

CANCER CARE IS NOT BLACK AND WHITE

With the number of people living with cancer as a long term condition increasing, HSJ gathered a group of experts to discuss what this might mean for the NHS. Claire Read reports

Macmillan Cancer Support estimates that there are now 2 million people in the UK living with or beyond cancer, a figure set to double by 2030. This is a statistic that indicates the changing nature of the disease: for many, cancer is a long term condition that requires management over many years. What this shift might mean for the NHS was on the agenda at a recent *HSJ* roundtable, in association with Bristol-Myers Squibb.

In opening the discussion, chair Mike Farrar highlighted the potential impact of the issue. "Traditionally, we have thought of cancer as being about survival and end of life care," said the former chief executive of NHS Confederation, who now works as an independent management consultant. "But

cancer as a long term condition challenges the fundamental mindset of the way in which the health service operates."

Many panel members felt that therein lies an opportunity, not least to learn from good practice in established long term condition care models. "I can see a lot of parity between some cancer and some long term conditions," said Catherine Thompson, head of patient experience for acute services at NHS England. "A patient arriving in hospital with acute exacerbation of chronic obstructive pulmonary disease and being diagnosed at that point has an average life expectancy of a year to 18 months, which is similar to lung cancer.

"From a clinician or service management point of view,

actually those two patients have very different experiences, very different access to services, very different approaches from clinicians but actually they need fairly similar things and need to be supported in fairly similar ways."

Louise Smith, cancer nurse specialist and lead for the survivorship project at Ipswich Hospital Trust, added: "I think there are lots of opportunities to learn from the other long term conditions, and benefits for patients in terms of the education and systems that are in place in those areas of care, which cancer hasn't ever adopted before."

That is not to say, however, that the classification of cancer as a chronic condition is necessarily a straightforward one. "I agree with the long term

- Anthony Blower** medical director, The Christie Foundation Trust
- Chris Carrigan** director, National Cancer Intelligence Network
- Michael Connors** director of services, Penny Brohn Cancer Care
- Shelley Dolan** chief nurse, The Royal Marsden Foundation Trust and clinical director, London Cancer Alliance
- Mike Farrar** independent management consultant and former chief executive, NHS Confederation (chair)
- Emma Greenwood** head of policy development, Cancer Research UK
- Professor Jane Maher** joint chief medical officer, Macmillan Cancer Support
- Teresa Moss** director, Transforming Cancer Services Team, London
- Helen Porter** director of nursing and quality, Clatterbridge Cancer Centre Foundation Trust
- John Rogers** chief executive, Skills for Health
- Louise Smith** cancer nurse specialist and lead for survivorship project, Ipswich Hospital Trust
- Catherine Thompson** head of patient experience for acute services, NHS England
- Martin Whitehead** national policy and access manager (oncology), Bristol-Myers Squibb
- Maggie Wilcox** president and trustee, Independent Cancer Patients' Voice

condition label bringing in a new mindset," said Michael Connors, director of services for charity Penny Brohn Cancer Care. "But I also know that cancer is very unique – even those cancers that require long term condition management – because of the nature of cancer and the nature of the impact of



The panel, left to right: Michael Connors, Jane Maher, Emma Greenwood, Shelley Dolan, Anthony Blower; (second row) Maggie Wilcox, Chris Carrigan, Helen Porter



cancer. So I'm a bit wary of it all being put into the long term condition pot."

"One of the difficulties is that we like to think of things in black and white, so cancer as either an acute condition or a chronic condition," suggested Jane Maher, joint chief medical officer of Macmillan Cancer Support.

"The reality is that some cancers are an acute condition. You have a whole range of cancers where you have an episode of care, and in 80 per cent of cases you will never have that cancer coming back. And then you'll have a whole bunch of cancers like upper gastrointestinal or lung where most people die within a year. And then there's a middle group where people may live more than a year and less than maybe five, six or seven years, where you do have a chronic relapse/remit condition – so for example, around 20 per cent of breast cancer [patients] will develop metastatic bone disease which may follow that pattern.

"I think there is a tendency for us to want it to be very simple: it's either an acute condition or it's a long term condition," she continued. "But by simply looking at the incidence, mortality and prevalence figures, we can actually divide it up into a more orderly fashion. And each of those three groups will require different interventions."

