Scoping Prehabilitation and Rehabilitation services for people with cancer across the Wessex Cancer Alliance

End of scoping report

The project was funded and commissioned by the Wessex Cancer Alliance.

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"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".

"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".

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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'

'You wouldn't run a marathon without training.'

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.

Phases of work

This work is phase one of a two phase approach to the work.

Phase one which this report is focussed on has involved scoping services providing prehabilitation and rehabilitation available within primary, secondary and community care across Wessex, identify gaps and setting out nine recommendations.

Phase two to commence in early 2023 will involve the implementation of the nine recommendations in collaboration with system organisations.

In this Executive Summary we provide a summary of the key messages, briefly outline the approach we have taken to the scoping and the recommendations to be progressed in phase 2 of the work.

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.

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.

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.

1.0. Introduction and Background

Wessex Cancer Alliance (WCA) recognised a need to identify services providing prehabilitation and rehabilitation to children, teenagers and young adults and adults (CTYA) with cancer across the alliance footprint. The alliance covers two Integrated Care Systems (ICSs); Hampshire and the Isle of Wight and Dorset.

As part of the Personalised Care Programme within the WCA the vision is to develop accessible and equitable prehabilitation and rehabilitation services for people with cancer providing universal, targeted and specialist services based on patients' needs.

The key deliverables of the work were to:

1. Scope services available within primary, secondary and community care linked to prehabilitation and rehabilitation and identify gaps.
2. Develop criteria to evaluate current and future prehabilitation and rehabilitation services for people with cancer
3. Create local prehabilitation and rehabilitation guidance and recommendations to inform the implementation of prehabilitation and rehabilitation services for people with cancer across Wessex.

This scoping work commenced in May 2022 and was completed in November 2022.

Allied Health Solutions (AHS) were commissioned to undertake this work on behalf of the WCA.

This report focuses on the outcomes of the first deliverable cited above.

For the purpose of this work 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'

'You wouldn't run a marathon without training.'

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.

It is recognised that prehabilitation is a continuum to rehabilitation (1) therefore it is important that both prehabilitation and rehabilitation were included in the scope of this work.

Prehabilitation and Rehabilitation are vital components in the care of people living with and beyond cancer and are part of the Cancer Taskforce recommendations.

'Despite growing evidence and recommendations for better integration of prehabilitation and rehabilitation into oncology care, prehabilitation and rehabilitation are relatively underutilized services. This care gap is well characterised internationally and contributes to a growing morbidity burden as the population of cancer survivors continues to increase '(2)

Several of the improving outcomes guidance documents previously published set out the guidance for different tumour types which included the importance of rehabilitation including head and neck cancers (3), brain and central nervous system cancers (4) and NICE supportive and palliative care guidance (5).

Alleviating this deficit should be a priority in oncology care as the population of cancer survivors will nearly double world-wide in the coming decades (6).

It is likely that demand for services will grow as our population ages, and more people survive cancer and live with the consequences of their cancer treatment.

Previous work by Macmillan Cancer Support has shown that cancer prehabilitation and rehabilitation is highly valued by patients and carers, and improving access to, and knowledge about services is a priority.

We know that more needs to be done to raise the profile and awareness of cancer prehabilitation and rehabilitation in WCA and outline the vital role it plays across every cancer pathway.

The publication of the NHS England 'Long Term Plan' (7) has highlighted the importance of an all age, whole population approach to personalised care. Empowering people and supporting them to build knowledge, confidence and skills, and to stay well within their communities, is central to the model of personalised care. Prehabilitation and rehabilitation plays a vital role in delivering this vision and can be mapped against NHS England's Personalised Care Operating Model. The domains within the model apply in the context of the prehabilitation/rehabilitation continuum and the factors that enable this which this scoping has considered (e.g. commissioning, finances, workforce including their training, involving people/co-production in services)

In addition, rehabilitation services support the integrated care agenda, physical, mental health and social needs plus integration across services and care environments . These services provide a range of benefits for the wider healthcare economy; most notably by

keeping patients out of hospital, supporting early discharge and providing care closer to home.

The national service specification for principle treatment centres within children's cancer networks (8) indicates that for central nervous system tumours there should be an operational relationship with rehabilitation services. In addition, it states in the specification that the Children's Cancer Operational Delivery Network should have representation from Allied Health Professionals (AHPs) including expertise in psychological support.

Children's Cancer services– Paediatric Oncology Shared Care Unit service specification (9) identifies the need to have sufficient access to services from AHPs, such as pharmacy, dietetics, physiotherapy, occupational therapy, speech and language therapy along with adequate access to psychology services.

Prehabilitation and rehabilitation is vital in supporting economic efficiencies across the NHS, therefore investing in rehabilitation makes sound economic sense.

Despite the importance of cancer prehabilitation and rehabilitation for people and populations, previous work has shown that there are many challenges facing prehabilitation and rehabilitation services nationally including:

- Poor awareness of the scope and breadth of rehabilitation and the fact that it happens along and across every pathway of care
- Limited/lack of national rehabilitation leadership
- Little to guide commissioners and others on what good looks like and how to measure it
- Lack of quality data relating to many aspects of rehabilitation service delivery

Research conducted by Macmillan Cancer Support (10) estimates that the number of people living with or after a cancer diagnosis will increase at a rate of 3% per year, suggesting the need for cancer prehabilitation and rehabilitation services is likely to grow. It is also predicted that the age profile of those living with or after a cancer diagnosis will change, with 73% of those living with or after a cancer diagnosis to be over 65 years of age by 2030. This population profile, including those with multiple clinical conditions, will also affect the numbers of people requiring access to targeted and specialist interventions. Nationally, if these increased needs are not met, there are likely to be significant impacts on quality of life, as well as cost implications for the NHS and the wider economy, with an increased longer-term demand on services and potential impacts on the ability to work or study.

Across Wessex in 2020/2021there were 19,987 people diagnosed with cancer (11) (table 1). This is shown by NHS Trust in table 2. These will all be people that will potentially require some form of prehabilitation and rehabilitation depending on their individual needs and circumstances.

Table 1: The number of new cancer diagnosis for 2019/2020, 2020/2021 and 2021/2022 for each age group across Wessex

Age group	19/20	20/21	21/22
0-16	98	101	102
17-29	160	116	135
30-39	380	352	373
40-49	801	755	801
50-59	2232	2019	2468
60-69	4089	3631	4318
70-79	5813	5666	6338
80+	4793	4772	5452
Total	**18366**	**17412**	**19987**

Table 2: The number of new cancer diagnosis for 2019/2020, 2020/2021 and 2021/2022 for each NHS Trust across Wessex

	Number of new cancer diagnosis		
Trust	**2019/2020**	**2020/2021**	**2021/2022**
Dorset County Hospital NHS Foundation Trust	2466	2233	2628
Hampshire Hospitals NHS Foundation Trust	3239	2950	3496
Isle of Wight NHS Trust	1457	1242	1397
Portsmouth Hospitals University NHS Foundation Trust	3826	4388	4555
University Hospitals Dorset NHS Foundation Trust	2845	2519	3144
University Hospitals Southampton NHS Foundation Trust	4533	4080	4767
Total	**18366**	**17412**	**19987**

The NHS England cancer quality of life survey (12) identified in the first published report in October 2021:

'Eighteen months on from a cancer diagnosis, patients rate their quality of life quite highly (75.2/100), slightly lower than the general population (81.8/100). People living with and beyond cancer are significantly more likely to report a problem across all five aspects of health (mobility, self-care, usual activities, pain and discomfort, and anxiety and depression) than the general population. These differences are particularly significant for 'usual activities' (such as work, study, housework, family or leisure activities) and mobility.' (13)

The aspects of health measured in the quality of life survey can be supported and improved by prehabilitation and/or rehabilitation interventions. Mental health was identified as a high priority in the survey with people with cancer reporting problems with anxiety and depression 1.5 times more than the general population. In addition it was noted that some patients experience ongoing symptoms and side effects most notably reported were sleep problems

(26.6%), fatigue (13.4%) and constipation (9.6%).Table 3 sets out the percentage of people with cancer who reported any level of problem (slight/moderate or severe/unable) on each aspect of health based on data released on 22.9.22.

Table 3: Percentage of people with cancer both within Wessex and across England who reported any level of problem (slight/moderate or severe/unable) on each aspect of health based on data released on 22.9.22

	Wessex Percentage of respondents	England Percentage of respondents
Mobility	39.8	42.4
Self-care	14.6	18.3
Usual activities	46.2	50
Pain/discomfort	58.6	61.9
Anxiety/depression	45.1	48.6
Any aspect of health	75.1	77.9

The latest adult Cancer Patient Experience Survey (CPES) results published in July 2022 have several questions that link indirectly to prehabilitation and rehabilitation. The Wessex results for a selection of these questions along with the England average is set out in table 4.

Table 4: Selection of results from the Wessex cancer patient experience survey July 2022

Question number in CPES survey	Question	Wessex result	England score	Link to elements in the personalised care operating model
Care planning				
24.	Patient was definitely able to have a discussion about their needs or concerns prior to treatment	**72%**	**72%**	**Shared decision making and patient choice**
25	A member of their care team helped the patient create a care plan to address any needs or concerns	**94%**	**93%**	**Personalised care and support planning**
26	Care team reviewed the patient's care plan with them to ensure it was up to date	**99%**	**99%**	**Personalised care and support planning**
Support available from hospital staff				
27	Staff provided the patient with relevant information on available support	**90%**	**90%**	**Supported self-management**

28	Patient definitely got the right level of support for their overall health and wellbeing from hospital staff	77%	76%	Supported self-management
29	Patient was offered information about how to get financial help or benefits	68%	69%	Supported self-management
Immediate and long term side effects				
44	Possible side effects from treatment were definitely explained in a way the patient could understand	74%	74%	Supported self-management
45	Patient was always offered practical advice on dealing with any immediate side effects from treatment	71%	70%	Supported self-management
46	Patient was given information that they could access about support in dealing with immediate side effects from treatment	87%	86%	Supported self-management
47	Patient felt possible long-term side effects were definitely explained in a way they could understand in advance of their treatment	60%	60%	Supported self-management
48	Patient was definitely able to discuss options for managing the impact of any long-term side effects	53%	54%	Shared decision making and patient choice
50	During treatment, the patient definitely got enough care and support at home from community or voluntary services	54%	51%	Personalised care and support planning
Living with and beyond cancer				
53	After treatment, the patient definitely could get enough emotional support at home from community or voluntary services	32%	32%	Personalised care and support planning
54	The right amount of information and support was offered to the patient between final treatment and the follow up appointment	80%	78%	Supported self-management
55	Patient was given enough information about the possibility and signs of cancer coming back or spreading	63%	63%	Personalised care and support planning

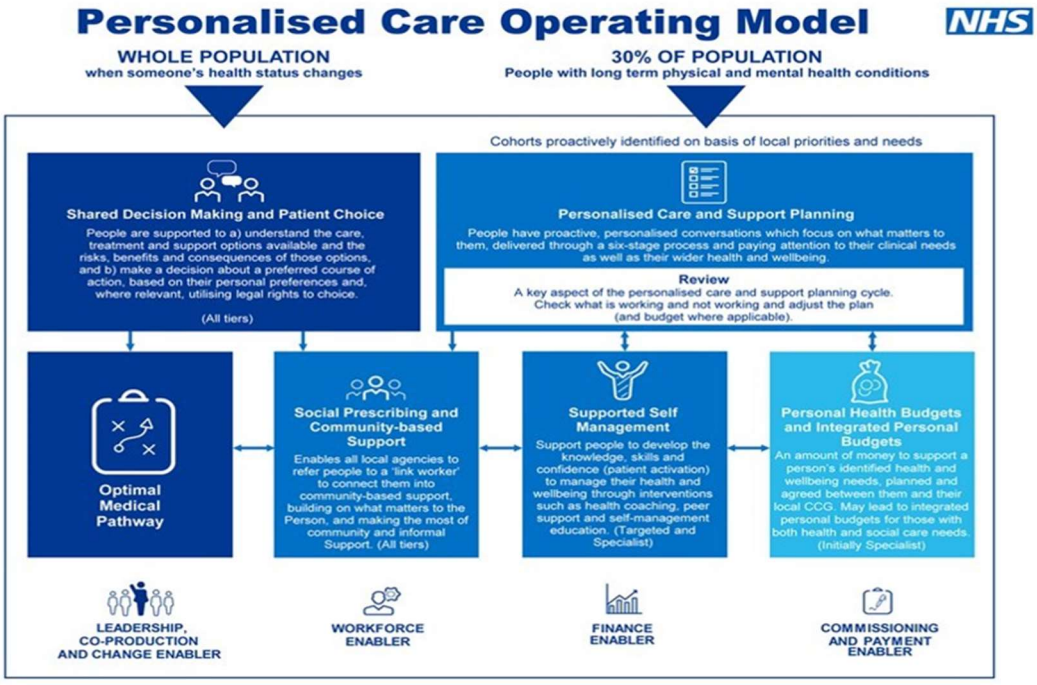
The Cancer Outcomes and Services (14) data set also has measures of relevance to prehabilitation and rehabilitation.

