard pathway, Janet falls on a Friday night and is taken to A&E. Due to the weekend, she waits in hospital until she can be properly assessed on the Monday. Due to a lack of beds, she’s shunted to another ward, which makes her disoriented, and she has another fall. It takes 14 days for her to be discharged. Ten days, in the average hospital bed, leads to the equivalent of ten years of ageing in the muscles of someone over 80.

The second pathway offers a brighter outlook; it also begins four years earlier. At the age of 80, Janet is given a gait speed test by the fire service, as part of a

fire prevention visit. They deem Janet to be showing the early signs of frailty. They give her *The Practical Guide to Healthy Ageing*, and put her in touch with a charity that runs exercise classes for the over-eighties. Five years later, she’s doing well but is becoming more frail, so after a visit to her GP, the system-wide multidisciplinary team (MDT) is referred to Janet. The MDT assesses her needs, makes her home “frailty friendly”, optimises her meds and engages her in the local memory service. They agree a personalised frailty and dementia care plan with Janet. Two years later, aged 87, she does have a fall. But this time, the out-of-hours GP has her care plan and her personal preferences; she doesn’t need to go to A&E, she doesn’t need a hospital bed, and rather than ending up in intensive care, she uses the new Community Geriatric Rapid Access Clinic. There are benefits both to the patient and the NHS: in the first pathway Janet’s life is shortened by her multiple falls and repeated visits to hospital, and total pathway cost is £35,000 at 2015-16 prices. The second, pathway costs £19,000 and offers Janet a longer, healthier life.

The argument for the RightCare approach is far from theoretical: early successes are demonstrating its validity at population level. Slough CCG, for example, used national and local data to compare its own results to other CCGs on performance in diabetes care. Combined with local data and “soft intelligence” it was able to pinpoint the specific areas where diabetes care could be improved. As a result of these measures, all 16 GP practices in the Slough CCG are now meeting national targets for delivering the eight care processes, and Slough ranks second best in England. Overall, there has been an increase in the number of people diagnosed with Type 2 diabetes. Individuals who are shown to be at risk of developing diabetes are now being recalled annually for review, meaning care starts earlier and outcomes are likely to be better. The opportunity for such transformative change exists in every CCG in the country.

For more information, visit:
www.england.nhs.uk/rightcare

What is the most appropriate setting for care?

Chair **Jon Bernstein** listened to leading experts in care and commissioning answer one of the most pressing questions in modern health care



“What can we do about unwarranted variation?”

The difference between care pathways is best illustrated when we consider the impact they can have on a person’s life. To illustrate this, **Professor Matthew Cripps** opened the discussion with the story of a fictional patient, Paul: “If Paul is from Leicester and has epilepsy, he’s 50 per cent more likely to have a seizure-free year than he would be if he was from Haringey – and yet Leicester and Haringey are, demographically, very similar. If he was born in Bradford, before they adopted the RightCare approach, he would be more likely to become a person with diabetes than if he was born in Luton, and he would spend his life at a higher risk of mortality as a result. We have to ask: are these variations unwarranted – and if so, what can we do about them?”

Professor Cripps then illustrated an “inconvenient truth” that exists in one significant area of population health care – diabetes. Of 211 Clinical

Commissioning Groups (CCGs) surveyed in 2015, “198 local health economies had at least one significant population health-care improvement opportunity. That’s just in diabetes. Everyone has huge opportunities to improve population health care.”

Returning to the theoretical patient, Professor Cripps illustrated two possible pathways for Paul receiving diabetes care. “In the standard system, at the age of 45, after two years of discomfort, Paul finally goes to the GP, who performs tests and confirms a diagnosis of diabetes. She’s a good GP, but she’s not working in a system that optimises diabetes pathways. So she seeks to manage his condition with diet, exercise and pills. He tries his best to stick to this, but we jump forward five years. He’s given up smoking, he’s still drinking, and his left leg has started to hurt. He’s been on insulin for a year, and he’s regularly going to an outpatient diabetic and vascular support service, which is ten miles away; he can’t drive or walk any more, so his wife is having to take time off work to drive him to the hospital. We look forward another two years, and his condition has deteriorated further: he’s had to have his leg amputated, he now has renal and heart problems and his vision is also deteriorating. He is a classic complex care patient. This is similar to the care journeys that happen to thousands of people every day, in every part of the country.”

Alongside the hugely detrimental effect this has on Paul’s life, this pathway is very expensive: “This costs £49,000, and that’s just the medical care: not the social care, not the welfare costs, not the costs involved in his wife having to take time off work to drive him to hospital.”

Professor Cripps then described “what would have happened if they’d adopted something like the RightCare approach (and optimised the local diabetes system): a health check picks Paul up a year earlier. At the age of 44, his system-supported case management begins. He’s referred to specialist clinics for advice and support that’s refreshed regularly; he’s referred to a better stop-smoking service, so that he quits a year earlier. He has a ▶

► care plan that he's a part of. He's supported in his self-management. Where the first journey cost £49,000, the second journey costs £9,000 – and it keeps him well. Good care,” concluded Professor Cripps, “is cheaper than bad care.”

The solution, said Professor Cripps, is found in four principles: “Get everyone talking about the same stuff; when we talk about it, talk about the fix and the future; while you're talking about the fix, demonstrate its viability, that we are doing the right thing and that it is doable; and once you've done that, you can look at delivery and isolate the true reasons for non-delivery, none of which can be that it isn't the right thing to do, or that it can't be done.