How many are in each of those groups is likely to fluctuate, argued Martin Whitehead, national policy and access manager (oncology) at Bristol-Myers Squibb. "There's a whole new genre of treatments coming down the line under the

'Cancer as a long term condition challenges the mindset of the way in which the health service operates'

umbrella of immuno-oncology. And what these products offer for a percentage of patients is the potential for long term survival," he said. "So more and more patients who are currently sitting in the end of life segment are likely to move up into the segment of long term conditions. We're going to find that many more patients are going to shift into the long term conditions category."

It was a theme on which Shelley Dolan built, though with a caveat. "I work in a place where we do lots of phase one clinical trials and I think immunotherapy is incredibly exciting," said the chief nurse of The Royal Marsden Foundation Trust, who also serves as clinical director of the London Cancer Alliance. "I'm seeing patients live for three [to] five years who previously would have lived a few months and that's

wonderful. But it's still not quite the same as a long term condition like diabetes, because the patients going into that phase one clinical trial knew they'd failed on everything else and there really was no other possibility. So at this moment in time, I think we are on the cusp of something incredibly exciting that might in many cancers really change the landscape, but we're not quite there yet. But there are lots of things we should be doing now to prepare for a time when it might be the reality. We have to do our planning now because otherwise we won't be ready for it."

That led to an inevitable question: what should that planning encompass? Many pointed to the need for deep consideration of workforce issues, and of the increasing need to support out of hospital care. John Rogers, chief executive of Skills for Health, was among them.

"I just can't imagine what treatments will be like in 20 years' time, but the time we take to change our workforce and change our services is over that kind of period," he pointed out. "And we talk about the NHS a lot, but probably don't particularly incorporate how hospices are engaging with this, how charities are engaging with

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this, how caregivers are – that wider side."

All agreed this collaborative approach would be important, especially given the common desire to shift care closer to home. "I think cancer services have traditionally been seen as the domain of acute services," argued Teresa Moss, director of the Transforming Cancer Services Team in London.

"Cancer patients can get dependent on their acute specialists and their hospital care and treatment. But if you talk to GPs who are confident about working with patients with cancer, they will say that you can actually structure support for cancer patients in the same way as optimal long term condition management."

She went on to cite data that suggests that this sort of support is sorely lacking at present. "We



The panel, clockwise from top left: Louise Smith, Catherine Thompson, Teresa Moss, Mike Farrar, John Rogers, Martin Whitehead





know from the National Cancer Patient Experience Survey that most patients report a really good experience of their care and treatment in hospital; in fact, 89 per cent rated their overall experience as excellent or very good. But there are very different levels of satisfaction when you ask them about whether they got enough support, care and help from health and social services post-discharge. So 41 per cent said they didn't get enough support post-discharge, and 34 per cent said their GPs and nurses could have done more."

What might that "more" be? What has to change if cancer is truly to be managed on a long term basis? "For me what looks good is [when] we begin to really understand the holistic needs of cancer patients," explained Mr Connors. "We begin to understand the impact of cancer as a life threatening illness. We acknowledge that, and start to create services that begin to address that. Currently, in the voluntary sector we are trying our best to meet some of those needs, but we are tiny compared with the whole need."

He also spoke of the importance of self-management; of ensuring that, from the outset

of treatment, patients are familiar with steps they can take to improve health and wellbeing.

Panellists agreed with the need to empower those with cancer, but many emphasised that there could not be a "one size fits all" approach.

"Make people feel responsible, but they still need that partnership in care," suggested Maggie Wilcox, president and trustee of Independent Cancer Patients' Voice. "And you've also got to cater for the patients who wouldn't take responsibility in any way."

Helen Porter, director of nursing and quality for Clatterbridge Cancer Centre Foundation Trust, said: "I think the concept of responsibility is interesting, and trying to understand what that means in practice.

"I think as a healthcare

'We must be clear about what the outcomes for cancer as a long term condition should be'

system we've gone on a journey from being very paternalistic to the working in partnership area we're in at the moment. Are we confident we're actually ready to move to responsibility? I'm not saying people shouldn't be responsible, but there's a difference between 'I have got the choice to be responsible' and 'this is my responsibility?'"

"We talk about supported self-management, but it isn't just the self-management that we have to support, it's the autonomy," argued Ms Thompson. "While the workforce and the system might be starting to get its head around the idea of supporting self-management, I don't know that it's acknowledged as a concept of supporting autonomy yet. And that's the autonomy to say 'I want to do this for myself', and the autonomy to say 'I don't or I can't'."

