



Scoping prehabilitation and rehabilitation services for people with cancer across Wessex Cancer Alliance

An Executive Summary



This report presents the findings from the scoping of services across the NHS, third sector and other voluntary organisations providing prehabilitation and rehabilitation across Wessex.

Definitions

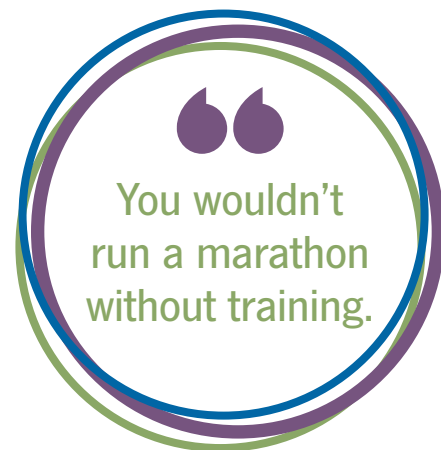
For clarity the definitions of prehabilitation and rehabilitation are set out below.

Prehabilitation:

- prepares people for cancer treatment by optimising their physical and mental health through needs based prescribing of exercise, nutrition, and psychological interventions.
- ‘a continuum to rehabilitation’

Rehabilitation:

- enables patients to make the most of their lives by maximising the outcomes of their treatment and minimising the consequences of treatment and symptoms such as fatigue, breathlessness, lymphoedema and others symptoms
- helps patients get well and stay well and addresses the practical problems caused by the disease and treatment
- helps patients become as independent as possible and minimise the impact on carers and support services.



Quotes/Case studies



Most people's first point of contact with health services is through the GP – GP has a huge role to play in this – awareness – signposting – it's the hub for information for most people getting health information.



It's easy with limited resources to plough those into a "easier" cancer but we must make sure that all cancers have a part to play in this and all individuals are given an opportunity – and that's why I question whether if you haven't got somebody overseeing it, in a role – however good individuals are in "head and neck" or whatever, there will still be gaps because there isn't somebody saying "what about haematology, what about dermatological, what about gynae and so on.



Mind, body and soul – the physical and mental – seeing counsellor/psychologist was very important – so that mentally you are strong enough to cope and you have some tools to help you cope.



Key messages

1. Prehabilitation and rehabilitation support for patients is integral to personalised care and support for people with cancer.
2. There is considerable current and rapidly emerging national and international evidence demonstrating the positive benefits of prehabilitation and rehabilitation to people with cancer, service provider organisations and commissioners.
3. This scoping work has highlighted the different levels of understanding of what prehabilitation and rehabilitation means to people with cancer, carers, professionals and commissioners.
4. There were just over 19,987 new cancer diagnosis covering all tumour types across Wessex in 2021/22. All of these people should have been offered and have equitable access at the very least to universal support.
5. Prehabilitation and rehabilitation service provision is mixed and not equitable across Wessex.
 - a. Universal interventions are appropriate for anyone with cancer. People with a cancer diagnosis should receive dietary, exercise and psychological advice and behaviour change support. Most universal support such as the provision of health and wellbeing support and advice to empower and enable self-management is delivered to some degree by the NHS as well as by the third sector and voluntary organisations and through website resources.
 - b. Targeted interventions which are for people with cancer with and at risk of late effects of disease or treatment and those with other long term conditions and specialist interventions for those with complex needs and receiving complex treatments are generally delivered by the NHS organisations in Wessex. These services are focused on acute Trusts, there is not universal coverage, planning is ad hoc, services are in the main, not specifically commissioned and services are set up for those with some tumour types and not others.



6. The importance of the provision of the continuum of services to provide prehabilitation through to rehabilitation is demonstrated in only a few (7) services.
7. The only reported rehabilitation service commissioned through specialised commissioning is for children, teenagers and young adults (CTYA) with cancer at University Hospitals Southampton. This service is funded in part by specialised commissioning and in part by charitable funds. No other prehabilitation or rehabilitation services for people with cancer were identified as commissioned. This is likely to have an effect on equity of service provision for people and poses a potential subsequent burden on health and social care.
8. Future plans for the development of services providing prehabilitation and/or rehabilitation to people with cancer requires greater involvement of primary care in the design and delivery of prehabilitation and rehabilitation, patient involvement throughout, clarity of funding for prehabilitation and rehabilitation, greater use of the generalist workforce as specialist roles are limited, Clearer pathways for all tumour sites for rehabilitation highlighting where there are significant gaps in services from acute across to community and greater multi-professional rehabilitation provision for cancer patients prior to palliative care in the community / primary care as this is currently very limited.



Approach to the scoping

The aims of the scoping work were to:

- Gain a greater understanding of services, including NHS, independent sector, third sector, in Wessex that provide prehabilitation and/or rehabilitation to people with cancer
- Identify gaps in service provision
- Make recommendations for improvements to the access and provision of prehabilitation and rehabilitation to children, teenagers and young adults (CTYA) and adults with cancer.

A five part methodological approach was undertaken to gather data.