National and international developments that have informed this work include the Macmillan cancer rehabilitation pathways (15) (produced from the National cancer Action Team tumour specific care ; London cancer rehabilitation commissioning guidance; service specification and mapping (16); Scottish Prehabilitation Scoping report (17); Commissioning guidance for rehabilitation (18) ; NHS England Comprehensive Model of Personalised Care (19) of which

the prehabilitation interventions triangle can be overlaid (1),a recently published international systematic review of 69 cancer rehabilitation guidelines (20) and prehabilitation and rehabilitation guidance recently developed by AHS for Surrey and Sussex Cancer Alliance.

Throughout this report references and alignment will be made to the components within personalised care operating model (Figure 1) for the NHS England Comprehensive Model of Personalised Care.

Figure 1: Personalised care operating model



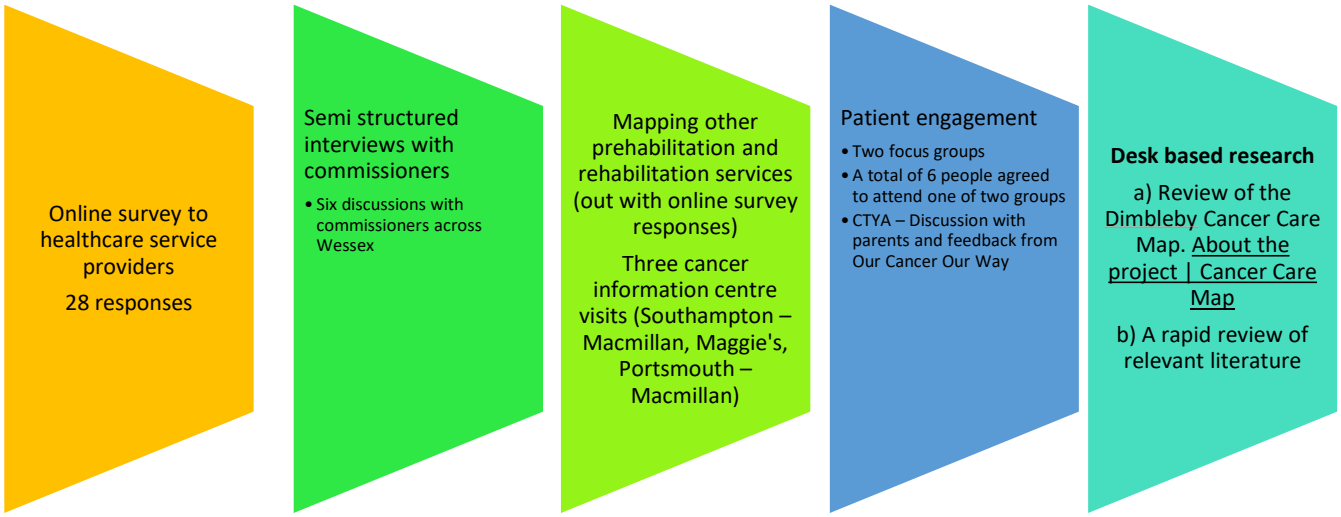
2.0. Project approach

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

A five part methodological approach was undertaken to gather data (figure 2).

Figure 2: Project approach



2.1. Online survey to healthcare providers

A JISC online survey (Appendix A) was developed in collaboration with the project task and finish group. 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

2.2. Semi structured interviews with commissioners

Semi structured interviews were held with six commissioners from across Wessex. The purpose of the interviews was to understand:

- How and what prehabilitation and rehabilitation services are commissioned
- Strategy for commissioning prehabilitation and rehabilitation services going forward

2.3. Mapping other prehabilitation and rehabilitation services

- A review of prehabilitation and in particular services providing rehabilitation to different population groups was reviewed across NHS organisations and hospices that did not respond to the survey.
- In order to understand the services provided through the cancer information and support centres across Wessex visits were undertaken to;
    - Macmillan Information and Support centre, University Hospitals Southampton NHS Foundation Trust
    - Macmillan Information and Support centre, Portsmouth Hospitals University NHS Trust
    - Maggie's Centre, University Hospitals Southampton NHS Foundation Trust
    - Discussion was held with Wessex Cancer Trust.

2.4. Patient engagement

The project team worked with Wessex Voices (WV) to help recruit and coordinate some focus groups with patients to help inform this work.

WV used its networks to invite people to attend focus groups. People were given a choice of dates, days and times. A brief was sent to WV/WCA volunteers and contacts including the local Macmillan Engagement Lead and various local support groups and Healthwatch covering the Wessex area.
A Patient Information Sheet was designed and sent to all those booked onto a group (the information a summary of the purpose of the project, any potential harms or risks, how data will be used, and a statement on their data subject rights to comply with all relevant data protection and GDPR requirements – copy available on request).
Focus group schedule/script/slides were drafted and shared with the project team for input/development. The questions/discussion topics were agreed as:

- What do you know about prehabilitation and rehabilitation?
- What is your experience of prehabilitation and rehabilitation?
- How should people be able to access prehabilitation and rehabilitation services?
- What might be the barriers to accessing services?
- What patient information would you like to see available on this topic, in what format(s) and in which languages?
- What do you think the services should offer in the future?
- What key messages would you like to see in the project recommendations?

A total of two focus groups were undertaken with six adults attending one of two focus groups.

Engagement with children, teenagers and young adults included:

- Two individual discussions with parents of teenagers with cancer
- Our Cancer Our Way (OCOW) (21) interviewed parents of CTYA undergoing (or having completed) cancer treatment. They also asked for feedback from CTYA directly. To support this scoping project comments about prehabilitation and rehabilitation have been extracted from feedback received from these discussions.

2.5. Desk based research

Review of the Dimbleby cancer care map (22) was undertaken with a focus on nutrition, exercise and emotional support provision included across Wessex and the neighbouring counties.

Additional desk based research of the published and grey literature of service models and provision elsewhere in the country was undertaken.

2.6. Project task and finish group

A project task and finish group comprising representation from key stakeholders (Appendix B) was formed and met virtually at least four times throughout the duration of the project. This group reported into WCA Personalised Care Board.

The task and finish group was responsible for:

- Monitoring the delivery of the project objectives via a clear project plan
- Enabling engagement of key stakeholders in the project in their respective organisations.
- Supporting AHS to provide regular reports to the WCA on project progress.
- Supporting and advising on the content of the surveys, focus groups and cancer prehabilitation and rehabilitation framework.
- Monitoring the evaluation and impact of the project activity.
- Supporting AHS to ensure that regular communication and progress of the project is shared with all key stakeholders.

3.0. Main findings

The findings from this project are presented from a service provider perspective, commissioner perspective, patient perspective and a review of other services found via the cancer care map and review of NHS and hospice websites.

This is set out in four sections:

3.1. Insights from service providers through the online survey
3.2. Commissioners perspectives
3.3. Patients perspectives
3.4. Review of other services

3.1. Insights from service providers through the online survey

There were 30 responses to the online survey which was distributed via the WCA to nursing and allied health professionals across all NHS, local authority, hospice and leisure facilities in Wessex. These responses were from 13 different organisations with 21 responses for adult services and 9 from CTYA services (Table 5). Table 6 illustrates the type of services provided by respondents.
A description of each service is provided in Appendix C.
The job roles of respondents is set out in table 7.

Table 5: Number of responses by organisation including whether adult and/or CTYA services provided for those with cancer

Organisation	Number of responses (Adult services)	Number of responses (Children, Teenagers and Young Adults services)
Dorsey County Hospital NHS Foundation Trust	3	0
Dorset Healthcare University NHS Foundation Trust	0	0
Hampshire Hospitals NHS Foundation Trust	2	1
Julia's House	0	1
Portsmouth Hospitals University NHS Foundation Trust	3	1
Solent NHS Trust	2	1
St Michaels Hospice	1	0
University Hospitals Dorset NHS Foundation Trust	4	1

University Hospitals Southampton NHS Foundation Trust	2	4
Other	4	
Total	**21**	**9**

Table 6: Number of responses based on whether prehabilitation, rehabilitation, prehabilitation and rehabilitation or no prehabilitation or rehabilitation provided

Number of responses (n=30)	
Prehabilitation service only	1 (all adults)
Rehabilitation service only	12 (8 adults, 4 CTYA)
Prehabilitation and rehabilitation services	7 (6 adults, 1 CTYA)
No prehabilitation or rehabilitation services	10

Table 7: Job roles of respondents

Job role
Advanced clinical practitioner
advanced practice physiotherapist
Advanced Nurse Practitioner - Acute Oncology
Associate Practitioner
Cancer Care Therapy Team Lead
Chief Executive
Clinical Lead Speech and Language Therapist
Community Children's Nurse
Consultant Physiotherapist
Head of Clinical Care
Health & Wellbeing Manager
Health and Personal Trainer
Highly Specialised Paediatric Physiotherapist
Lead Cancer Support Worker
Lead nurse for paediatric oncology
Lead nurse for the Teenage and Young Adult service
Macmillan Occupational Therapist
Macmillan Physiotherapist and Team Lead for Cancer Care
Macmillan Principal Clinical Psychologist
Oncology dietitian
Paediatric Neurology Nurse Specialist
PCN dietitian

Perioperative Medicine Nurse
Research lead
Senior Paediatric Physiotherapist
Speech and language therapy team lead
Specialist Occupational Therapist
Specialist Palliative Care Team Lead
Speech and Language Therapist
Therapy lead

Findings going forward are based on the 18 responses where it was indicated that services were being provided.

3.1.1.Location of services

Prehabilitation and rehabilitation services identified by respondents at different providers across Wessex are set out in table 8. Six services provide prehabilitation for adults and one offered prehabilitation to CTYA. Ten services provide rehabilitation to adults and five provide rehabilitation to CTYA.

Table 8: Services identified providing prehabilitation and/or rehabilitation to adults and/or CTYA

Organisation/Service	Adults		Children and Young people	
	Prehabilitation	Rehabilitation	Prehabilitation	Rehabilitation
Dorset				
Dorset County Hospital NHS Foundation Trust				
Macmillan Therapy Team, Dorset County Hospital Foundation Trust	✓	✓	-	-
University Hospitals Dorset NHS Foundation Trust				
Cancer information team	✓	✓	-	-
Therapy Services/Head and Neck Oncology	✓	✓	-	-
Support via CNS teams Moving Forward Macmillan	✓	✓	-	-
Pulmonary rehabilitation	✓	✓	-	-
Acute Paediatric Physiotherapy and Children's therapy services	-	-	x	✓
Hampshire and the Isle of Wight				
Active Nation	✓	✓	-	-

Hampshire Hospitals NHS Trust	x	✓	-	-
Portsmouth Hospitals University NHS Trust				
Speech and language therapy	x	✓	-	-
Inpatient therapy service	x	✓	-	-
Surgery school	✓	x	-	-
Macmillan clinical psychology service	✓	x	-	-
Solent NHS Trust				
Specialist palliative care team	x	✓	-	-
Children's therapy services	-	-	x	✓
St Michaels Hospice				
St Michaels Hospice	x	✓	-	-
University Hospitals Southampton NHS Foundation Trust				
Preop Fit	✓	✓	-	-
Cancer care Therapy service	x	✓	-	-
Robbies Rehab	-	-	✓	✓

3.1.2. Access, location and methods of service delivery

Access to services

For services providing prehabilitation, 64% of people are referred by healthcare professionals with 36% self-referring and for those services providing rehabilitation, 65% of referrals are from healthcare professionals and 31% are self-referrals.

Location of services

The majority of services reported being delivered predominantly 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 (table 9).

Table 9: Location of where services are delivered divided into prehabilitation and rehabilitation

Service location	**Prehabilitation** Number of responses (n=18)	**Rehabilitation** Number of responses (n=18)
Outpatient clinic	5	10
Hospital	6	12
GP practice	0	0
Patient home	4	7

Care home	0	0
Hospice	1	4
Other e.g., leisure centre, gym, community facility	2	4

Methods of service delivery

Services for both prehabilitation and rehabilitation were predominantly reported as being delivered one to one face to face or one to one virtual/remote. There were fewer responses for group face to face or virtual/remote delivery (table 10).

Table 10: Method of service delivery identified by respondents for prehabilitation and rehabilitation

Method of service delivery	**Prehabilitation** Number of responses (n = 18)	**Rehabilitation** Number of responses (n = 18)
One to one face to face	6	16
One to one virtual/remote	5	9
Group face to face	5	5
Group virtual/remote	0	2

3.1.3. Stages in the pathway when patients are seen

For those services providing prehabilitation as expected 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 (table 11).

