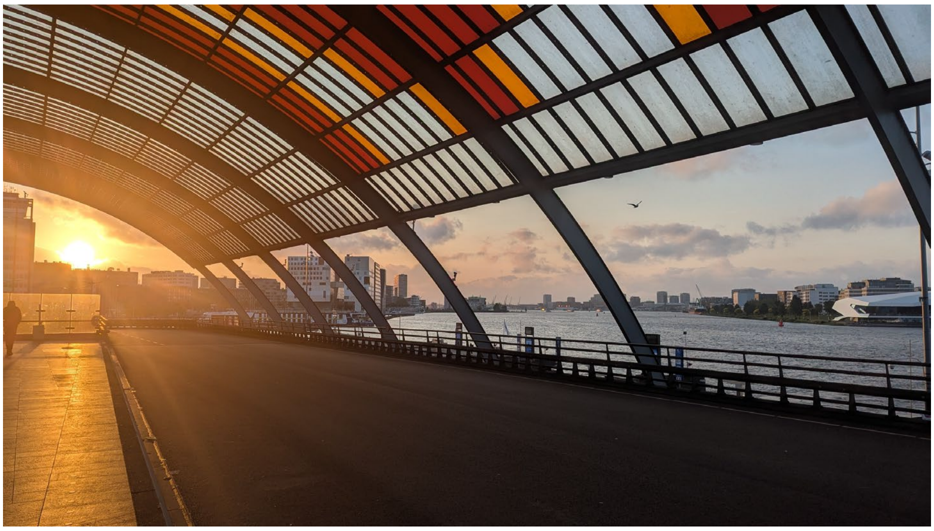


# INTERNATIONAL LEARNING IN PHYSICAL ACTIVITY

## Applications in Head and Neck Cancer and Laryngectomy Care

More people
More active
More often

Mirjana Rasovic-Noruzi
2024 Churchill Fellow

## Acknowledgements

Thank you to my family, especially my husband, for supporting me throughout my Fellowship. The food and drink supplies got me through.

Sincere thanks to everyone I have had the opportunity of meeting and speaking with. Your approachability, generosity and love of the job have shone through and enabled me to learn so much from all of you. It has been wonderful to see how we are all striving for the same thing: ensuring patients get the best outcomes.

I will never be the same speech therapist again.

Mim

Instagram: @mimontour

# Contents

# About Me

As a Principal Speech and Language Therapist specialising in head and neck cancer care, my professional journey has been deeply shaped by personal experience. With 16 years in the NHS, I have seen first-hand the importance of supporting people to live well beyond treatment, and I am passionate about improving access to physical activity for those recovering from cancer.

This commitment has been developing for many years. Witnessing the challenges my relatives faced after their own cancer treatments instilled in me a strong belief that we can – and must – do more to help people thrive after cancer. When my aunt reached her five-year sign-off, the absence of structured survivorship care became starkly apparent. Instead of reassurance, she faced lasting physical and emotional effects and persistent fear of recurrence, which sadly came true.

The loss of my uncle further deepened this conviction. Despite his palliative diagnosis and rapid decline, his determination and zest for life were extraordinary. I have no doubt he would have embraced every opportunity to remain active had such support been available.

As for my patient Rich, where shall I start? He is the catalyst who set me on this journey. Hearing those words, ‘they told me I would never be able to swim, so I showed them I could’, made me reflect that we need to change how professionals talk about adaptation – reducing fear of the unknown and fostering self-efficacy rather than limitation.

What he has achieved, completing a triathlon, is nothing short of inspiring. I feel privileged to know and to have treated him, occasionally offering some useful advice along the way. His inner drive and determination are unrivalled, and I thank him for motivating me to pursue this Churchill Fellowship.

Through my Churchill Fellowship I aim to transform these experiences into action – empowering patients and healthcare professionals to promote physical activity, confidence, and wellbeing for people living beyond head and neck cancer.

# Executive Summary

The initial focus of this project was to enhance access to physical activity for patients following laryngectomy surgery, given the unique challenges associated with managing a neck stoma. However, further investigation revealed that limiting the scope to this cohort excluded the broader head and neck cancer population, who also experience significantly lower rates of physical activity participation compared to other cancer groups, despite the established benefits of exercise. The UK can benefit from adopting inclusive approaches seen internationally, ensuring rehabilitation services are not limited to specific subgroups.