“The phases that proceed from this are: where to look; what to change; and how to change. By using the ‘ingredients’ of clinical leadership, indicative and evidential data, clinical engagement and effective improvement processes, you can decide on your priorities. If a CCG is spending nearly £400,000 more than the 75th percentile of its demographic group on a particular drug, it can find out why it is spending that money, and ask if there's something else it could do with it that adds more value. When the Vale of York CCG used this approach to focus on circulation, neurology, cancer and system management, it was able to produce 136 new clinical guidelines, which resulted in a 17 per cent reduction in referrals in those areas. When Ashford adopted this approach, it reduced referrals to the acute musculoskeletal service by 30 per cent.”

Philip Schwab agreed that “there's still a great deal of diversity, from our standpoint, in how health-care economies view hospital-based treatment or home-based treatment, and how optimal patient experience can be provided.” Alongside the NHS RightCare programme, Schwab said that AbbVie is “looking at the Carter Review, and the directive to move care out of the hospital and into the community, the combination of health and social care”. What AbbVie offers, said Schwab, is “a package of programmes” that involves the patient

in optimising their pathway – “offering more than just the medicine to the health economy.”

Helen Buckingham observed that reporting is crucial to the success of these methodologies: “Often people will come back and say: ‘You can't say that, because the data's wrong.’ We need to say: ‘It's your data. How are you going to help us improve it, to support better decisions?’”

Sarah Henderson agreed that: “It's also what people are measuring. Which data represent the most value to people in these communities?”

Matthew Cripps agreed that a data-driven, evidence-based approach also made the most effective argument for change: “going down to pathway level, fixing simple components – that's the principle of reduction, it's how scientific and medical research discovery has occurred in history.”

Alf Collins observed that “the transformation between the pathways in the case study – sub-optimal and optimal – is a significant change in the relationship between the system and the patient. I saw a system that was reactive, waiting for people to get ill, and then in the optimal case I saw a system that was becoming proactive, that was empowering patients through care planning, through self-care support, through shared decision-making. You're commissioning a different conversation, a different relationship.”

Sal Brinton raised two questions. Firstly, she referred to “a personal example of when I was forced to have a drug, a substance that my consultant didn't want me to have. But the CCG said: ‘she's got to have it, because it's next on the list and if she doesn't have it, we're going to refuse her permission for the next stage along.’ I just wondered if there was a consequence to taking two or three of the priority areas and then not the others that have used the CCG commission, not to work on the others?”

“Secondly, I want to pick up on the other partners; whether it's Public Health England, local authorities, social care – what's the involvement of those partners? Especially local government.” Brinton supported her



concerns with an informal case study of her own: “a friend's aunt, who had diabetes, had social care support at home from the beginning. She developed an abscess on one leg, and the nurse from the GP's surgery would come in to dress it. The woman realised she was getting another problem with the other leg, but her social care was removed. The result was that the nurse was told that she could only dress one leg, because it was only one leg that was NHS covered, and the other leg was social care. The aunt ended up in hospital and cost the state an awful lot more than an extra dressing and an extra five minutes.” While Brinton acknowledged that “everything you've talked about is admirable and brave”, she voiced the concern that “it falls over when the other partners don't have the money, or can't participate.”

Well-meaning public perception, too, can get in the way of addressing



variations in care, said Brinton. “Every time I start talking about the fact that I don’t want specialist services in my local district hospital, I want them at a regional centre of excellence, I get told: ‘You mean you want honest people to get closed down!’ How do we change the way the public think about their medical care?”

Sal Brinton referred to her own experience of the chronic condition of rheumatoid arthritis (RA): “Patients with my illness were spending up to two weeks in hospital, three times a year. Now, they never have stays in

“I’m so happy to have support in the home”

hospital – the treatment pathway has been transformed. I treat myself at home, under supervision – it really has changed the way that hospitals work.”

Such changes can clearly only be made if patients can participate confidently in them, said **David Barker**: “Patients want to know: what do I need to do? Am I qualified to do this? There’s a job, particularly for charities, to look at how we can support and empower patients.”

For Sal Brinton, patient support programmes have made her “an empowered patient, informed about my disease and its management. This involved a learning process: I didn’t know, when I was first diagnosed, that I was automatically entitled to a referral visit to an occupational therapist. For me, that happened fairly quickly, but I know other patients who didn’t get it for two to three years, by which time their muscles, tendons and joints had

all deteriorated much further.” Brinton says taking good patient support means she can be treated at home, not via a hospital visit: “As an empowered patient, I wouldn’t ring the doctor – I would often ring the rheumatology nurse, or I would go straight to my physio with a specific problem, because I now understand the different strengths and areas. If you’ve got support at an early stage in primary care, you learn pretty quickly.”

Olivia Kessel highlighted “the importance of local solutions, and of bringing care back into the community and away from the hospitals. What’s interesting to us is that sometimes there’s an incentive for hospitals to bring patients in. But we see that patients that have care in the home do better, at least from the data that we’ve collected. We’ve had, verbatim, people who have said: ‘I didn’t think that I could have done this in my own home environment, but now I can. And I’m so happy to have that support in the home.’”

Sarah Henderson reiterated that there are two kinds of value at play here: “The system should think not just about finances, but about the wider societal impact as well. The broader health and welfare outcomes, not just specific clinical outcomes but incentives and rewards around the bigger issues of value.” What is needed, Henderson said, is a way “for commissioners to give permission to invest in things that may not have the direct financial benefit to them, but will do for the population”.

Alf Collins summed up the challenges and advantages he has experienced as a local commissioner: “In Somerset, we’ve taken two years, working across the system, dealing with people living with conditions, working with social care, to define those outcomes and to sit them alongside what you’re doing with RightCare. It’s tough stuff,” he admitted, but added that “when people are fully engaged in the conversation about their mode of care and support, they tend to choose less interventive, less expensive options. So if we do shared decision-making, properly, it’s going to cost less.”

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