Table 11: Stages in the pathways when patients are seen for prehabilitation and rehabilitation

Stage in pathway when patients seen as identified by respondents	**Prehabilitation – Number of responses (n=18)**	**Rehabilitation – Number of responses (n=18)**
Pre-diagnosis	2	3
Diagnosis and before treatment	8	8
During treatment	6	14
After treatment	7	13
Palliative care	3	12
End of life care	2	11

3.1.4. Tumour types seen

There were two responses and nine responses respectively where it was reported that all tumour types are see. 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 system tumours and those with lung cancer were reported as being seen the most in rehabilitation services with other tumour types reported as being seen less from the responses gathered (table 12).

Table 12: Number of respondents identifying seeing specific tumour types in prehabilitation and rehabilitation services provided

Tumour type	Prehabilitation Number of responses (n=18)	Rehabilitation Number of responses (n=18)
Brain and Central Nervous system	2	9
Breast	2	5
Colorectal	3	5
Gynaecology	2	4
Head and Neck	2	8
Lower gastrointestinal	2	5
Lung	3	6
Haematology	1	5
Prostate	2	3
Sarcoma	1	6
Skin	2	5
Upper gastrointestinal	1	4
Urology	2	3
All tumour types seen	2	9

3.1.5. Staff involved in delivering services

Staff who reported delivering prehabilitation include dietitians, clinical nurse specialists and physiotherapists, psychologists, fitness instructors, occupational therapists, speech and language therapists, counsellors and support workers. Physiotherapists and occupational therapists followed by support workers, clinical nurse specialists, dietitians, speech and language therapists and psychologists are the predominant staff groups delivering rehabilitation (Table 13).

Table 13: Staff groups involved in delivery prehabilitation and rehabilitation

Staff group involved	Prehabilitation Number of responses (n=18)	Rehabilitation Number of responses (n=18)
Clinical Nurse Specialist	4	7
Counsellor	2	5
Dietitian	5	7
Exercise physiologist	0	1
Fitness instructor	3	1
Information and support team	1	2
Occupational therapist	2	13
Physiotherapist	4	14
Psychologist	3	7
Psychotherapist	1	0
Social prescribing link worker	0	0
Social worker	0	0

Speech and language therapist	2	7
Support worker, rehabilitation assistant, therapy support worker	2	8
Therapeutic radiographer	0	1
Volunteers	1	1
Other (play specialist, anaesthetist, respiratory physiologist)	3	2

3.1.6. Waiting times across services

The majority of services delivering prehabilitation reported waiting times from one week or less up to one month with those providing rehabilitation reporting waiting times predominantly 1 week or less (table 14).

Table 14: Waiting times reported for prehabilitation and rehabilitation services

Waiting times	Prehabilitation Number of responses (n=18)	Rehabilitation Number of responses (n=18)
1 week or less	1	8
2 weeks or less	2	2
3 weeks or less	1	1
1 month	2	2
Greater than 1 month		0
1 month – 3 months	1 (generic service rather than cancer specific service)	2
Other		2

3.1.7. Number of patients seen by services

The data set out below sets out:

- The number of new patients seen in generic services per annum and the percentage and number of people with cancer seen within these services (table 15)
- The number of new patients seen in cancer specific services per annum and the proportion and number of people with cancer seen within these services (table 16)

Conclusions cannot be made from this data alone as to how many new patients with cancer are supported with prehabilitation and rehabilitation across Wessex as this data does not include services that may not have responded to the survey both within and out with the NHS.

Table 15: The number of new patients seen in generic services per annum and the proportion and number of people with cancer seen within these services

	Prehabilitation		Rehabilitation	
Service code	**Number of new patients seen per annum**	**% of new patients with cancer**	**Number of new patients seen per annum**	**% of new patients with cancer**
1	800	26%-50%	700	26%-50%
2	40	26%-50%	40	26%-50%
3	Service not provided		5000	0-25%
4	Service not provided		1870	0-25%
5	50	0-25%	Service not provided	
6	Service not provided		1500	0-25%
7	Service not provided		240	51%-75%
8	Service not provided		6500	0-25%

Table 16: The number of new patients seen in cancer specific services per annum and the proportion and number of people with cancer seen within these services

	Prehabilitation		Rehabilitation	
Service code	**Number of new patients seen per annum**	**% of new patients with cancer**	**Number of new patients seen per annum**	**% of new patients with cancer**
A	Service not provided		300	76%-100%
B	Service not provided		450	76%-100%
C	no data	76%-100%	no data	76%-100%
D	Service not provided		480	76%-100%
E	400	76%-100%	Service not provided	
F	Service not provided		100	76%-100%
G	1200	76%-100%	1200	76%-100%

H	100	76%-100%	300	76%-100%	
I	Service not provided		3000	76%-100%	
J	35	76%-100%	Data not available as yet		

3.1.8. Screening and assessment for prehabilitation and rehabilitation

Screening patients for prehabilitation and rehabilitation

Respondents were asked *how* they screen patients for prehabilitation and rehabilitation. Responses are shown in table 17.

Table 17: Screening methods for used by services for prehabilitation and rehabilitation

Screening methods used for prehabilitation	Screening methods used for rehabilitation
• Inclusion criteria for the service • Holistic Needs Assessments • Online referral forms • PHQ-9 (Patient Health Questionnaire) (23) and GAD-7 (Generalised anxiety Disorder Assessment) (24) (where patients are being referred for psychological assessment)	• Several cases indicated that no validated screening is used • Referrals made to services by multidisciplinary teams/oncology teams however no consistency was reported about the process • Montreal Cognitive Assessment Test (MoCA) • Mental capacity assessments • Malnutrition Universal Screening Tool (MUST) • EAT-10 (25) - a swallow screening tool • Western Aphasia Battery (26) - a diagnostic tool used to assess the linguistic skills and main non-linguistic skills of adults with aphasia

Assessment of patients for prehabilitation and rehabilitation

Respondents were asked *how* they assess patients for prehabilitation and rehabilitation. Responses are shown in table 18.

Table 18: Assessment methods for used by services for prehabilitation and rehabilitation

Assessment methods used for prehabilitation	Assessment methods used for rehabilitation
• In house therapy assessment including housing and social needs.	• Patients assessed by the individual teams when they are referred to them

• Specific therapy assessment / outcome measures (e.g., FIM/FAM – Functional Independence Measure and Functional Assessment Measure (27), KOSCHI (28) - Kings Outcome Scale for ,Childhood Head Injury, Modified Rankin Scale (29), Berg balance (30)) cognitive assessment including MoCA, completed at the start and end of therapy. • Full neuro cognitive assessment completed 9-12 months post injury • Malnutrition Universal Screening Tool • Head and Neck Performance Status scales • Montreal Cognitive Assessment (MoCA) • Physiotherapy: Functional neck, shoulder assessments. Balance, postural defects. Weakness and fatigue. • PHQ-9, GAD-7, subjective ratings of difficulty and distress (rated on 0-10 scale). • 6 minute walk test • Quality of life assessments.	• MoCA • HADS (Hospital Anxiety and Depression Scale) (31) • Timed Up and Go Test (32) • TUSS Timed Unsupported Steady Stand) (32) • 30 second chair stand • Berg balance • Range of movement/power • MUST • Barthel (33) • Lung function tests • Patient Reported Outcome Measures • Facit-F (34) - Functional Assessment of Chronic Illness Therapy – Fatigue Scale • IPOS (35) – Integrated Palliative Care Outcome Scale

Holistic needs assessments

In addition, five respondents indicated that holistic needs assessments were undertaken for prehabilitation, and thirteen respondents indicated they were undertaken for rehabilitation

3.1.9. Interventions delivered, duration and frequency

Interventions delivered

It is interesting to note that for those services providing prehabilitation, with or without rehabilitation, the respondents reported delivering the majority of universal, targeted and specialist interventions for the patients they were seeing. For those services providing rehabilitation, with or without prehabilitation, the majority again reported delivering universal, targeted and specialist interventions (table 19).

Table 19: Universal, targeted and specialist Interventions delivered during prehabilitation and rehabilitation

Interventions	Prehabilitation	Rehabilitation

	Number of responses (n=18)	Number of responses (n=18)
Universal		
Personalised prehabilitation care plans are developed for each patient	6	6
Making referrals to other healthcare professionals	7	17
Advising on self-management	7	17
Universal interventions including the promotion of healthy lifestyle in people living with cancer which may include exercise and/or nutrition and/or emotional support/smoking and alcohol advice	6	10
Supporting those with commonly presenting side effects and rehabilitation needs	4	15
Targeted interventions		
Exercise	6	14
Nutrition	6	8
Emotional support	6	13
Specialist interventions		
Delivering specialist interventions to patients with severe functional and cognitive impairment	6	13
Complex emotional, financial or practical needs to support patients with activities of daily living	7	14
Delivering specialist interventions to patients having radical surgery or combinations of treatments	5	14
Delivering specialist interventions to patients with advanced diseases, complex palliative and end of life care issues	5	13

Duration of interventions

Duration of prehabilitation interventions varied widely depending on the service and patient need. Some examples from respondents are set out in table 20. These range from duration

of interventions being 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 (table 21).

Table 20: Examples of the duration of prehabilitation interventions

2-12 weeks is offered initially.
as needed
*Inpatient rehabilitation (*Southampton children's integrated rehabilitation team - *SCIRT) duration varies from 3 weeks to 3 months. Transition session (outpatient) sessions post discharge in first 6 weeks. Elective 2 week admission for intensive rehab post treatment. Robbies Rehab transition episodes lasting 6 weeks or to complete a piece of work – i.e., emotional support, transition to new school*
Pre-treatment- 1 information session and then 6 weekly support via on treat clinic Post treatment agreed with patient to help them achieve functional goals within agreed time span. Some complex HN patients e.g., those who have undergone Laryngectomy require lifelong support but with less frequency or with agreed patient initiated follow up plan.
Pre-surgical appointments for head and neck cancer patients are usually 1 session only, unless additional support is required. Counselling is typically six sessions. Psychology fear of recurrence group interventions are 6 x 2 hour sessions. Psychology 1:1 / couples' interventions vary in duration. This is because psychology interventions are formulation-driven and tailored to the individual. We offer up to a maximum of 18 sessions but would not usually work with clients for this long.
Seven weeks
Varies depending on the services offered. Wessex Cancer Trust offer 18 weeks of services Exercise programs can offer 8 weeks of supported free exercise Live Well Dorset offers support and coaching over 6 months Hospital dietetic team can support patients through and beyond treatment

Table 21: Examples of the duration of rehabilitation interventions

Agreed package of rehab with patient, varies across tumour site. Anywhere between 1 to 2 interventions to interventions lasting 6 -12 months.
As long as required, though due to large and busy caseloads, patients often over booked into diaries in order to be seen.
As long as therapy needs are identified whilst they are an inpatient. If patients are discharged once medically optimised and there are still ongoing therapy needs, patients will be referred to inpatient rehabilitation, community therapy or MSK teams.
Input is delivered as deemed appropriate to meet the client's needs at any given time.
The intervention can be anywhere from 30 mins to several hours depending on their needs.

this is individualised depending on the needs of the person. Sometimes we may only see them for 1 assessment, though if their needs are complex, we may review and reassess over several months for instance
This varies according to individual needs. We work with patients until their issues are stable or until end of life if needs remain complex. Following discharge patients can re-refer themselves back into the service at any point.
Until rehabilitation goals achieved or felt maximum potential met
Whilst an inpatient in the hospital, limited scope to provide intervention post discharge but can do one/two follow up visits before referring on to other services.
This would depend on the intervention and the patient required

Frequency of interventions

The frequency of prehabilitation interventions varies dependent on the service, patient need, service opening hours and clinical condition. A few quotes from respondents are shared below.

'SCIRT (Southampton children's integrated rehabilitation team) is 7 day service. All therapy (Physio, OT, SLT, psychology, school, play) is timetabled according to therapy need. Maximum twice daily Mon- Fri sessions of PT, OT, SLT, school and play. Once daily psychology. Sat-Sun once daily physio and OT sessions. Weekly sessions for Robbies Rehab.'

'Varies - as above pre-treatment 1 -3 sessions On treat weekly Post treat Initially up to 1 to 3 x weekly for 6 weeks, then agreed with patient with many on self-management with access to Patient initiated follow up.'

The frequency of rehabilitation interventions varies based on patient need, tumour site, staff availability and informed by the patients care plan. A few quotes from respondents are shared below.

'patient dependent, with complex rehab likely multiple times per week in initial treatment stages and weaned as able. '

'We aim to delivery therapy sessions 3 times per week, but this can be as limited as 1-2 times per week. The therapy service is also only Monday-Friday.'

'Flexible approach to interventions as dependent upon patient need.'

'Daily if an inpatient where needs require this.'

3.1.10. Outcome measures used in services

Respondents were asked to identify quality of life measures, functional measures, health economic measures and disutility of care/degree of health measures (Appendix D).

All services identified a range of quality of life and functional measures used. Health economic measures was captured for some services. 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.