Notably, the only UK facility supporting post-laryngectomy swimming discontinued its service due to equipment from Europe no longer being economically favourable to bring to the UK. Learning, from the closure of specialised centres, demonstrates there is a clear opportunity to advocate for sustainable, accessible physical activity programmes for head and neck cancer survivors. Through the Churchill Fellowship, I examined the parallels and distinctions between head and neck cancer patients and those with other cancers, seeking to answer the following:

- How can insights from physical activity services for other cancer types inform approaches for head and neck cancer, including laryngectomy?
- What strategies do other countries employ to address the rehabilitation needs of cancer patients within government policies and service frameworks?
- In what ways do speech and language therapists contribute to multidisciplinary rehabilitation?

Findings were categorised into six key themes:

- Patient values and workforce
- Information technology
- Guidelines
- Service delivery
- Education and research.

## Recommendations and Next Steps

All health professionals should actively promote physical activity, leveraging national and international models to drive improvements in service delivery. Physical Activity Clinical Champions (PACC) training for Allied Health Professionals (AHPs) is one way of supporting this in the UK.

Collaboration with local organisations and trusts is essential for developing comprehensive business cases. Charitable partners such as The Swallows, Macmillan, Health Education England (HEE), and the National Association of Laryngectomee Clubs (NALC), alongside patient stakeholders, should be engaged to support service development.

Engagement with commissioners, including a review of commissioning models and analysis of return on investment for AHPs, is recommended.
Involvement with quality improvement teams will help ensure changes are effectively implemented and measurable.

Key service gaps requiring attention include:

- Establishment of robust prehabilitation cancer multidisciplinary (MDT) services for head and neck patients.
- Enhancement of AHP services during head and neck radiotherapy, ensuring compliance with best practice guidelines and facilitating collaborative working as demonstrated in Australia.
- Development of an integrated clinic for late effects, providing access to physiotherapists, exercise physiologists, dietitians, speech and language therapists (SLT), occupational therapists (OT), consultants, and nursing staff.
- Investment in MDT survivorship clinics to support ongoing patient outcomes.
- Expansion of online resources for patient self-help and advocacy.
- Creation of a national directory of oncology-specialist exercise professionals.
- Increased accessibility to profession-specific rehabilitation, particularly for long-term dysphagia.

- SLT-led initiatives to advance research and participate in international collaborations, recognising existing limitations in workforce planning.
- Engagement with FAHL representatives to assess the Larchel® device’s potential, identifying barriers and opportunities for developing a patient-driven water therapy programme for individuals with altered airways.

# Introduction

Head and neck cancer (HNC) represents a major public health concern in the UK – ranking as the fourth most common cancer in men and eighth in women – with men from deprived areas experiencing rates over twice as high as those from more affluent regions (Head and Neck Cancer Coalition). Approximately 2,300 people are diagnosed with laryngeal cancer each year (Royal Marsden NHS Foundation Trust), many of whom present with frailty or complex medical and social needs that demand tailored, multidisciplinary care.

Malnutrition and muscle loss are pervasive: up to 60% of patients are malnourished or at risk at diagnosis, and over half develop sarcopenia, both of which worsen during treatment and are associated with poorer outcomes, reduced quality of life, and increased complications. Treatment effects are often extensive and long-lasting – ranging from dysphagia, xerostomia, altered taste, and voice or speech changes to fatigue, pain, and disfigurement. Many survivors face ongoing challenges including weakness, sleep disturbance, and reduced independence, which affect return to work, social reintegration, and financial stability (Homer et al., 2024).

Laryngectomy patients experience high rates of depression and social isolation, especially among women, underscoring the need for comprehensive psychosocial and physical rehabilitation (Jimenez-Labaig et al., 2025; Hammermuller et al., 2021; Rohde et al., 2018). Common late effects such as fatigue, lymphoedema, neuropathy, metabolic changes, and fear of recurrence mirror those in other cancers but can be exacerbated by co-morbidities, further limiting access to rehabilitation and future treatment options. Head and neck cancer patients can have co-morbidities and long-term health conditions, leading them to be more at risk (twice as likely) to be inactive as those without and have a higher mortality rate (Doughty et al., 2025; Fried et al., 2021).

