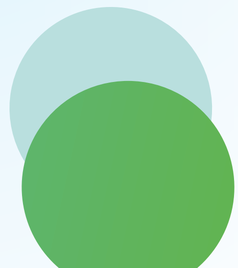
NHS
Wessex
Cancer Alliance

What people think of a possible new cancer frailty service

A feedback report



Background

Wessex Cancer Alliance (WCA) is looking to improve cancer services and outcomes for people who are frail or at risk of frailty in Dorset, Hampshire and Isle of Wight.

We know in some other areas, hospitals have a team of people who older people with cancer and frailty are referred to for a specific assessment of their needs. The aim of this is to help people make decisions about cancer care and treatment that are right for them, and to support people through treatment.

To find out what people feel about the development of such a service locally, WCA asked people what they thought of this idea and what would be important in the design of such a service. We focussed on hearing from older people as they are representative of the over 65-year-old population that would meet the criteria to use this service. More details of what we are doing to address the findings can be found in the 'Next Steps' section at the end of this report.

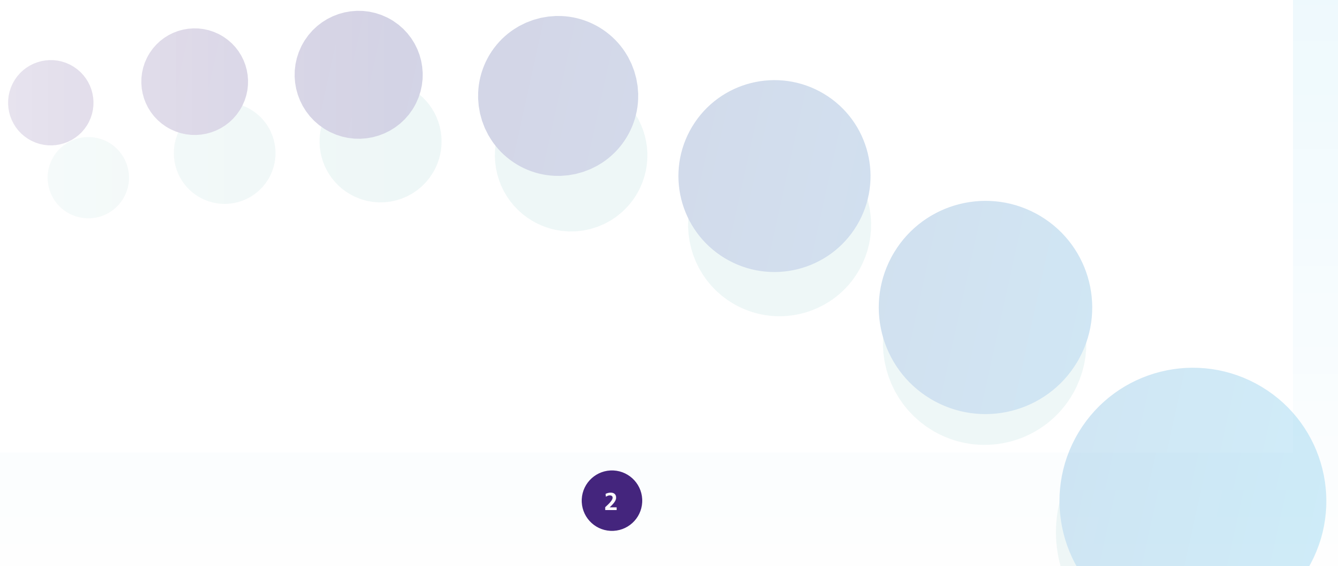
Who we heard from

WCA colleagues asked three different groups of older people if they would make use of such a service if they had a suspected cancer or a cancer diagnosis, and whether:

- They thought it would be useful
- What would be important to them in a service like this
- What would make it easier for them to use it, including where best to do the assessment.

We heard from just over 30 older, predominantly White British people. Most were women.

The focus groups were organised through the Christchurch Community Partnership; Southampton Football Club's Saints Foundation and Age Concern, Basingstoke.



What they told us

1. Would it be useful?

People generally felt that a service like this would be useful, especially if they were frail and/ or unwell as they would be less likely to be able to articulate their needs. It could help with decision-making but the service may vary depending on the type of cancer and prognosis.

They said the service should be driven by need rather than age. The feeling was that some people younger than 65 would need help and others at 65 or older will not. One group who had complex health needs explained that they did not consider themselves frail, and others said people should be described as *'older'* rather than old. Concerns were expressed that older people may be ignored or under-treated due to age and this needs to be addressed. However there should be honest discussions about the expected outcomes, such as whether the treatment will make a significant difference to length of life or give just a few extra months.

Examples were given about the value of having support at the point of diagnosis and through treatment. Some people spoke highly of positive experiences, via their GP practice, and the difference it made to them at a difficult time. People also spoke highly of District and GP Nursing teams. Conversely, another had to *'beg and plead'* for help for a disabled husband whilst she went into hospital. In the latter case there was no support from social care, and she had to pay for private care. Some people were grateful for temporary family support but once family had returned home, they found it very difficult, and felt services didn't really consider this sufficiently.

The assessment itself would be useful but more importantly the follow up on identified issues needs to be put in place. People spoke of having various and multiple assessments and then not receiving any follow up action, and that there is a lack of consistency and equity in services across different areas. The voluntary sector was seen as key in the delivery of support services.

Communication and coordination of care (across primary, secondary and community services) and sustained support were seen as essential. People voiced frustration with lack of communication between different specialists, no one holding a full picture of the patient's health. *'One hand doesn't know what the other is doing'*, one participant said.