3.1.11. Funding of services and service specifications

Respondents were asked about funding for services delivered. 3 and 7 services offering prehabilitation and/or rehabilitation identified permanent funding. 1 offering prehabilitation and 1 offering rehabilitation had temporary funding and 3 services offering prehabilitation and 7 services offering rehabilitation did not know about funding or identified no funding for services (Table 22).

Table 22: Funding status of services providing prehabilitation and/or rehabilitation

Funding of services	Prehabilitation Number of responses (n=18)	Rehabilitation Number of responses (n=18)
Permanent funding	3	7
Temporary funding	1	1
I do not know about funding	1	3
No funding for the service	2	5

57% of services providing prehabilitation had a service specification describing the service to be provided and 53% of services providing rehabilitation had a service specification.

3.1.12. Research underway in services providing prehabilitation and rehabilitation

Respondents were asked about any research underway. The majority of respondents stated that they were not involved with research with two stating they were involved for prehabilitation and two responses for rehabilitation.

3.1.13 Plans for the development of services

Respondents were asked about any future plans for the development of services providing prehabilitation and/or rehabilitation to people with cancer. There were five themes from the feedback including:

Involvement of primary care - in the design and delivery of prehabilitation and rehabilitation

Funding and resourcing services - There were several examples where funding was required to support therapy services and psychological support services to increase capacity. It was

highlighted by some that there were discussions with senior management teams about benchmarking and evidence required for the improvement of outcomes.

Patient involvement – in particular in the design and development of services

Workforce – This included feedback about considering a greater use of the generalist workforce as specialist roles are limited, More involvement from support workers, exercise instructors and wellness coaches across the pathway to reduce reliance on hospital and acute services, investment in multidisciplinary team opportunities for advanced practitioners and all healthcare professionals being aware of what rehabilitation facilities/ classes are available in their area

Service development/design/improvement – Feedback included the need for:

- Clearer pathways for all tumour sites for rehabilitation highlighting where there are significant gaps in services from acute across to community
- More multi-professional rehabilitation provision for cancer patients prior to palliative care in the community / primary care as this is currently very limited.
- Collaboration with third sector organisations to develop services
- More joined up services as patients can get referred to individual services depending on need and there isn't a specific package for them which might be a useful principle to pursue.

3.1.14 Patient engagement by service providers

Respondents were asked about different aspects of patient engagement. Quotes are included from respondents set out under each question asked.

Information provided to patients about the services

Services identified that information about their services is provided in the form of leaflets, websites and verbal information

Quotes:

'HNA information is given to all patients and once assessed, patients have access to leaflets, booklets and a resource directory with links to all local and national support.'

'Our website has background information on the rehabilitation and primary prevention pathways and the benefits of specialist, tailored exercise programmes. Patients receive information from NHS referrers such as HHFT staff and PCNs about exercise rehabilitation and primary prevention.'

'Discussion with parent/carers/child when referral is received to advise on the support our service will offer and how.'

'Our colleagues within the four GP surgeries we work with tell patients about our service. Having met and spoken with more clinicians to talk about our service means they can inform patients about what it involves, as well as other group interventions we deliver. Surgeries also have our information on their websites.'

Involving and engaging patients and the public in the planning and design of prehabilitation and rehabilitation services

Services involve and engage patients in service design and development and evaluation through patient representation at board level and other various forums, through dedicated focus groups, audits and questionnaires.

'We have a hospice user group run by patient/family support.'

'We have occasionally involved patients / public in service design but not often.'

'We complete patient satisfaction surveys which ask questions about the inpatient service they have received and what they might like to receive e.g., outpatient services.'

'Being a new service, we gather feedback after patients have completed our service. This feedback is delivered back to the referrer. It also gives us insight into what is useful for patients and what things can be improved. We have also done a survey to gauge interests about our current group intervention offering and what we can deliver in the future.'

Involving and engaging patients and the public in the evaluation of prehabilitation and rehabilitation services

Overall patients families, carers and others are included in discussions/services where appropriate and agreed with the patients.

'Engagement with comms team and use of social media.'

'Personal goals and outcomes from the programmes are reviewed after 20 sessions and our annual report reports on the outcomes of the cohorts of exercisers during the year. Outcomes are also shared at a cohort level with the local GPs.'

'We have a comms team who have a clear understanding of our service and work hard on social media to represent that to the public. We seek our service user views annually and respond to them with any service developments made as a result.'

'We request feedback from service users after they have received input from the service and we act on feedback received.'

Inclusion of patients/carers/family to enable interventions to be implemented

Inclusion was reported as being face to face and telephone conversations with family/carers/patient, Family members and others joining patient in consultations/activities/appointments and feedback forms.

'We allow support exercisers to attend alongside the patient to encourage and support them to keep going.'

'Patients and families supported from point of referral, holistic approach - access to counselling if required. Direct support offered from allocated therapist to patient and family as rehab ongoing.'

'For those who need to have carers with them to attend appointments, it states this on the referral forms that are sent to us. We ensure that all the relevant information is passed on to those who need it.'

'Regular communication with family/carers by phone and face to face on the ward or at home during home visits.'

'The TYA service works very closely with our patients and their families to provide the right support at the right time for our young people involving constant dialogue and support structures.'

Ensuring health inequalities are addressed in the planning, design and access to services

It was identified by services that further work was required to ensuring health inequalities are addressed in the planning, design and access to services.

'Our services are open to all but as we are not funded by NHS commissioning, we have to make a small sessional charge to patients who attend. Any who are on benefits receive a discount and in the event of inability to pay, the service is free.'

'The vast majority of our patients are from lower socio-economic groups. we try to place classes when buses are frequent and parking easy. Free parking is available, and the course has free drinks. There is no fee for on-going exercise classes, therefore anyone can attend, and it is only based on the ability to travel rather than the cost of a class.'

'We have identified any inequalities but unless we receive additional funding and there are changes to historic contracts we will not be able to address this.'

'Initial assessments take into account health inequalities but access to hospital/ clinics and virtual services are very challenging and there is inequality of access for some patient groups.'

'We know our patients and their families very well so would be aware of any barriers that might affect the way they can access services. We are a relatively small service so can provide bespoke plans for our patients depending on need.'

Gathering patient insight into the effectiveness of services

Insight about the effectiveness of services was gathered through patient surveys, questionnaires and discussion with local support groups.

'We have an annual exerciser survey which covers all aspects of the service, including the support they receive from instructors, the building facilities, their feeling about their health and wellbeing etc.'

'Service users are asked to provide anonymous feedback at the end of psych/counselling input. Psychology service aims to use outcome measures post-treatment.'

'Ask patients, family and carers via all modes of communication in order not to disadvantage anyone.'

'We use the hospital feedback form so patients and families can feedback on services, we also have a number of initiatives underway around getting feedback about the service so we can improve moving forward.'

3.1.15 Education and training undertaken

Respondents were asked whether they had undertaken any education and training related to prehabilitation and/or rehabilitation. 13 respondents stated that they had undertaken some education and training. This included:

- PRosPer (36)
- Exercise referral courses
- Cancer prehab pathway
- Hight Intensity Interval Training
- MSc module in cancer rehabilitation
- Rehabilitative palliative care
- Psychological skills training
- Symptom treatment and management e.g., lymphoedema, pain, breathlessness, neurological issues
- Perioperative medicine module
- Making Every Contact Count
- Pinc and Steel Certification in Cancer Rehabilitation (37)
- Motivational interviewing

14 respondents stated they had not had any education and training.

Topics respondents identified they would like training and development in is shown in (table 23)

Table 20: Topics identified by respondents that they would like to have education and training in

Topic	Number of responses (n=20)
The role of different professionals in supporting people with prehabilitation and rehabilitation	16
Prehabilitation interventions	20
Rehabilitation interventions	17
Personalised care planning	18
Self - management	15
Behaviour change	19`
Exercise	14
Nutrition and diet	15
Psychological support	15

3.2. Commissioners perspectives

Discussions held with commissioners identified the following perspectives for a) Hampshire and the Isle of Wight and b) Dorset.

It is noted that the commissioning of elements of cancer pathways is split across several commissioning teams.

a) Hampshire and the Isle of Wight

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 UHS. This service is funded in part by specialised commissioning and in part by charitable funds.

It was identified that pulmonary rehabilitation and cardiac rehabilitation were commissioned.

There was a view that economies of scale were needed to support patients. Prehabilitation and rehabilitation does fit very well with several of the commissioning teams priorities such as frailty, dementia, discharge and independence, urgent community response, population health and emergency department streaming.

Some links to and mapping of leisure centre providers had been made in North and Mid Hampshire.

Several organisations and website links were referred to as useful resources and places where patients could be supported e.g. IsleFindit Cancer Archives - Islefindit, https://hiveportsmouth.org.uk/hive-directory and https://actionhampshire.org/ - below is an example of the current information available; Communities Against Cancer - Action Hampshire, Friends Fighting Cancer, GIST Cancer UK and the Roy Castle Lung Cancer Foundation - Portsmouth

Surgery school was identified as being available at Portsmouth Hospitals and University Hospitals Southampton.

b) Dorset

Live Well Dorset (38) was identified as a good resource providing links to universal interventions. It was reported that Dorset is one of the most searched areas on the Cancer Matters Wessex website.

Surgery school was identified as being available at the acute Trusts in Dorset and it was noted that health and wellbeing events were also held.

3.3. Patients perspectives

3.3.1. Adult patient engagement

6 people attended 2 sessions (1 session of 2 people and 1 session of 4 people). There were 4 women and 2 men, all aged 40 and above. Geographical spread of people from Bridport in the west of Dorset to Southampton in the east of the region. All attendees had either lived experiences of cancer or were caregivers for someone with a cancer.

Eight themes emerged and are set out below along with a sample of quotes to support each theme.

Theme 1 - "Prehabilitation" is not a word that many had heard of or understood or received

"I'd never heard the expression prehab before…… I was very busy at the time (of diagnosis) – so idea of doing any prehab would never have occurred to me and it would never have occurred to me that it existed"

"I have heard of it – I am Chair of Stepping Out – which is a rehab cancer support scheme and what we effectively find is – yes, we've heard about prehab but often treatment is so quick that there isn't much time beforehand in which it can happen."

Theme 2 - The need for a specific role to oversee and promote prehab/rehab services and ensure the linkages between services

"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".

"Their job (clinicians) is to make you better and that's why it's really important to have an individual to oversee the other bits otherwise it will be lost."

"The reason why nothing comes of the HNA is not that people don't care – it's that they don't have the time. That's why it's so important to employ someone to oversee all this – otherwise it won't be done, and it will be just another tick box exercise".

Theme 3 - There should be proactive psychological support pre, during and after treatment for the patient but also for family and caregivers

"….I have cost the NHS further money – quite a lot of further money as a consequence of not being looked after emotionally and physically. I was very active beforehand and as a consequence of trying to get active again I have had to have numerous operations because I have ruptured cartilage and torn ligaments cos I was moribund for far too long a period of time. I have also had to have a fair bit of counselling – and a bit like E – the person in the bed is not in isolation – complete lack of psychological input during my treatment. It is terrifying on a daily basis – the nurses would often rush into my room because I was having night terrors about dying."

"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".

Theme 4 - People with any cancer should have access to prehab/rehab services

"….It should be uniform across all cancers and (like J said) it should not be cherry picked e.g.; bowel cancer is "flavour of the month". Everybody should have prehab and rehab".

Theme 5 - Ensure all the various (and new) roles fit together and don't duplicate or overlap e.g., Social Prescribers, Right by You, Patient Navigators, Cancer Support Workers

Theme 6 - Make services relevant, accessible and fit for our area (e.g., Dorset rurality is very different to Southampton City)

"You have to keep travelling further and further distances – need to keep things as local as possible especially for rural areas".

Theme 7 - Primary care has a more proactive part to play in helping people access these services

"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".

"Needs to be in primary care – part of the conversation – what would you like to happen – when things are explained to you, and you get a diagnosis".

Theme 8 – The importance of third sector organisation. Make better use of them and ensure they are properly supported and resourced

"The NHS often wants to have lots of experts – but we (Stepping Out) have level 4 cancer rehab specialists. They design the whole scheme themselves and lead the activity themselves.

"I had lots of instructions about prehab and rehab – but when you come to say Stepping Out – you are assessed by the scheme – they can talk through with you what you need specifically for you – a tailored scheme. We look at the whole person. People may also have other issues – so we take that into account as well".

The following limitations of this piece of work have been identified here (note these are not comprehensive).

- Due to the timescales/logistics it was not possible to undertake any face-to-face groups at this time.
- Although there were a number of interested people who expressed interest in attending a group, only 6 actually attended. This may be due to tight timescales but possibly also due to emails being captured by spam/junk folders depending on individual's email security. A learning point to ask for telephone numbers in the future and to ask people to check spam/junk folders when sending out invitations.
- All attendees were WV volunteers. Learning point to ask contacts to confirm where invitations were sent (we rely on contacts to ensure information is sent to their networks).

3.3.2. Children, Teenagers and Youngs Adults engagement

Themes from discussion with two parents of teenagers with cancer are set out below.