Evidence across cancer types – particularly breast, colorectal, and prostate – demonstrates that physical activity improves cancer-specific survival and overall wellbeing (Courneya et al., 2025; Vardy et al., 2019). Yet, these benefits remain underutilised in head and neck cancer populations, where the physical and psychological barriers to activity are profound. Changes to appearance, swallowing, speech, and identity can erode motivation and confidence, making engagement with rehabilitation particularly complex. Head and neck patients also often had inaccurate perceptions of the amount of physical activity they were completing, perceiving their mostly low-intensity activities as already sufficient, as well as having a fear of doing potential harm (Sealy & Stuiver 2021). In the UK, a recent study by Doughty et al. (2024) found that only 39% of health professionals routinely discussed physical activity with their patients, and just 38% felt confident initiating these conversations. Moreover, 76% reported needing additional training to do so effectively. This reflects not only my own professional experience but also aligns with findings by Schwartz et al (2017), who noted that healthcare professionals often lack awareness of exercise recommendations and timing, leading to hesitation in encouraging physical activity behaviours.

Recognising this, my Fellowship explored international models of promoting physical activity and behaviour change across cancer populations, focusing on how communication, motivation, and system design shape adherence and empowerment. A unifying insight from all centres was that promoting physical activity extends far beyond providing exercise prescriptions – it requires an understanding of human behaviour, readiness for change, and the power of the therapeutic relationship. Speech and language therapists are uniquely positioned to integrate these principles into care.

Concepts such as motivational interviewing, change talk, and self-efficacy were embedded in patient interactions and service design. Centres with established prehabilitation and rehabilitation frameworks demonstrated how variety and flexibility – through interventions such as yoga or ballet – enable culturally sensitive, individualised care. Strong research integration and academic partnerships ensured that evidence-based practice was continuously embedded and evolved.

Within the UK, a new political emphasis on prevention, reflected in the political paper, ‘10 Year Health Plan for England: fit for the future’ (2025) and related government strategies, signals growing recognition of the importance of proactive health interventions. However, the “People Plan” lacks clarity on who will lead the physical activity agenda, and chronic underfunding of allied health professions continues to constrain service delivery. Coupled with commissioning models that prioritise short-term income over long-term health gains, significant gaps in cancer rehabilitation are created – issues all underscored by Aggarwal et al. (2024).

## Physical activity refers to:

The World Health Organization (WHO) (2024) defines physical activity as **any bodily movement produced by skeletal muscles that requires energy expenditure**. Physical activity refers to all movement including during leisure time, for transport to get to and from places, or as part of a person's work or domestic activities.

**Exercise** is a subcategory of physical activity. It is **planned, structured, repetitive, and purposeful with the aim of improving or maintaining physical fitness** (Caspersen et al., 1985). Examples include running, weightlifting, or attending a yoga class. Exercise focuses on specific health goals, such as cardiovascular endurance, muscular strength, or flexibility, making it a targeted intervention for improving overall health. Exercise follows a defined routine, whereas physical activity is often spontaneous and integrated into daily life (Faleye, 2025).

This report synthesises international learnings, considers their relevance to UK head and neck cancer and laryngectomy rehabilitation, and reflects on professional insights gained throughout the Fellowship.

## Objectives of the project

The overarching aim of this project was to explore transferable strategies, evidence-based practices, and service designs that could inform improvements in UK cancer care. In particular, the project sought to support the development of consistent, person-centred approaches to physical activity within head and neck cancer (HNC) pathways, and to highlight the underused potential of Allied Health Professionals (AHPs) in promoting recovery and long-term wellbeing.

## Purpose of the report

This Fellowship draws on international learning to identify key themes and practical recommendations for strengthening survivorship care in the UK. The report aims to stimulate professional discussion about the role of physical activity in HNC rehabilitation – both at a **system level**, through service design and policy, and at a **community level**, through local engagement and support networks. Ultimately, it seeks to bridge the gap between what is known to be effective and what is currently implemented in practice.