People said that there is often a lack of support on leaving hospital. People felt it would be important to be *'checked up on'* at home and given reassurance they are doing what they need to in the correct way. They should be given clear explanations about what will happen in the immediate and longer term.

2. What would be important to you?

The assessment would need to be respectful and personalised, as would the support.

In many cases people felt it would be important to have family and/or advocates with them during the assessment, to be and extra *'pair of ears'*, take notes or ask questions. It was identified that people who live on their own may need more support.

The conversation and support needs to be empathetic and holistic covering: all other conditions (specifically Dementia) and medications; emotional support for patients and care-givers; practicalities, such as cleaning, laundry, home adaptations, getting and attending appointments; benefits and finances; (patient) transport and parking; social or other activities the person enjoys; power of attorney; end of life planning, wills, funeral and what do following a death. People should be told about the support that is available to them as *'you don't know what you don't know'*.

Treatment options should be discussed early, ideally at the beginning when referred for treatment, to allow patients to consider their options before investigations and treatments. There should be clarity about how people might feel after treatment and what the process will be like so patients can discuss what they will be able to tolerate.

A question was raised about whether there would always be time to do an assessment and put support in place if there was a tight turn around between diagnosis and a need to start treatment.

3. What would make it easier to use, including where best to do the assessment?

The service needs to be accessible, and it cannot be assumed that people will be digitally literate. There will need to be hard copy letters and written records of discussions, as well as help completing forms. Those who want to use technology but need help could be shown how to use it. Likewise contact with the clinical team would need to consider different access preferences. People should be given information to take away with staff highlighting key considerations for the patient.

For frail patients, their appointments should be coordinated or combined. They would like to be assessed by the Oncologist and Geriatrician at the same time. Thought should be given to the (one) location and timing of appointments according to individual needs. Everyone should not be given the same appointment arrival time when they will not be seen till later in the day; and should not be made to wait for medication before discharge.

Conclusion

People thought the assessment and management of frailty for someone who was diagnosed with cancer would be useful. They would like it to be personalised and holistic, and the discussions with patients and care-givers should be dealt with sensitively, preferably at home. A key message was that support needs to be put in place for people once the assessment identifies their needs. People would also really appreciate much more joined up and coordinated care.

Next steps

We appreciate the time and insights shared by everyone who met with us.

Wessex Cancer Alliance is piloting integrated neighbourhood team–based management of frailty and cancer in two areas. These pilots will enable proactive, closer-to-home care that draws on the wider workforce's expertise in frailty and rehabilitation, directly reflecting the themes identified in this report. Led by primary care and community teams, the model will support comprehensive assessments in people's homes or nearby clinics and, crucially, provide holistic support for patients and their families.

We are establishing new models of care, which include multi-agency groups—spanning primary, secondary and community care, and the voluntary/charity sector—to deliver seamless, coordinated care. We look forward to sharing the results.

For further information, please contact: Mary Edwards, Wessex Cancer Alliance on mary.edwards@wca.uhs.nhs.uk.

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Appendix A

Example of invitation used to recruit participants for our feedback sessions.

Patient and Care-giver invitation to get involved

Help shape a new service that will support people over 65 with cancer who are vulnerable to frailty

Wessex Cancer Alliance is looking at ways to support people over 65 who have suspected or diagnosed cancer who have or are vulnerable to frailty in Dorset, Hampshire and Isle of Wight.

We are thinking about developing a new service that can help people in this situation and would like to hear from you or your care-giver. You can take part in different ways that suit you so do get in touch on wessexcanceralliance@wca.uhs.nhs.uk or by calling, texting or WhatsApp 07961 062883.

More information about the project:

What is frailty?

Taken from the *'People's Definition of Frailty'*, it describes your state of health or that of someone you care for. Being described as *'frail'*, having 'frailty' or 'living with frailty' may occur when your body loses its natural reserves. This may be due to a range of factors such as illness, disability or aspects of the ageing process. This means frailty is:

- **Sometimes complicated**: it is not inevitable or a disease, or a list of specific conditions or symptoms
- **Individual**: it is different for everyone
- **Varied**: a range of things that may interact and impact on each other in ways they didn't use to
- **Changeable**: it can improve or get worse

Whatever the reasons, you may find:

- You need a bit more help to do the things you usually did
- You take a bit longer to *'bounce back'* from something simple, like a common cold and one health problem may lead to another
- You tire more easily or feel less strong than you used to
- You may feel more apprehensive and less confident

What we would like to explore with you?

We know that in some other parts of the country, hospitals have a team of people who older people with cancer and frailty are referred to have an specific assessment of their needs. Their aim is to help people make decisions about cancer care and treatment that are right for them and to support people through cancer treatment.

During this assessment they:

- review overall health, including other health conditions you may have as well as cancer
- look at the medicines you are taking at the moment
- look at your mobility and physical strength
- support you management of daily activities
- support independence and autonomy
- looking at the risk of falling, and how risk might be lowered
- look at any memory issues and how to support with this
- assessing nutritional status and diet, considering any symptoms that may affect this, and working to develop a nutritional plan that suits you
- support your caregivers and liaise with your GP

We would like to hear from you if you and your care-givers if you think you would make use of such a service locally if you had a suspected cancer or a cancer diagnosis.

We would like to know:

- if you think this would be a useful service
- what would be important to you if you needed a service like this
- what would make it easier for you to make best use of it, including where best to do the assessment.

If you are interested in getting involved get in touch on: wessexcanceralliance@wca.uhs.nhs.uk or by calling, texting or WhatsApp 07961 062883.