Experience of prehabilitation/rehabilitation

- No advice about diet, exercise or self-care/self-management before, during or after treatment on both occasions
- An end of treatment meeting on the TYA ward involved discussing general healthy living and the provision practical advice including discussing minimising the risks of a secondary cancer.
- There was access to emotional support, an offer to see a was open ended where the person could request the frequency of appointments and course
- Resources were identified through conducting own online research.
- Advice was given about symptoms and side effects however this advice was not necessarily personalised.
- No awareness or use of the Cancer Care map
- Not clear where to search for trusted and credible resources and information
- One parent and their daughter joined an online community Facebook page for the specific cancer type which they found very helpful and supportive
- Parent weekend set up by Penny Brohn was very supportive and a What's app group was formed.
- Good support from the Teenage Cancer Trust

Improvements & recommendations

- Closure meetings after treatment is a good idea, it felt like a nice summary of treatment and an opportunity for Ellie to ask any questions she had
- Young lives matter and other support were proactive in contacting Ellie and Dianne, this made the family more receptive
- Visibility on TYA wards for support and help is important
- Simple visuals/information would be really helpful on general healthy lifestyle advice such as exercise and heathy eating.
- It was suggested that some teenagers like board games. The board game idea could be developed to have fun and quick messages about health lifestyle advice.

Feedback from Our Cancer Our Way

Our Cancer Our Way (OCOW) interviewed parents of CTYA undergoing (or having completed) cancer treatment. They also asked for feedback from CTYA directly. Extracts of relevance from this work have been used to help inform this scoping work.

Prehabilitation

Feedback from OCOW commented that because diagnosis to treatment was usually almost immediate, there was little opportunity to intervene at that stage.

During treatment

OCOW asked about general support through treatment. Many people were very positive about this, mainly mentioning the emotional support offered by the service, support from charities and in some cases specific psychological support. There were also some comments about the need to improve support during treatment. For example, there were needs identified including:

- advice on / better nutrition
- psychological support for the whole family
- reaching out more when treatment is at home

Support post treatment

Comments from parents of CTYA about support post treatment are summarised below.

One parent commented that her child had not heard about post treatment trips she was entitled to (this was probably due to Covid – 19 having prevented trips from taking place) – and clearly thought this was important.

Another parent commented that “support drops off after treatment”, which was something this parent found problematic.

Several commented that post treatment:

- *“it hits you”*
- you can *“feel alone”*
- it’s *“difficult to adjust”*
- it can be hard *“dealing with side effects of the treatment”*
- you *“need support”*
- not *“realising the impact”*
- feel “dropped like a hot coal”

OCOW were also asking about the whole family. As a result, people mentioned the need for siblings to be supported, and for there to be a focus on the whole family’s emotional wellbeing.

In terms of waiting for results post treatment, parents mentioned waiting for results post treatment as being an anxious time and hoped for clinic appointments rather than phone calls, as clinic appointments were seen as more supportive (again a covid phenomenon).

One parent also mentioned that school did not understand the emotional impact of the illness and treatment on the child, when they asked for support a texting service was offered.

One parent commented that they suddenly realised “it would take time for immunity to build” and that this was stressful – they weren’t able to go back into “normal life” for some time and hadn’t been prepared for this.

A couple of parents mentioned that it would helpful / nice to be contacted post treatment in order to check how their child was doing.

Given treatment for CTYA is so long, perhaps the concept of so pre and post hab needs to be adjusted to include “during hab”!

3.4. Review of other services

3.4.1. Review of prehabilitation and rehabilitation to different population groups

Healthcare organisations and services that provide prehabilitation and/or rehabilitation to those people with clinical conditions other than cancer were reviewed to understand wider services available (Appendix E). This has highlighted inpatient and outpatient/community based services within NHS and hospice organisations in particular where professionals are providing more targeted and specialist support to those with more complex needs and with multiple clinical conditions. It cannot be ruled out that these services may well be providing support to people with cancer along with other conditions. These services may have the potential to support people with cancer. This would need to be explored further and is likely to be dependent on what current services are funded to deliver, to which groups in the population and the skills, knowledge and capabilities of the staff working within these services.

3.4.2. Review of services provided at cancer information and support centres across Wessex

In order to understand the services provided through the cancer information and support centres across Wessex visits were undertaken to;

- Macmillan Information and Support centre, University Hospitals Southampton NHS Foundation Trust
- Macmillan Information and Support centre, Portsmouth Hospitals NHS Trust
- Maggie’s Centre, University Hospitals Southampton NHS Foundation Trust

Discussion were also held with the Wessex Cancer Trust who have centres in Bournemouth, Chandlers Ford, Isle of Wight, Waterside (Hythe) and a newly opened drop in centre at Andover.

Each of these centres provides a range of different services to support people with cancer along with their family, carers and wider networks. These services include emotional

support, physical wellbeing, complementary therapies, counselling, finance, benefits advice, employment advice and support to help people with self-management (Appendix F).

Many of these offers support people with universal interventions.

In discussion with the Maggie's Centre, the eight Maggie's centres located in Scotland were commissioned in 2021 by the Scottish Government to provide universal support including exercise, nutrition and emotional support. Eight films (one by each centre) have been produced. The offer comprises weekly universal sessions of 90 minute group session for people diagnosed with cancer at any stage with any prognosis covering information about nutrition, exercise and emotional/psychological support. Patients are referred or can refer themselves. Those attending have a unique identifier and there is a short questionnaire at end of the session which includes patient activation. Between April 2021 and July 2022 615 people including carers been through programme. The aim is to follow up patients at 3 months and 6 months. Evaluation is underway. The Scottish Government wish to have the content of the session shared for any willing provider to offer as well.

3.4.3. Review of the Cancer Care Map

Cancer Care Map (22) is a simple, online resource that aims to help people find cancer support services in their local area wherever they are in the UK. Cancer Care Map is run by The Richard Dimbleby Cancer Fund charity. The cancer care map displays psychological/emotional support services, medical services, those providing health and wellbeing support and those providing practical support. Some of these services are cancer specific and more generic. Services include those provided by the NHS, charities and third sector organisations, local authorities and independent sector companies and practitioners.

A user of the cancer care map can input their postcode and services in their area will be displayed.

Findings from a review of the cancer care map as part of this scoping work identified that services offering emotional support are largely from peer support groups, there are many services offering exercise and emotional support however far less offering nutrition support. There are little-to-no services listed that offer physical, nutritional and emotional support together. There are some private services that offer a package for a fee.

4.0. General discussion, conclusion and recommendations

This scoping report has provided an overview of prehabilitation and/or rehabilitation service provision for people, both CTYA and adults, with cancer across Wessex. The recommendations included in this section will be progressed in phase 2 of this work which will follow on from this initial scoping work. The recommendations should be considered along with the WCA psychological support mapping work underway.

There is considerable inequity of prehabilitation and rehabilitation cancer service provision across Wessex. The impact of unmet prehabilitation and/or rehabilitation can be described as follows;

> *Whether an individual is supported through rehabilitation affects not only their health but their life chances, their earning potential, how active they are in their community, if they become socially isolated, how happy they are. Without rehabilitation people can be stuck in a downward spiral where having one long term condition leads to other health conditions, including further long-term conditions, with loss of mobility and poor mental health and multiple medication regimes. Ensuring everyone who needs rehabilitation can access it can reverse this downward spiral.(39)*

Access to services providing prehabilitation and/or rehabilitation is predominantly through referral from a health care professional in approximately 64% of services with 33% via self-referral. There is a need to promote supported self-management and patient choice and as such there are many services in Wessex, provided by the NHS, leisure sector, third sector and independent sector identified that provide universal support to people with cancer. These services often provide a wide range of offers, mostly with no charge, which include emotional support and health and wellbeing support. For those patients accessing these services they see great benefit however these may not be known by all patients that might benefit or by professionals who can then signpost patients to them.

In addition, there are many excellent resources that provide credible, reliable and trusted information on nutrition, exercise and emotional support for people with cancer. However, it is unclear how well known or accessed these resources are.

The recommendations described below include the organisations to whom the recommendations are intended.

The majority of prehabilitation and/or rehabilitation was identified as being undertaken in secondary care or in outpatient clinics within secondary care. There is significant potential to increase the universal support provided to people with cancer in primary care. In particular this could be achieved through the support from additional reimbursement roles (ARRS) such as social prescribers, cancer care coordinators and health and wellbeing coaches.

Recommendation 1 - WCA, Healthcare service providers

For CTYA and adults, collate and promote a) the range of universal support service 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 the Cancer Matters Wessex websites which can be shared widely with patients and healthcare professionals.

Recommendation 2 - WCA, Primary Care Networks

Identify how some roles in 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, and understanding any training and development needs identified through the ENRICH [1] Wessex Cancer Alliance project.

Services specially designed to provide services to people with cancer have been identified along with more generic services who may well see people with cancer. However, there may be various reasons for services not doing so such as service specifications and funding set out to deliver specific services to specific groups in the population and the skills, knowledge and capabilities of the staff working within these services to deliver appropriate care.

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.

Only seven services reported providing the continuum of services from prehabilitation through to rehabilitation. This is likely to be for a variety of reasons including how services have historically been set up and funded, services being set up to support a specific patient group at a particular point in the pathway and finite resources to only enable a focus of care at a particular point in the pathway.

Overall prehabilitation and/or rehabilitation services for people with cancer were not identified as specifically commissioned. The exception to this was the rehabilitation services to children, teenagers and young people with cancer at University Hospitals Southampton which is funded by specialised commissioning. This service is funded in part by specialised commissioning and in part by charitable funds. In the absence of commissioned services, the impact for patients and the potential subsequent burden on health and social care shouldn't be under estimated.

The majority of services scoped and identified focus on the surgical pathways with some supporting those having surgery and chemotherapy. There are far less, if any, obvious

[1] Increase communication and engagement with the non-specialist workforces who support people affected by cancer, Maintain the currency of the education plan and resource table , Provide a forum to collaborate and avoid duplication of training and education offers

prehabilitation and rehabilitation services for non-surgical cancer patients including radiotherapy and novel therapies such as immunotherapy. Services are primarily delivered by allied health professionals, followed by support workers and nurses. A few services involve the wider workforce, such as fitness instructors and counsellors, in delivering interventions.

Where services are provided, patients are seen either at one stage or multiple stages of the pathways from pre-diagnosis through to palliative and end of life care.

Targeted and specialist interventions for prehabilitation and/or rehabilitation are provided across some NHS provider organisations however some services see patients with a) one tumour type such as head and neck cancer b) some services see patients with different tumour types.

It is unclear how patients with targeted and specialist needs are supported who are out with specific services set up for particular tumour types. This scoping has identified gaps in service provision for targeted and specialist support.

A proposed set of principles to support prehabilitation and rehabilitation services across Wessex is set out below:

1. Referral processes are explicit, easy, efficient and equitable
2. Prehabilitation and rehabilitation interventions should be:
    a. timely
    b. co-ordinated both within and between NHS, third sector, leisure and independent services.
    c. prevent avoidable disability
3. Prehabilitation and rehabilitation interventions should:
    a. meet people's needs and support them to identify and work towards personalised goals/outcomes based around things that matter to them in the recovery/lives
    b. be delivered in a way that is most effective for that person and gives people a sense of choice and control.
4. Prehabilitation and rehabilitation pathways should:
    a. address physical, cognitive, social, communication and mental health needs
    b. be delivered locally where possible making best use of community assets and increasing accessibility of services.
    c. allow access to targeted and specialist interventions by the right person with the right skills.
5. Any prehabilitation and rehabilitation should:
    a. be adequate to allow attainment of personal goals, optimisation of function, and support the best quality of life possible
    b. incorporate teaching the skills that allow maintenance and/or optimisation of function through self-management
    c. include regular review for people with complex disability that is likely to deteriorate and equip people with understanding to recognise deterioration/anticipate any likely change and know how to access appropriate services for support.

6. Services providing prehabilitation and rehabilitation need to be:
    a. well led
    b. adequately staffed in terms of range of disciplines, skill mix and expertise.
    c. supported by a rehabilitation network
7. Services providing prehabilitation and rehabilitation service should:
    a. recognise the role of families and patient wider networks
    b. actively involve families and the patients wider networks (provided this is what the patient and the family agree to)
    c. support families and a patients wider networks to work with patients

Recommendation 4 WCA, Healthcare service providers, ICSs

Produce a quick guide for service providers which will include the set of principles above 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, Service providers, ICSs

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

Leadership is one of the four enablers within the personalised care operating model to ensure service change and transformation. Leadership has also been identified both as a vital ingredient to support change within this scoping work and also in previous publications (40). In order to support implementation of recommendations 4,5 and 6 the overall leadership and accountability for prehabilitation and rehabilitation for people with cancer within healthcare provider organisations needs to be understood and identified through

designated roles in healthcare providers acting as ambassadors to champion, promote and shape services.