## Methodology

Over an eight-week period, I visited leading cancer and rehabilitation centres in Australia, Germany, Italy, and the Netherlands. Insights were gathered through interviews, observations, and reviews of clinical and educational resources, focusing on innovative and person-centred approaches to physical activity and recovery.

I had the privilege of being alongside a wide range of professionals within the multidisciplinary team (MDT), including ENT consultants, exercise physiologists, physiotherapists, occupational therapists, psychologists, dietitians, yoga and ballet instructors, and speech and language therapists. Conversations with patients, clinicians, and industry representatives – both planned and serendipitous – provided valuable perspectives on how culture, motivation, and system design influence engagement in rehabilitation.

These countries were chosen for three main reasons:

1. A strong evidence base supporting physical activity in cancer care
2. Well-established research and innovation networks in rehabilitation
3. Specialist expertise and unique approaches to speech and language therapy within cancer pathways.

# The Importance of Patient Values: Professional Perceptions and Information-Giving to Promote Physical Activity

## Aligning activity with identity

The idea of improving access to physical activity in head and neck cancer is challenging; not only due to time frames but also establishing how clinicians can get to know a patient in a relatively short space of time to promote the importance of physical activity in their cancer care, whilst understanding their unique needs, perspectives and priorities. Behaviour change theories highlight that there are a few factors to consider when enabling physical activity including: humans are social beings, and we need a social reward to successfully maintain physical activity. It needs to be socially based and relatable. If not, then we deem it unnecessary leading to low adherence and low effect. This is echoed in my conversation with Tim McCallum, pioneer of the Australian pilot project Singing Cords, designed to promote vocal and pulmonary health as well as psychological wellbeing.

> *"You need to know who I am as a person and what interests me, because I'm going to be so much more motivated if it's something that I already love, it can get me back to where I was beforehand and so I still use those skills today."*

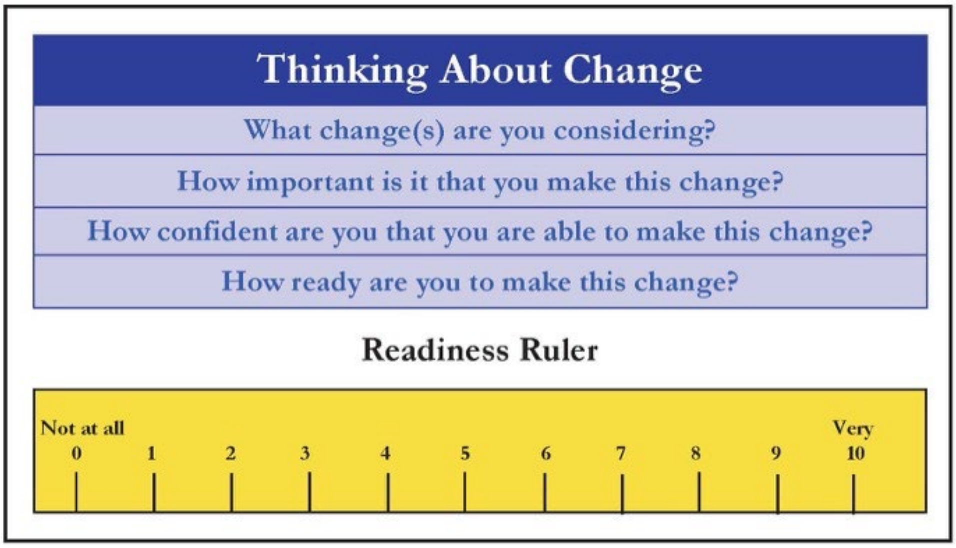
He recalled:

> *"Everyone was so focused on the disability … up until that point of my rehab [it] was about the biomechanics of what the body does, and not about what the emotional impact of the activity was."*
>
> *"It's about being able to project in loud places, being heard and feeling comfortable; that QOL around going to a café where there's music and you've got to speak up over that or going to a sporting event or concert with a friend."*

He reflected how he felt when he was offered an irrelevant activity during recovery:

> *"I hate chess. I was 18 and into basketball and music. I just said, look, I wanna know the objectives – then we can apply something that I'm interested in that still achieves the same results."*

This approach – anchoring rehabilitation in personal meaning – improves adherence and morale. It is relatable when considering head and neck patients and the psychosocial impact of their treatment. Person-centred care was evident across different centres through the use of structured tools such as the readiness ruler:


**Thinking About Change**

What change(s) are you considering?