Professor Maher was keen to stress that the shift to self-management will take time. "We have to acknowledge how long a change in perspective about illness takes," she suggested.

"I think I introduced self-management for breast cancer in 1990, and it's taken years for it to become accepted practice.

"So it's thinking about how you keep the momentum going

but play the long game. I would say that it's the acknowledging, describing, coding and reporting of things that actually matter to patients that is really important," she continued. "And the things that are going to matter are independence, cognition, continence; those sort of things that we don't measure but are often going to be the key impact as to whether having an anti-cancer treatment in a long term situation, where you're not going to be cured, makes a difference."

Ms Greenwood agreed. "I think we need to be clear about what we want the outcomes to be for cancer as a long term condition," she contended. "But not about survival, about what the patient means by 'my outcome' and what it means to survive and live through treatment and long term condition management in cancer."

The National Cancer Intelligence Network has been coordinating efforts to get that sort of data. "My basic philosophy is that unless you measure, you'll never be able to demonstrate improvement," Chris Carrigan, the network's director explained. "Talking to people going through services and asking how they feel about

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it is a measurement.”

The network is now combining patient experience data with “hard” information from activity and registration databases – something that places the UK ahead of the rest of the world, Mr Carrigan explained. But there remains one area where he knows greater progress is needed.

“The big gap we have in our data, and therefore in our ability to generate information and intelligence, is primary care,” he said. “We haven’t got strong enough links between secondary care data and primary care data – it’s as simple as that.”

It was a point that brought the debate back to the need to develop tighter connections between hospitals and general practice. Ms Moss explained that this had been an important part of thinking about cancer in the capital.

“In London, we have a pan-London cancer commissioning board and we did some work around thinking of cancer as a long term condition,” she explained. “The board agreed that cancer was a long term condition, and felt it important to name it as such for the focus of our work, and we’ve got a group that’s looking at primary

care education and training.”

Education was a common theme when Mr Farrar asked what one practical change would most support the new understanding of cancer as a long term condition. “It’s education of all healthcare professionals, including in primary care and then patient education as well, which is a much bigger challenge,” argued Anthony Blower, medical director at The Christie Foundation Trust. “Listening to this debate as a consultant has made me think: how do we handle these patients when they come to a clinic? How much do we treat the cancer rather than the patient? How much time is spent discussing holistic needs? And the answer is probably a tiny percentage. So I think there are huge educational opportunities here that we may be able to influence.”

Summing up the debate, Mr Farrar argued that it had served to challenge the notion that cancer and long term condition management is an oxymoron. “But it does require a mindset shift; it’s about fundamentally thinking quite differently. And I think bringing together the perspectives we’ve had today is part of the solution.” ●

MARTIN WHITEHEAD ON GIVING HOPE TO CANCER PATIENTS

In recent years we have seen scientific breakthroughs deliver huge progress in cancer treatment and patient outcomes. Now, for the first time, more than half of all cancer patients can expect to live for 20 years, with cancer becoming a long term condition for many of the 2 million people now living with the disease.

One of the most exciting fronts in the battle against cancer is immuno-oncology. This approach uses the natural capability of a patient’s own immune system to fight cancer, rather than directly targeting the tumour itself.

Importantly, because the immune response being targeted is common to all cancers and is not tumour dependent, immuno-oncology therapies are potentially effective against many types of cancer. Early signs are hugely positive and suggest that immuno-oncology treatments have the potential to significantly boost patient survival from cancer.

Last year, immuno-oncology was selected as the Scientific Breakthrough of the Year award by the journal *Science*.

If NHS patients are to experience the benefit of these advances, the NHS will need to examine the way in which services are delivered.

For instance, this may mean changes to how patients are supported to manage their condition and consideration of whether current pathways are adequate for this step-change in treatment. Similarly, there are implications for regulators to consider, particularly regarding value assessments and the way that survival benefits are captured.

Bristol-Myers Squibb is committed to helping the NHS to address these challenges and improve cancer services. Innovation in cancer, such as the emergence of new immuno-oncology treatments, provides fresh hope for patients.

We are pleased to support this important roundtable and hope that it prompts further consideration of how this hope can be translated into improved outcomes for cancer patients.

Martin Whitehead is national policy and access manager (oncology) at Bristol-Myers Squibb.
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