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, 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.**

The understanding and perception of what prehabilitation and rehabilitation is by different healthcare staff is important to be clear about. Promotion of a common understanding of prehabilitation and rehabilitation should be an important focus for Wessex going forward. This includes linking to work underway in the WCA to develop easily accessible information and contact details for a) reablement and rehabilitation teams within the acute and community Trusts who may well see people with cancer and need to make contact with oncology specialist teams within the Trusts and b) oncology specialist teams that may need to refer people with cancer for rehabilitation

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.

There are many innovations underway to support people with prehabilitation and/or rehabilitation in the form of different online resources, software and apps.

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.

References

1. Macmillan Cancer Support, Royal College of Anaesthetists, NIHR Cancer and Nutrition Collaboration (2019) Prehabilitation for people with cancer: Principles and guidance for prehabilitation within the management and support of people with cancer. www.macmillan.org.uk/assets/prehabilitation

2. Stout, N et al (2020). A systematic review of rehabilitation and exercise recommendations in oncology guidelines. CA: A Cancer Journal for Clinicians. A systematic review of rehabilitation and exercise recommendations in oncology guidelines - Stout - - CA: A Cancer Journal for Clinicians - Wiley Online Library https://doi.org/10.3322/caac.21639

3. National Institute for Health and Care Excellence (2004) Improving outcomes in head and neck cancers. Improving outcomes in head and neck cancers - The Manual (nice.org.uk)

4. National Institute for Health and Care Excellence (2006) Improving outcomes for people with brain and other CNS tumours. Improving outcomes for people with brain and other CNS tumours - the manual (nice.org.uk)

5. National Institute for Health and Care Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer Palliative care Adults CSG REP (nice.org.uk)

6. Truant TL, Fitch MI, O'Leary C, Stewart J. (2017) Global perspectives on cancer survivorship: From lost in transition to leading into the future. *Can Oncol Nurs J.* ;27:287 Global perspectives on cancer survivorship: From lost in transition to leading into the future - PubMed (nih.gov)

7. NHS England (2019) NHS Long Term Plan NHS Long Term Plan

8. NHS England (2021) Children's cancer services - Principle treatment centres service specification NHS England » Children's cancer services: Principal treatment centres service specification

9. NHS England (2021) NHS England » Children's cancer services: Paediatric oncology shared care unit service specification

10. Macmillan Cancer Support (2019) Statistics fact sheet (macmillan.org.uk)

11. Cancer Services - Data - OHID (phe.org.uk)

12. NHS England » Quality of life metric

13. NHS England (2021) Cancer Quality of Life Survey. Summary report. First data release October 2021. SummaryReport.pdf (england.nhs.uk)

14. National Cancer Registration and Analysis Service Cancer Outcomes and Services Dataset (COSD) (ncin.org.uk)

15. Macmillan Cancer Support (2018) Cancer rehabilitation pathways. Cancer rehabilitation pathways guidance - Macmillan Cancer Support

16. Healthy London Partnership (2019) Cancer rehabilitation - Healthy London Partnership

17. NHS Scotland and Macmillan Cancer Support (2020) Prehabilitation Services for People Diagnosed With Cancer in Scotland - Scoping & Recommendations. Prehabilitation-Services-in-Scotland-for-Cancer-FINAL-150920.pdf

18. NHS England (2016), Commissioning Guidance for Rehabilitation https://www.england.nhs.uk/wp-content/uploads/2016/04/rehabilitation-comms-guid-16-17.pdf

19. NHS England (2019) Comprehensive model of Personalised Care NHS England » Comprehensive model of personalised care

20. Stout, N et al (2020). A systematic review of rehabilitation and exercise recommendations in oncology guidelines. CA: A Cancer Journal for Clinicians. A systematic review of rehabilitation and exercise recommendations in oncology guidelines - Stout - - CA: A Cancer Journal for Clinicians - Wiley Online Library https://doi.org/10.3322/caac.21639

21. Our Cancer Our Way - Welcome to Wessex Cancer Alliance

22. Cancer Care Map Homepage | Cancer Care Map

23. Patient Health Questionnaire (PHQ-9) Patient Health Questionnaire-9

24. Generalised Anxiety Disorder Assessment (GAD-7) Generalised Anxiety Disorder Assessment

25. Nestle Health Science EATING ASSESSMENT TOOL (EAT-10) | NHS (nestlehealthscience.ca)

26. Stroke Engine. Western Aphasia Battery (WAB) – Strokengine

27. The UK FIM and FMA user group (2010) The UK FIM+FAM (Functional Assessment Measure) (kcl.ac.uk)

28. Calvert S, Miller HE, Curran A, Hameed B, McCarter R, Edwards RJ, Hunt L, Sharples PM. The King's Outcome Scale for Childhood Head Injury and injury severity and outcome measures in children with traumatic brain injury. Dev Med Child Neurol. 2008 Jun;50(6):426-31. doi: 10.1111/j.1469-8749.2008.02061.x. Epub 2008 Apr 14. PMID: 18422680.The Kings Outcome Scale for Childhood Head Injury (KOSCHI) | GLA Rehab (gla-rehab.com)

29. Stroke Engine. Modified Rankin Scale (MRS) – Strokengine

30. Shirley Ryan Ability Lab. Berg Balance Scale | RehabMeasures Database (sralab.org)

31. Stroke Engine. Hospital Anxiety and Depression Scale (HADS) – Strokengine

32. Very Well Health. Timed Up and Go (TUG) Test: Uses, Procedure, Results (verywellhealth.com)

33. MD Calc. Barthel Index for Activities of Daily Living (ADL) - MDCalc

34. FACIT.org. FACIT-Fatigue

35. Palliative Care Outcome Scale. Palliative care Outcome Scale (POS) - Integrated POS (IPOS) in English (pos-pal.org)

36. Health Education England and Macmillan Cancer Support (2022) PRosPer - Cancer Prehabilitation and Rehabilitation - elearning for healthcare (e-lfh.org.uk)

37. Pinc and Steel. Our Certification Programs | Pinc and Steel (pincandsteeleducation.com)

38. LiveWell Dorset | Health & Wellness Coaching | Free Advice & Support · LiveWell Dorset.

39. The Chartered Society of Physiotherapy (2022) Easing the pain: rehabilitation, recovery and reducing health inequity. Easing the pain: rehabilitation, recovery and reducing health inequity | The Chartered Society of Physiotherapy (csp.org.uk)

40. Robb, K.A. & Davis, J. (2015) *European Journal of Cancer Care* 24, 601– 604 Examining progress in cancer rehabilitation: are we closer to parity of esteem? Examining progress in cancer rehabilitation: are we closer to parity of esteem? - Robb - 2015 - European Journal of Cancer Care - Wiley Online Library

Appendices

Appendix A - Health and care service providers survey

Section A: About you

1. What is the name of the organisation you work for? (Please tick)

NHS Trusts

Dorset County Hospital NHS Foundation Trust
Dorset Healthcare University NHS Foundation Trust
Frimley Health NHS Foundation Trust Hampshire Hospitals NHS Foundation Trust
Isle of Wight NHS Trust
Jersey General Hospital
Princess Elizabeth Hospital, Guernsey
Portsmouth Hospitals University NHS Trust
Salisbury NHS Foundation Trust
Solent NHS Trust
Southern Health NHS Foundation Trust
University Hospitals Dorset NHS Foundation Trust
University Hospitals Southampton NHS Foundation Trust

Local authorities

Bournemouth, Christchurch and Poole Council
Dorset Council
Hampshire County Council
Isle of Wight Council
Portsmouth City Council
Southampton City Council

Hospices

Forest Holme Hospice
Jacks Place
Julia's House
Lewis Manning Hospice
Macmillan Unit, Christchurch
Mountbatten, Hampshire
Mountbatten, Isle of Wight
Naomi House
Rowans Hospice
St Michaels Hospice
Weldmar Hospice Care Trust

Other, e.g., primary care networks, charity, third sector, independent community providers please specify

2. Which department/team/service do you work in?

3. What is your job title?

Section B: About the provision of prehabilitation services for people with cancer

Definition of prehabilitation: Prepares people for cancer treatment by optimising their physical and mental health through needs based prescribing of exercise, nutrition, and psychological interventions.

4. Are there any services providing prehabilitation to cancer being offered in your organisation?

Yes, please go to Q5

No, please go to Q22

5. Please state the name of the service(s)
6. Please state the geographical area covered by the service(s)
7. What age groups does the service (s) support? (please tick all that apply)

   ≤ 16 years

   ≥ 16 years – 24 years

   ≥ 25 years and above
8. Please describe prehabilitation available to cancer patients

a. Screening: Please describe how patients are screened

b. Assessment:

   Are holistic needs assessments used?
   Yes
   No

   Please describe other assessments used e.g., assessments for nutrition, exercise, emotional support, frailty, cognition

c. Referral routes/access to the services – Please tick those that apply
   -self referral
   -via a healthcare professional
   -Other – Please state

d. Inclusion criteria – Please describe

e. Exclusion criteria - Please describe

f. With regards to prehabilitation, at which **stage** do you see patients (please tick all that apply)

Pre-diagnosis
Diagnosis and before treatment
During treatment
After treatment
Palliative care
End of life

9. Tumour types seen (please tick all that apply)

Brain/Central Nervous System
Breast
Colorectal
Gynaecology
Head and neck
Lower gastrointestinal
Lung
Haematology
Prostate
Sarcoma
Skin
Upper gastrointestinal
Urology
All tumour types seen

10. Types of interventions offered used– Please tick all that apply

Personalised prehabilitation care plans are developed for each patient	
Making referrals to other healthcare professionals	
Advising on self-management	
Universal interventions including the promotion of healthy lifestyle in people living with cancer which may include exercise and/or nutrition and/or emotional support/smoking and alcohol advice	
Supporting those with commonly presenting side effects and rehabilitation needs	
Targeted interventions e.g., exercise, nutrition and emotional support that are applicable to those people with cancer with and at risk of late effects of disease or treatment and those with other long-term conditions.	
a) Exercise	
b) Nutrition	

c) Emotional support	
Specialist interventions e.g., exercise, nutrition and emotional support to people with cancer who have complex needs, complex treatment e.g., major surgery, severe impairment and/or disability.	
a) Exercise	
b) Nutrition	
c) Emotional support	
Delivering specialist interventions to patients with severe functional and cognitive impairment	
Delivering specialist interventions for emotional, financial or practical needs to support patients with activities of daily living	
Delivering specialist interventions for patients having radical surgery or combinations of treatments	
Delivering specialist interventions for patients with advanced diseases, complex palliative and end of life care issues	
Other, please describe	

11. Duration of interventions offered – Please describe
12. Frequency of interventions delivered – Please describe
13. Where are the service(s) are delivered? (Please tick all that apply)
    Outpatient clinic
    Hospital
    GP practice
    Patient home
    Care home
    Hospice
    Other, please state

14. How the service is delivered – (please tick all that apply)
    One to one face to face
    One to one virtual/remote
    Group face to face
    Group one to one

15. Which staff groups are involved in the delivery of the prehabilitation services? Please tick all that apply.

    Counsellor
    Dietitian
    Fitness instructor
    Information and support team
    Nurse
    Occupational therapist
    Physiotherapist
    Psychologist

Psychotherapist
Social prescribing link worker
Social worker
Speech and language therapist
Support worker
Therapeutic radiographer
Volunteers
Other (please state)

16. a) What is the total number of new patients (not just those with cancer) seen by the service annually?

    b) What percentage of the total above are people with cancer?

0-25%
26%-50%
51%-75%
76%-100%

17. Please indicate waiting times for access to your service

    1 week or less
    2 weeks or less
    3 weeks or less
    1 month
    Greater that 1month
    1-3 months
    Other

18. What outcome measures are being used to determine the effectiveness of prehabilitation services offered? Please tick all that apply.

Outcome measure category	**Outcome measures to be used**	**Please tick all that apply**
Quality of life measures	EQ-5D-5L EORTC-QLQ C30 Peds QL Patient Activation Measure Self-efficacy for self-management of chronic disease (Lorig) Patient health questionnaire (PHQ-9) Generalised anxiety disorder assessment GAD7 Hospital anxiety and depression scale (HADS) – Depression Hospital anxiety and depression scale (HADS) - anxiety Warwick Edinburgh Mental Wellbeing Scale Holistic Needs Assessment	

Functional measures	Cardiopulmonary exercise test Sit to stand Timed up and go test Dukes Activity Status Index Incremental shuttle walk test WHO Disability Assessment Schedule Hand grip strength Patient generated Subjective Global Assessment (PG-SGA) Malnutrition Universal Screening Tool (MUST) Rockwood clinical frailty scale Brief fatigue inventory	
Health economic data	Readmissions Length of stay Outpatient visits A and E attendance	
Degree of health/Disutility of care measures	Days alive and out of hospital at 30 days Days alive and out of hospital at 60 days Days alive and out of hospital at 90 days	
Other, Please state		

19. Does the prehabilitation service have:

Permanent funding
Temporary funding (if temporary, when is funding expected to cease) Please state below:
I do not know about funding

No funding for the service

20. Does the prehabilitation service have a service specification?

Yes
No

21. Is there any research underway about prehabilitation in your organisation?

Yes
No
If yes, please describe including funding and whether this has led to development of prehabilitation services

22. Are there any plans to develop prehabilitation for people with cancer in your local area?

Yes
No

Do not know

23. Please share your thoughts on how local pathways could be transformed to support prehabilitation for people with cancer and optimise patients for treatment. (you may wish to include barriers and/or enablers to prehabilitation)

Section C: About the provision of rehabilitation services for people with cancer

Definition of cancer rehabilitation; Enables patients to make the most of their lives by maximising the outcomes of their treatment (where applicable) and minimising the consequences of treatment and symptoms such as fatigue, breathlessness, lymphoedema and other symptoms

Section B questions are repeated for rehabilitation

Section D: Patient Engagement

41. What information is provided to patients about the service (s)?

42. How do you involve and engage with patients and the public in the:

- Planning and design of these services?
- Evaluation of these services?