How important is it that you make this change?

How confident are you that you are able to make this change?

How ready are you to make this change?

**Readiness Ruler**

Screening instruments like the Hospital Anxiety and Depression Scale (HADS) and bespoke prehabilitation assessments such as red, amber, green (RAG) rating were used to identify barriers, vulnerabilities and motivational cues enabling staff to quickly gather a glimpse of the patient needs throughout the pathway. Whilst in the UK we have the health needs assessment, this is not always utilised by staff, making its purpose, to empower patients to own their care and educate staff on their concerns, defunct.

## Understanding motivation and behaviour change

In 2021, Santa Mina et al. concluded that “*motivational interviewing techniques and screening for readiness for behavioural change may impact how and when physical activity is accessed*.” This insight underscores the value of psychological frameworks in shaping patient engagement and the need for clinicians to recognise the individuality of each patient’s journey toward activity and recovery. As pointed out by a consultant at the Netherlands Cancer Institute (NKI), whether someone is at the start of their cancer journey or not dramatically changes their perspective and priorities. Nurse Passchier at the NKI outlined that she often asks patients what they want to be doing in 3 months’ time and then works to make the goal measurable and attainable via SMART goal setting with the patient.

The importance of having professional support is highlighted in my discussion with survivorship Nurse Practitioner Kim Kerin-Ayres who, spearheaded by Professor Vardy, set up the first Australian survivorship cancer clinic in Sydney. She recalled early patient feedback:

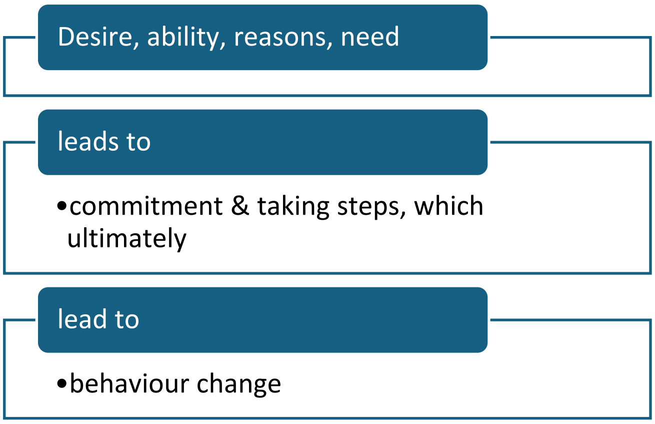
> *"You know, we're not stupid, kid. We know what we need to do. It's just not that simple."*

This statement reflected a key truth – that knowledge alone does not equate to action. Similarly, the way a professional frames information can either ignite confidence or fear in a patient, either promoting or stifling independence to act:

> *"Tell us what we can do and how to adapt, rather than what we can't."*

This statement from a gentleman from the Brisbane Laryngectomy Group echoed my laryngectomy patient's perspective regarding how he was told he wouldn't be able to swim again. These reflections emphasise the need to change how professionals talk about adaptation; not focusing on limitations.

When discussing these challenges with Dr Maree Grier, Senior Clinical Psychologist at the Royal Brisbane Hospital, she emphasised that meaningful interactions must achieve a balance of offering advice, meeting individual needs, working with motivation and supporting self-efficacy. As she explained, the response will vary depending on what needs a "boost of support." This understanding reflects the essence of change talk – the language of motivation within motivational interviewing.



This is also a constant theme to success that is shown throughout all the service examples.

## Information as empowerment and embedding motivational theory

The exercise guide ‘Preparing for bone marrow transplant’ by Peter Mac and The Royal Melbourne Hospital is a clever example of putting psychological theory into practice.

It is a 27-page document addressing barriers, staying motivated, discussing evidence-based practice (EBP), patient and professional opinions and habit building. It also addresses common themes and barriers, and provides patients with signposting and suggestions, finishing with a page for the patient to complete their own goal setting.

It includes an introduction about how motivation is influenced by a variety of things including beliefs; cost benefit ratio; enjoyment; confidence; planning. It utilises a ten point questionnaire and flow chart with agree/disagree answers required, enabling patients to consider what may be influencing their motivation to exercise as well as preparing for readiness for change.

