
Frequently asked questions

About the programme

1. What exactly are you trying to do?

Macmillan, the NHS and local councils are working together to transform cancer and end of life care in Staffordshire because patients are telling us that it is not as good as it should be, that services do not always meet their needs, that it is inconsistent and that they get lost in the system. We want to change this.

2. Why are you doing this?

People with cancer and people who have experienced end of life care tell us that things are not as good as they should be or services do not meet their needs at times within their cancer journey. There are a range of problems, for example, people not knowing who to turn to in a crisis leading to inappropriate and unnecessary admissions into hospital, or people having to explain their situation many different times to different health or social care professionals. We have heard from patients and carers who have been lost in the system, or who have struggled to get the support when and where they need it.

We also know that access to care at the right time is a problem, for example, people are not able to die at home if they wish to do so because of the lack of support available. We want to develop the support needed to make sure that people have real choice as to where they are cared for.

3. What is causing this?

At the moment there are several organisations responsible for managing the provision of different areas of cancer and end of life care through multiple contracts and this is leading to disjointed and inequitable care and support. Making significant changes across the whole of cancer and end of life care, to provide seamless and joined up care, is almost impossible because of the barriers and boundaries within the current system. We want to change this.

4. What is your solution?

The intention is to appoint one organisation to be responsible for managing the provision of the whole cancer journey, right from prevention and health promotion, self-referral, diagnosis and through to treatment and beyond, and one organisation to be responsible for managing the provision of all end of life care in Staffordshire. The current providers of care will remain the same, but will be responsible to the prime providers, rather than directly to CCGs and NHS England. The prime providers will be accountable to the CCGs and NHS England for ensuring that the whole pathway works effectively, providing seamless care for people with cancer and at the end of their lives.

5. What are you hoping to achieve with this programme?
We want to provide the people of Staffordshire with world-class cancer and end of life care appropriate to their local needs. We want to make sure that they receive the best possible support wherever and whenever they need it, and that no-one feels as though they have been lost in the system. We want to make sure that people are able to receive treatment where they want, and ultimately, that if it comes to it, they are able to die in a place of their choosing. This is about providing a seamless service from diagnosis and throughout the treatment process and beyond, putting the patient at the centre of their care.
6. Why do you think that the 'prime provider' model is the best one
We think that, given the complexity of the current arrangements, making one organisation, or consortium, responsible for managing the whole of the cancer and end-of-life pathways is the best way of removing the current barriers to providing seamless and integrated care. It is also the best way of being able to monitor and hold services to account for the way that they are delivering care.
7. Who is part of this partnership?
Macmillan Cancer Support has funded four Clinical Commissioning Groups (CCGs) in Staffordshire and Stoke-on-Trent to work on this programme. They are Stafford and Surrounds CCG, Cannock Chase CCG, Stoke-on-Trent CCG and North Staffordshire CCG. We will also be working closely with NHS England for Specialised Commissioning, Public Health England, and Staffordshire and Stoke-on-Trent local authorities.
8. Why is Macmillan Cancer Support included in this partnership?
Macmillan has more than 100 years' experience centred on cancer care and is a respected and independent authority on all aspects of cancer in the UK. Yes, in the past we have been recognised for the iconic Macmillan nurse, and have also been associated with end of life and palliative care, but over the last few decades we have been steadily expanding our field of influence to include all aspects of service development, design and delivery, across the whole cancer and end of life pathways.

Macmillan's fear is that if the NHS is not able to learn how to make the changes that are urgently needed in order to make significant improvements to the experience of patients, carers and family members, others will be brought in to do so, and that may include the provision of services, not just their management. So we have chosen to support this programme to provide the expertise and support to enable this level of change to happen. Our primary goal is to improve the lives of people affected by cancer and if we do not support this transformational change, it will not happen as it is not feasible to expect the NHS to take resources away from frontline services to support such an intensive programme of work. Without it, demand will rise and the disjointed and inequitable nature of the current system will only get worse.

Our innovative approach and history of successful partnerships with the public and private sector allows us to understand what is needed to create world-class cancer care, and our independence allows us to bring the patient perspective to the fore and frees us from working within some of the constraints we are all aware of in the NHS

and elsewhere. Macmillan provides expertise in all things that affect people affected by cancer, for example, the latest clinical developments, support and information, volunteering, healthcare environments, well-being, workforce strategy and carer support; we believe that no one should face cancer alone.

Macmillan will not be contracting the prime providers, that will be the CCGs and NHS England, we are there as facilitators and advisers. Nor does Macmillan want to bid to be the prime provider.

9. Why Staffordshire?

In Stoke-on-Trent the number of people with cancer and deaths rates are higher than average. South Staffordshire also has higher than average rates for both cases of breast cancer deaths from breast cancer. Macmillan has invested over £4 million in cancer services in Staffordshire and Stoke-on-Trent in the last five years and has strong relationships with health professionals and people affected by cancer in the county. All partners collectively want to develop patient-centred care, and we all have an aspiration to provide world-class cancer treatment and care locally.

10. What happens if we do nothing?

We know that the number of people living with cancer is going to double over the next 20 years, and services are already stretched within current resources. If we do nothing, then it is likely that there will be significant unmet demand for services, there will be a real danger of inequity of services and it will be very difficult to maintain or ensure an adequate quality of service.

11. How long is it going to take?

The intention is that the CCGs will have appointed the prime providers in time for them to start delivering services under their contracts in July 2015. Improving services to the best they can be will take time, but we expect to see real improvements within two years. To achieve the best they can be could take ten years.

12. Have you talked to patients and carers to see what they want?

Yes, patients have been and will continue to be at the centre of decision making. We have held workshops and focus groups and have also undertaken research into what is happening now and what people say that they want to happen in the future. These discussions are informing the specifications for the future service provision that the prime providers will have to follow.

We have recruited three board members, without any previous formal links to the NHS or Macmillan, to the programme who will have a presence on all of the decision-making groups. We have also set up a network of champions across Staffordshire to ensure we have sufficient input from patients, carers and families throughout the programme.

13. Have you talked to doctors/clinicians to see what they want?

Yes, we have held workshops and discussions with doctors and other health and social care professionals and we are also working with clinicians to write the

specifications for future services. This is because we want to gain an insight into what the system is like now and to see what they think can be done to improve how services are delivered in the future.

14. How can I get involved?

If you are a patient or carer and would like to get involved then please contact Rachel Bentley on 01785 221041 or Rachel.bentley@northstuffs.nhs.uk

15. Where can I keep up to date with progress on this programme?

We will be putting regular updates on our website, which is www.staffordshirecanceranddeol.com.