43. How does the service include/support/engage with family/friends/carers to enable interventions/plans to be implemented?
44. How do you ensure health inequalities are addressed in the planning, design and access to services?
45. How do you gather patient insight on the effectiveness of the service from their perspective?

Section E: Education and training in prehabilitation and rehabilitation

48. Have you had specific education and training about prehabilitation and rehabilitation in supporting people with cancer?

Yes
No
If you answered 'yes' above please describe the education and training you have received in the box below.

49. From the list below please select those topics you would welcome training on to help you support people with cancer

Topic	Please tick all that apply
The role of different professionals in supporting people with prehabilitation and rehabilitation	
Prehabilitation interventions	
Rehabilitation interventions	
Personalised care planning	
Self-management	
Behaviour change	
Exercise	
Nutrition and diet	
Psychological support	

Please indicate any other topic areas you would wish to learn about to support people with cancer with prehabilitation and/or rehabilitation

Appendix B - Project task and finish group membership

Name	Role	Organisation
Abi Desouza	Quality improvement lead	Wessex Cancer Alliance
Olivia Birch	Macmillan Physiotherapy Team Lead AHP Clinical Advisor for Wessex Cancer Alliance and HIOW	Solent NHS Trust
Hilary Boddington	Macmillan GP	Wessex Cancer Alliance
Steve Bond	Engagement officer	Wessex Voices
Rob Chambers	Head of programmes	Wessex Cancer Alliance
June Davis	Director and project lead	Allied Health Solutions
Mary Edwards	Project lead, ARRS and ACP work	Wessex Cancer Alliance
Gill Faley	Head of Adult Speech and Language Therapy Macmillan Therapy Team Lead Joint AHP Strategic Workforce Project Lead	Dorset County Hospital NHS Foundation Trust
Steph Heath	Personalised care programme manager	Wessex Cancer Alliance
Louise Hooker	Children and Young people's Lead	Wessex Cancer Alliance
Andrew Merwood	Clinical Psychologist	Portsmouth Hospital NHS FT
Professor Sandy Jack	Professor of Prehabilitation Medicine Clinical Experimental Science, Faculty of Medicine University of Southampton	University of Southampton
Jane Winter	Lead for nurses and AHPs	Wessex Cancer Alliance

Appendix C - Description of services

Where are services? Hampshire and the Isle of Wight

Organisation	Service name	Geographical area covered	Inclusion criteria
Prehabilitation only (adults)			
Portsmouth Hospitals University NHS Trust	Surgery School	Any area covered by our surgeons	Major abdominal surgery and any other patient the surgeons or anaesthetists feel would benefit
Prehabilitation and rehabilitation (adults)			
Active Nation	Prehab	Hampshire	Long term health conditions
Portsmouth Hospitals University NHS Trust	Macmillan Clinical Psychology Service. Surgery School	Portsmouth, South-East Hampshire plus areas of IoW and W. Sussex in accordance with catchment for regional cancer centre.	Adults affected by cancer - this includes patients and their family members/ carers. The psychology service works alongside a counselling service. The counselling and psychology service will see adults affected by cancer at any stage of the cancer pathway, from pre-diagnosis through to end of life care. The services will accept referrals provided that a person's difficulties are related to, or impacting on, cancer diagnosis/ cancer care. Referrals are triaged to counselling vs. psychology primarily based on complexity and a patient's level of need.
University Hospitals Southampton NHS Foundation Trust	Preop fit (pilot)	Hampshire and the Isle of Wight and Bournemouth in due course	Upper GI, colorectal and urology surgery
Prehabilitation and rehabilitation (CYP)			
University Hospitals Southampton NHS Foundation Trust	Robbies Rehab - paediatric neurology	Hampshire, Dorset, West Sussex, IOW, channel Islands	Brain or spinal tumour under 16 years and under care of Southampton Oncology service


NHS
Wessex
Cancer Alliance

Where are services? Hampshire and the Isle of Wight

Organisation	Service name	Geographical area covered	Inclusion criteria
Rehabilitation only (adults)			
Hampshire Hospitals NHS Foundation Trust	MSK physiotherapy	North and mid Hampshire	An MSK condition limiting MSK function. Not a specialist cancer service. MSK physiotherapy seeing these patients amongst our usual MSK caseload
Portsmouth Hospitals University NHS Trust	Portsmouth Hospitals Speech and Language Therapy	Acute service - Hampshire, Fareham and Gosport and Portsmouth City. Some out of area outpatients with head and neck cancer as far as West Sussex if under the care of the Head and Neck team at Portsmouth hospital	We prioritise using a risk and impact model
Portsmouth Hospitals University NHS Trust	Inpatient therapy service - no specific rehabilitation services as outpatients (patients will get referred to their local palliative care team or community therapy service), however standard therapy intervention is provided to the inpatient cancer care unit.	Patients admitted to PHU from Hampshire and if transferred across from another hospital for treatment e.g. patients who are from the PHU catchment but were transferred to Southampton for treatment, Isle of Wight for radiotherapy or Chichester and West Sussex locality for radiotherapy.	Any patient with issues impacting on their functional ability and mobility e.g. strength, fatigue, breathlessness etc, a history of falls not related to medical causes, diagnosis of MSCC/Cauda Equina, Stem Cell Transplant, end of life patients who require equipment and/or a mobility aid who are not bedbound.
Solent NHS Trust	Portsmouth Specialist Palliative Care Team, Solent NHS Trust	Patients registered with a GP in PO1 - PO6	•Those with persistent symptoms not responding to routine therapy. •Those and their carers having difficulties in adjusting to their disease, including the need for a psychologist's assessment for high levels of depression and anxiety. •Those having difficulty with completing their normal activities of daily living, for example transfers, who may benefit from assessment; aids; equipment; and minor adaptations. •Patients with complex symptoms who require more in -depth mobility assessment or moving and handling review; physiotherapy treatment and advice including respiratory care. •When health care professionals require specialist advice and support with case management. •When significant events or the results of investigations trigger a need for re -evaluation and advance

Where are services? – Hampshire and the Isle of Wight

Organisation	Service name	Geographical area covered	Inclusion criteria
Rehabilitation only (adults)			
St Michaels Hospice	Out patient Lymphoedema by senior Physiotherapist trained in manual lymphatic drainage. We are about to relaunch out patient groups running sessions on managing symptoms such as fatigue, breathlessness for patients and main carer. There are complementary therapy out patients at our hospice.	Basingstoke and surrounding areas covered by specific surgeries. Includes west, as far as Whitchurch, north, Baghurst, East Hartley Wintney, South, Bentley.	over 18. Palliative diagnosis, within geographical area.
University Hospitals Southampton NHS Foundation Trust	UHS Cancer Care Therapy Service provides therapy input to all the inpatient adult and TYA Cancer Care wards, in total 114 beds.	Regional Oncology Centre: Central South Coast, Isle of Wight, Jersey, Guernsey.	Any inpatient adult on TYA cancer care patient on the cancer wards referred to us by a member of the MDT.
Rehabilitation only (CYP)			
Solent NHS Trust	NHS Solent Children's Therapy Services	Hampshire wide	No specific criteria. Case by case decisions as to whether our services can help or not.

Where are services? – Dorset

Organisation	Service name	Geographical area covered	Inclusion criteria
Prehabilitation only (adults)			
University Hospitals Dorset NHS Foundation Trust	Pulmonary rehabilitation	Dorset and west Hampshire	have lung cancer or a chronic lung disease and need to have prehab.
Prehabilitation and rehabilitation (adults)			
University Hospitals Dorset NHS Foundation Trust	Cancer information team	Bournemouth, Poole and some of Hampshire	All patients with a diagnosis of cancer are offered an assessment
University Hospitals Dorset NHS Foundation Trust	Therapy Services/Head and Neck Oncology	Dorset	All patients undergoing Head and neck cancer treatment who consent to attending prehab sessions either virtual or in person.
Dorset County Hospital NHS Foundation Trust	Macmillan Therapy Team, Dorset County Hospital Foundation Trust	West Dorset, Weymouth/Portland and North Dorset and Purbeck	Any inpatient who has been admitted to hospital because of their cancer.
University Hospitals Dorset NHS Foundation Trust	Support via CNS teams Moving Forward Macmillan	Dorset	Not sure
Rehabilitation (CYP)			
University Hospitals Dorset NHS Foundation Trust	Acute Paediatric Physiotherapy and Children's therapy services provide rehabilitation for those children referred from Oncology team. Funding is not provided from Oncology for this and comes out of physio budget.	Dorset	Any child with pain, functional or mobility issues

Appendix D - Outcome measures used in services providing prehabilitation and rehabilitation

Quality of life measures

Outcome measures	Prehabilitation Number of responses (n=18)	Rehabilitation Number of responses (n=18)
EQ-5D-5L	2	3
EORTC-QLQ C30	1	2
Paeds QL	1	2
Patient Activation Measure	0	2
Self-efficacy for self-management of chronic disease (Lorig)	0	1
Patient health questionnaire (PHQ-9)	3	2
Generalised anxiety disorder assessment GAD7	3	3
Hospital anxiety and depression scale (HADS) – Depression	1	2
Hospital anxiety and depression scale (HADS) - anxiety	1	2
Warwick Edinburgh Mental Wellbeing Scale	0	1
Holistic Needs Assessment	3	7
None	1	5
Other	3	3

Functional outcome measures

Outcome measures	Prehabilitation Number of responses (n=18)	Rehabilitation Number of responses (n=18)
Cardiopulmonary exercise test	0	2
Sit to stand	2	6
Timed up and go test	2	5
Dukes Activity Status Index	1	1
Incremental shuttle walk test	0	1
WHO Disability Assessment Schedule	0	1
Hand grip strength	0	2
Patient Generated Subjective Global Assessment (PG-SGA)	0	1
Malnutrition Universal Screening Tool (MUST)	2	4
Rockwood clinical frailty scale	0	2
Brief fatigue inventory	0	3
None	3	4
Other	2	4

Health economic data

Outcome measures	Prehabilitation Number of responses (n=18)	Rehabilitation Number of responses (n=18)
Readmissions	4	3
Length of stay	2	6
Outpatient visits	1	3
A and E attendance	1	1
None	2	7
Other	2	1

Degree of health/disutility of care measures

	Prehabilitation Number of responses (n=18)	Rehabilitation Number of responses (n=18)
Days alive and out of hospital at 30 days	0	0
Days alive and out of hospital at 60 days	0	0
Days alive and out of hospital at 90 days	0	0
None	7	14
Don't know	0	1

Appendix E – Prehabilitation and rehabilitation services in Wessex

a) Prehabilitation and rehabilitation services in Wessex - NHS providers

Organisation	Prehabilitation and/or rehabilitation services provided
Dorset	
Dorset County Hospital NHS Foundation Trust	**Outpatient physiotherapy** - providing an outpatient physiotherapy service at Dorset County Hospital, Weymouth Community Hospital and at many of the local GP Practices.
	Inpatient physiotherapy - provides treatment to patients who are admitted to hospital and require our assessment and care. The inpatient service aims to rehabilitate patients within the hospital setting to achieve the best recovery possible. This includes the treatment of patients with respiratory, neurological and orthopaedic problems.
	Occupational therapy - 3 teams supporting a) Neurology b) surgery and orthopaedics c) Elderly care and medical
	Speech and language therapy – Supporting inpatients, outpatients including head and neck cancer
	Dietitians - The department consists of Acute and Community Dietitians, a Nutrition Nurse Specialist, a Diabetes Dietitian, a Macmillan Dietitian, Renal Dietitians and secretarial staff. There is also a Home Enteral Nutrition (HEN) Team who provide support to adults and children receiving enteral feed (tube feed) in the community.
Dorset Healthcare University NHS Foundation Trust	**Community rehabilitation services -** Nine Integrated community rehabilitation teams providing rehabilitation support at home and in hospital to help people recover from injury or illness, and to live as independently as possible. The teams consist of physiotherapists, occupational therapists and rehabilitation nurses offer assessment, care and therapy for patients across Dorset. This support means that some people can avoid a stay in hospital, while others can be safely discharged from hospital as soon as possible. The teams can also bring in other specialists, such as speech and language therapists or social care workers, if necessary. The support available ranges from short-term, intensive help for up to six weeks, to longer term therapy for people with conditions such as rheumatoid arthritis or strokes, which require more sustained help.
	Community neurology service - offers practical support and advice to patients and carers, helping people to manage the impact of their condition and live as independently as possible. Staff include specialist neurology and Multiple Sclerosis nurses, occupational therapists and physiotherapists. Following assessment, the team can develop an action plan tailored to the needs of the patient and their family/carers, and support them in achieving their goals. The team is based at Kings Park Hospital in Bournemouth, but works out in the community across south and East Dorset, including Bournemouth and Poole.
Hampshire and the Isle of Wight	
Hampshire Hospitals NHS Foundation Trust	**Basingstoke and North Hampshire hospital services, Royal Hampshire County Hospital services, Andover war memorial hospital and Alton community hospital services provide:** Orthotics, Occupational Therapy, Adult Speech and Language, Dietetics & Nutrition, Acute Therapy Team, Musculoskeletal (MSK) Physiotherapy, Hand Therapy/Rheumatology Therapy