The questions are below:

***Q1. I believe exercise is a good thing I can do for my general health***

***Q2. I believe exercise will help me prepare for my bone marrow transplant***

***Q3. I will feel guilty if I don’t exercise***

***Q4.I enjoy exercising***

***Q5. I am confident I can do strength-training exercises with proper technique***

***Q6. I am confident I can walk regularly***

***Q7. I have people to support me to exercise***

***Q8. I have somewhere safe and comfortable to exercise***

***Q9. I make plans concerning what exercise I am going to do each week.***

***10. I usually exercise at the same time of day***

*Extracts from the exercise guide ‘Preparing for bone marrow transplant; overcoming exercise barriers, building capacity, and staying motivated to exercise’ by Peter Mac and The Royal Melbourne Hospital.*

This approach is both **visually engaging and psychologically informed**, offering patients evidence-based information that is reinforced by both professional expertise and patient perspectives. The materials embody a **consistent, team-driven message**, reflecting a universal theme of empowerment through movement and self-awareness. By incorporating **psychological theory and behaviour change principles**, such as motivational interviewing and self-efficacy frameworks, the resources actively promote engagement rather than passive information sharing.

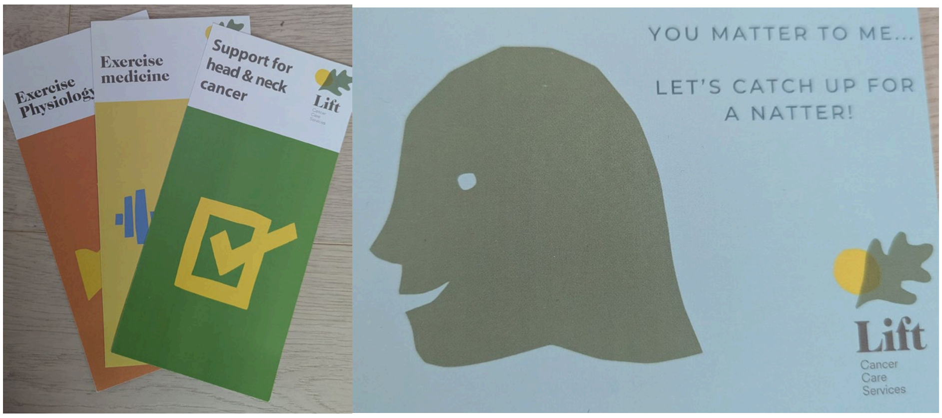
The inclusion of **motivational tools, reflective quizzes, and tailored advice** creates a safe and interactive space for patients to process information at their own pace. These resources encourage self-reflection, allowing individuals to explore their readiness for change and decide what information they wish to share with the clinical team. In doing so, they lay the groundwork for **self-empowerment and sustained behavioural change**, while providing a valuable starting point for meaningful dialogue between patients and healthcare professionals. A reference list for those seeking further information reinforces transparency and supports informed decision-making.

Overall, this model exemplifies how educational materials can complement clinical care – **bridging the gap between patient reflection and professional reinforcement**. It helps patients to engage in the preparatory stages of change, setting the tone for collaborative goalsetting during consultations.

## Application in the UK

To implement this effectively in the UK, **clear pathways and professional ownership** must be established. Patients should know exactly who to discuss their quiz results and exercise concerns with, and at what point in their care pathway this occurs. Designated roles – whether within speech and language therapy, physiotherapy, or clinical nursing – should be responsible for reviewing responses and reinforcing key messages.

For maximum impact, the tool must be **integrated into multidisciplinary practice**, with a shared understanding among all professionals that it represents an important, evidence-based component of rehabilitation. Its value should be reinforced by the **consultant team** to demonstrate leadership endorsement and consistency across the care pathway. Embedding this tool into UK services could therefore strengthen patient engagement, improve self-efficacy, and promote a unified culture of empowerment and shared responsibility in cancer rehabilitation.



*Lift Cancer Care Services, Adelaide (2025)*

Many centres shared the ethos that **information is power**. Alongside verbal communication from the multidisciplinary team (MDT), information was reinforced through **leaflets, online resources, and videos**, ensuring accessibility across varying levels of health literacy and reducing the risk of decision regret. Presenting information in multiple formats allows patients to **engage at their own pace**, revisiting details when they feel ready.