- a) An online survey aimed at service providers, with 30 responses received was developed. The survey included the following components:
- Description of the service, where it is located, and geographical area covered by and reach of the service.
 - How and at what stage patients access the service including at diagnosis, during treatment, after treatment and palliative care, service waiting times where applicable, how do patients access the service e.g., self-referral, health care professional referral, signposted via social prescribing link workers etc...and which patients access the service i.e., those with specific tumour types
 - How the service is delivered e.g., face to face, virtual or a combination, groups, classes
 - Interventions provided within the service (universal, targeted, specialist), number of patients seen and number with cancer diagnosis seen
 - Workforce involved in the delivery of the service
 - Commissioning, service specification and funding of the service
 - Outcome measures collected including clinical and cost effectiveness, patient experience and patient safety
 - Service evaluation and quality assurance

- b)** Semi structured interviews were held with six commissioners from across Wessex
- c)** A review of prehabilitation and in particular services providing rehabilitation to different population groups was reviewed across NHS organisations, information and support centres and hospices that did not respond to the survey
- d)** A total of two focus groups were undertaken with six adults attending one of two focus groups. Discussions with two parents were held along with a review of feedback that related to prehabilitation and rehabilitation from the Our Cancer Our Way work
- e)** Rapid review of the literature



Main findings

- Six services provide prehabilitation for adults and one offered prehabilitation to CTYA. Ten services provide rehabilitation to adults and five services provide rehabilitation to CTYA.
- For services providing prehabilitation, 64% of people are referred by healthcare professionals with 36% self-referring and those services providing rehabilitation, 65% of referrals are from healthcare professionals and 31% are self-referrals.
- The majority of services are delivered in the hospital setting or outpatient clinics, with some in patients homes, a few in hospices and some in the leisure sector. There were none reported being delivered in GP practices.
- For those services providing prehabilitation patients were predominantly seen from diagnosis, before, during and after treatment.
- For those services providing rehabilitation were before and after treatment, palliative care and during end of life care.
- There were no particular tumour types seen more than another for services providing prehabilitation. Those with head and neck cancer, breast cancer, Brain and Central Nervous tumours and those with lung cancer were reported as being seen the most in rehabilitation services.
- Staff who reported delivering prehabilitation include dietitians, clinical nurse specialists and physiotherapists. Physiotherapists and occupational therapists followed by support workers are the predominant staff groups delivering rehabilitation.
- Duration of prehabilitation interventions varying widely depending on the service and patient need. These range from one session up to 18 sessions and 18 weeks of support in some cases. The duration of rehabilitation interventions varies very widely across services and is highly dependent on patients' goals, need and choice.
- All services identified a range of quality of life and functional measures used. Health economic measures was captured for some services offering prehabilitation and rehabilitation. Disutility of care/degree of health measures such as days alive and out of hospital at 30, 60 and 90 days were not collected by any services from the responses received.
- Three and seven services respectively offering prehabilitation and/or rehabilitation identified permanent funding. One service providing prehabilitation and one providing rehabilitation had temporary funding and three services offering prehabilitation and seven services offering rehabilitation did not know about funding or identified no funding for services
- There were no specifically commissioned prehabilitation and/or rehabilitation for people with cancer identified. The exception to this was specialised commissioning commissioning rehabilitation for paediatric patients at University Hospitals Southampton NHS Foundation Trust. This service is funded in part by specialised commissioning and in part by charitable funds.

Recommendations

There are nine recommendations with each one indicating the organisation(s) to which they are intended.

Recommendation 1 – WCA, Healthcare service providers

For CTYA and adults collate a) the range of universal support offers across Wessex b) the wider range of universal support resources available that are free to access in one area on both the Wessex Cancer Alliance and Cancer Matters Wessex websites for sharing widely with patients and healthcare professionals.

Recommendation 2 – WCA, Primary Care Networks

Identify how some roles within the ARRS scheme, such as health and wellbeing coaches, social prescribers, care coordinators, could support adults with cancer with universal support, including the development of easy to use resources e.g., including a video about universal support including soundbites on nutrition, exercise and emotional support

Recommendation 3 – WCA, Healthcare service providers

Identify and understand the barriers and opportunities as to how generic/non specialist rehabilitation services across Wessex could support CTYA and adults with cancer who may not currently do so.

Recommendation 4 – WCA, Healthcare service providers, ICSs

Produce a quick guide for service providers which will include a set of principles to:

- a) Increase the profile and promote the benefits of prehabilitation and rehabilitation for CTYA and adults with cancer as part of work to support people with other long term conditions within the Integrated Care Boards
- b) Support the design, development and delivery of cancer prehabilitation and rehabilitation.

Recommendation 5 – WCA, Healthcare service providers, ICSs

Develop a local quality dashboard that enables service providers to collect relevant quantitative and qualitative data about prehabilitation and rehabilitation in CTYA and adults and enable benchmarking between services.

Recommendation 6 – WCA in collaboration with healthcare service providers and commissioners

To support and measure adherence to the principles (recommendation 4) and quality measures in the dashboard (recommendation 5) develop:

- a)** A self-assessment service improvement audit tool for services providing care to CTYA and adults based on both the principles of prehabilitation and rehabilitation and the themes from the patient engagement work (involving patients, accessibility and timeliness of services, care coordination and communication, adequately trained staff, demonstration of exemplary patient experience and management and leadership of the service)
- b)** A self-assessment patient experience audit tool

Recommendation 7 – WCA, ICSs

Produce a role profile for a cancer prehabilitation and rehabilitation clinical leader which can then inform and guide the development of this crucial clinical leadership role

- a)** In each local delivery system, at a minimum of 0.4 whole time equivalent/2 days per week, supported by a stakeholder group in Wessex to support adults with cancer.
- b)** 0.6 whole time equivalent/3 days a week role with a focus on CTYA for Wessex as a whole.

Recommendation 8 – WCA, Healthcare service providers, ICSs

Promote prehabilitation and rehabilitation and support the multidisciplinary training of health and care staff working with CTYA and adults to ensure prehabilitation and rehabilitation are meaningfully and personalised in their approaches. This includes ensuring that education and training offers focus on personalised goal setting/outcomes to support return to/sustaining usual activities and on what matters to people in their support and recovery.

Recommendation 9 – WCA, Healthcare service providers, ICSs

It will be important for the Wessex Cancer Alliance and the healthcare system across Wessex to remain contemporary and up to date with these initiatives through identified programme leads having responsibility and awareness for new innovations and technologies in this area of practice.

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