Isle of Wight NHS Trust	**Community prehabilitation service -** launched in Trust in March 2022. Patients are seen face-to-face for a one-off appointment in their own homes by Healthcare Assistants where they carry out a comprehensive assessment that includes blood pressure, height, weight, medical history and a lifestyle questionnaire. Assessments are reviewed by the Clinical Team Lead and any underlying concerns, such as raised blood pressure, uncontrolled diabetes, asthma or COPD, are referred to the patient's GP for review and treatment. This means that patients can get any treatment needed and make lifestyle changes prior to their pre-assessment, avoiding any delay and prevention of surgery.
	Laidlaw Day Unit is an outpatient unit caring for patients who require diagnosis and rehabilitation covering many of the disease specialties and services. Patients may be asked to attend for a review appointment with their designated clinician or attend for investigations. A comprehensive assessment is undertaken of all patients needs and a care plan is agreed which provides treatment and support. There are strong links with staff working in the community and within the hospital setting.
Portsmouth Hospitals University NHS Trust	**The Physiotherapy and Occupational Therapy Departments** provide a service of assessment and treatment for patients with either permanent or temporary disabilities, with the aim of maximising function and preventing further disability. The service is provided across a wide range of clinical specialties in the Trust. In addition, they have a Specialist Cancer Care Therapy team (OT and Physio) for in patient oncology and haematology patients, providing rehabilitation. There is also speech and language therapy, dietetics for oncology and prehabilitation provided via surgery school.
Solent NHS Trust	**Royal South Hants Therapies -** Lower Brambles and Fanshawe are inpatient wards which take patients from the acute sector and from the community providing rehabilitation. The therapy team work alongside our dedicated nursing team to support patients to reach their full potential.
	Community Bladder and Bowel Service Portsmouth - The service promotes continence and the management of incontinence, along with all aspects of pelvic floor dysfunction, through interventions by specifically trained nurses and a womens' health physiotherapist. These clinicians provide an assessment service for clients with bladder, bowel and pelvic floor difficulties following clinical pathways agreed with consultants and GPs.
	Solent Musculoskeletal Services
	Spinnaker ward - Spinnaker Ward provides Specialist Inpatient Rehabilitation for patients with complex physical disability excluding new Stroke diagnoses. The unit is primarily commissioned to manage the needs of adults 65 years of age and older, however younger patients [between the ages of 60 – 65 years of age] may also be considered following review by our ward Consultant. 12 beds are step-down beds for patients admitted to the acute hospital. 4 beds are available for step-up from community settings. The ward is situated on St Mary's Community Health Campus.
	Specialist palliative care team, Portsmouth - The multidisciplinary team (who all have advanced or specialist palliative care skills) consists of: - Consultants in palliative medicine, Clinical Nurse Specialists, Specialist Physiotherapists, Specialist Occupational Therapists,

	Clinical Psychologists, Re-enablement Social Worker. The SPCT also hold a weekly Early Palliative Care Clinic for those newly diagnosed as palliative. Support palliative rehabilitation needs and the lymphoedema needs of those on the caseload.
	Portsmouth rehabilitation and reablement team - integrated health and social care team the purpose of which is to provide responsive support for people whose needs have intensified, often as the result of an acute illness.
	Community neurological gym - Physiotherapists with a special interest in neurology and Rehabilitation Assistants providing individual neurological assessment and treatment sessions. Providing self-management for people living with long term neurological conditions.
	Snowdon at home - A community neurological therapy team comprising of physiotherapists, occupational therapists and rehabilitation assistants. Specialising in the treatment of people with a neurological diagnosis or symptoms such as head injury, multiple sclerosis.
	Vocational rehabilitation service - Can help people with neurological conditions identify the barriers that prevent them from returning to work. We provide treatment programmes with specific goals to help reduce or overcome those identified barriers.
	Specialist community neurological rehabilitation team - specialising in the treatment of people with neurological conditions such as Multiple Sclerosis, Parkinson's Disease, Motor Neurone Disease, Head Injury, Cerebral Palsy, Stroke. The team will accept patients who present with neuro specific symptoms with a stable oncology diagnosis and not considered end of life stage of their condition, with rehabilitation goals and / or management optimisation needs. There is a gap in service provision for patients with a brain tumour diagnosis whose needs are unstable, but they are not considered palliative.
	Pulmonary Rehabilitation Team - provides combined exercise and education classes to patients with specific long-term respiratory conditions, such as Chronic Obstructive Pulmonary Disease (COPD), Bronchiectasis, Interstitial Lung Diseases (ILDs) and Asthma (Portsmouth CCG only). People with lung cancer are also seen.
	Southampton Community Independence Service East (CIS) - provides bespoke multi-professional rehabilitation, reablement and social care assessment and support. The service specialises in falls prevention and encompasses community physiotherapy and occupational therapy.
	Mental Health Rehabilitation Services - provide support for people who have been using the secure, inpatient or community mental health services and who need help with their recovery and wellbeing. The team works closely with individuals to help them understand and manage their condition more effectively. The team can help people develop and practice the skills that are important to them, preparing them to move back into the community. Some of the rehabilitation services are residential, and most people will stay at a residential unit for around nine months, but the length of stay will depend on individual needs.
	In Portsmouth - Community physiotherapy team, Adult Social Care Occupational Therapy service and Speech and Language Therapy service all support patients in the community and caseloads will include cancer patients.
Southern Health NHS Foundation Trust	**Romsey Hospital -** provides a wide range of physical health services there are also two rehabilitation wards on the site.
	Petersfield hospital - provide physiotherapy, community mental health teams, older peoples mental health teams and integrated care teams
	Community physical health services - Provide physical health services across much of Hampshire – both in the community and in our inpatient services. We have a number of care pathways, based on different conditions (such as physiotherapy or respiratory) which are used to provide very tailored treatment for service users.
	Inpatient wards - Alton community hospital, Fordingbridge, Lymington, Gosport War Memorial Hospital, Alton community hospital

	Inpatient mental health services
	Specialist Palliative Care Team for South East Hampshire and Fareham and Gosport - multidisciplinary team (who all have advanced or specialist palliative care skills) consists of: - Consultants in palliative medicine, Clinical Nurse Specialists, Specialist Physiotherapists, Specialist Occupational Therapists, Clinical Psychologists.
University Hospitals Dorset NHS Foundation Trust	Physiotherapy, occupational therapy, speech and language therapy, children's health services, therapy classes
University Hospitals Southampton NHS Foundation Trust	**Occupational therapy and physiotherapy, including the Cancer Care Therapy Team (OT and Physio)** **Children's therapy services** **Oncology dietetic team** **Surgery school led by perioperative medicine team**

b) Hospice provision of prehabilitation and/or rehabilitation services in Dorset, Hampshire and the Isle of Wight

Organisation	Prehabilitation and/or rehabilitation services provided
Dorset	
Lewis Manning Hospice	Breathlessness service, lymphoedema clinic, creative arts and wellbeing
Weldmar Hospice	Occupational therapy and physiotherapy
Julia's House	Children's hospice for Dorset and Wiltshire
Hampshire and the Isle of Wight	
Forest Holme Hospice	Emotional support, counselling and psychology services, lymphoedema clinic
Jacks Place	Jacks Place is the only hospice for young adults in our region, offering the care and support they need, but also giving them the independence
Naomi House	Supports families from across Hampshire, Dorset, Wiltshire, Berkshire, Isle of Wight, West Sussex, Surrey and beyond.
Macmillan unit, Christchurch	Community specialist care team
Mountbatten Hampshire	Living well programme - fatigue, sleep, yoga, tai chi, breathlessness. Physiotherapy and Occupational therapy for palliative rehabilitation in the inpatient unit
Mountbatten Isle of Wight	Physiotherapy, occupational therapy, art therapy, music therapy
Rowans Hospice	Living well centre. In patient Physiotherapy and Occupational therapy for palliative rehabilitation.

St Michaels Hospice	Physiotherapy and occupational therapy. Provision of a lymphoedema service

Appendix F - Health and wellbeing support provided at the information and support centres across Wessex

Service/support offers	**Macmillan Information and Support Centre[2], Portsmouth Hospitals University NHS Trust**	**Macmillan Information and Support Centre[3], University Hospitals Southampton NHS Foundation Trust**	**Maggie's Centre [4], University Hospitals Southampton NHS Foundation Trust**	**Wessex Cancer Trust[5] Bournemouth cancer support centre (Andover, Bournemouth, Chandlers Ford, Isle of Wight, Waterside (Hythe))**
Emotional support	Supportive listening service HOPE (Help Overcoming Problems Effectively) workshop Mindfulness workshops Carers support group	HOPE (Help Overcoming Problems Effectively) course Carers support	Psychologist support (Level 1,2 and 3 psychological support provided – level 2 and 3 targeted interventions including acceptance and commitment (ACT) therapy) Carers support Group support e.g., Fight Bladder cancer support group, Heads2Together Bereavement support	1:1 befriender telephone calls or emails Zoom befriending groups and catch ups MENtalk Sing for life (4 groups Isle of Wight, Cosham, Totton, Salisbury)

[2] Macmillan Information and Support Centre (porthosp.nhs.uk)
[3] Macmillan Cancer Information and Support Centre - University Hospital Southampton (uhs.nhs.uk)
[4] Maggie's Southampton | Maggie's (maggies.org)
[5] Wessex Cancer Trust

Service/support offers	Macmillan Information and Support Centre[2], Portsmouth Hospitals University NHS Trust	Macmillan Information and Support Centre[3], University Hospitals Southampton NHS Foundation Trust	Maggie's Centre [4], University Hospitals Southampton NHS Foundation Trust	Wessex Cancer Trust[5] Bournemouth cancer support centre (Andover, Bournemouth, Chandlers Ford, Isle of Wight, Waterside (Hythe))
Physical wellbeing	Taster sessions in yoga, beginners circuits, aquacise, Pilates/stretching	SafeFit Solent University exercise referral scheme Chair yoga Links to leisure centres Fatigue and tiredness service Dentaid[6]	Prehabilitation/rehabilitation group sessions including exercise, nutrition and emotional support Yoga Relaxation Qigong	Online videos guiding you through meditation, tai chi, yoga, self-massages to ease Lymphedema Sound therapy Dance and movement
Complementary therapies	Reflexology, body massage, Reiki, Indian head massage, aromatherapy	Reflexology, Reiki, aromatherapy, hypnotherapy, acupuncture, sound therapy, massage		Reiki aromatherapy, massage, hypnotherapy, acupuncture, lymphoedema massage
Counselling	Talking therapy Fear of recurrence group therapy	Counselling		Telephone and online counselling
Finance/Benefits/employment advice	Help with welfare benefit applications, fuel schemes, financial advice, employment advice, housing issues, accessing charitable grants	Macmillan citizens advice	Benefits advice Help with money worries	Signposting to specialist support such as financial/ benefits advice or support getting online
Self-management	Look good feel better – advice on skincare	Moving Forward Course with Breast Cancer Now	Look good feel better – advice on skincare	

[6] Dentaid in the UK - Dentaid

Service/support offers	Macmillan Information and Support Centre[2], Portsmouth Hospitals University NHS Trust	Macmillan Information and Support Centre[3], University Hospitals Southampton NHS Foundation Trust	Maggie's Centre [4], University Hospitals Southampton NHS Foundation Trust	Wessex Cancer Trust[5] Bournemouth cancer support centre (Andover, Bournemouth, Chandlers Ford, Isle of Wight, Waterside (Hythe))
Other services	Wig service	Hair loss clinic	Crafts and natter Where now? support beyond treatment Chemotherapy workshop	Art group Craft group Stitch and chat group Two buses used to take people to appointments across the region