With advances in digital technology, **valid and credible online tools** – including YouTube videos and digital leaflets – are increasingly important for supporting understanding of services, physical activity, and speech therapy exercises. The range of online resources available across trusts is impressive, reflecting best practice in **team-based, consistent messaging** that reinforces the importance of movement and adherence to rehabilitation exercises. Notably, many conclude by inviting patients to contact healthcare professionals with questions, helping to build confidence and maintain open communication throughout the care pathway.

## Reflection

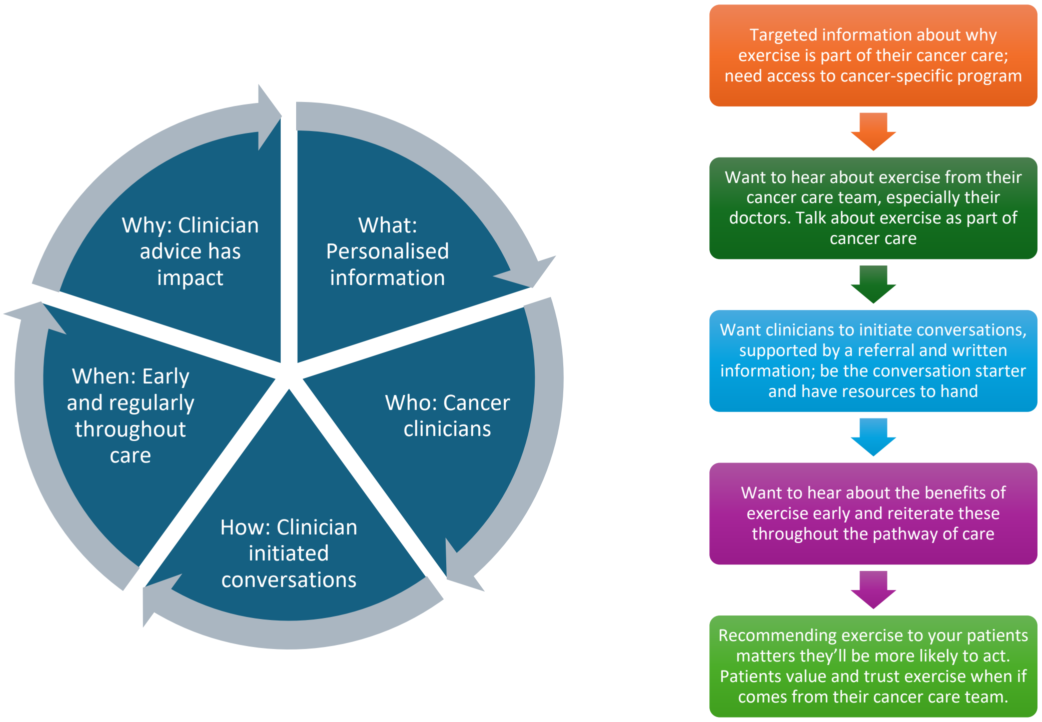
This approach embodies the Fellowship's central theme – **empowerment through accessible, evidence-based information**. By combining professional guidance with patient choice and digital accessibility, these resources transform education into a tool for self-management, motivation, and shared responsibility in recovery.

| Facility | Timing | Name | Link |
|---|---|---|---|
| Peter Mac (Victoria, Australia) & Royal Melbourne Hospital | Prehab – surgical | ERAS – enhanced recovery after surgery | https://www.petermac.org/patients-and-carers/health-services-for-cancer-patients/prehabilitation/surgery-school<br>https://www.youtube.com/watch?v=_d4JDbm2kBQ<br>https://www.youtube.com/watch?v=DmkB9mfYIXY<br>https://www.youtube.com/watch?v=Z_zfhtrJUiM<br>https://www.youtube.com/watch?v=frLQ6tPECSw |
| Amsterdam UMC | Prehab – surgical & oncological | Head Matters & in tune without cords (laryngectomy) | https://youtu.be/fAVyKkIrGg4?si=rH88d42O5wWLb9rF<br>https://youtu.be/CvJQyhRirQ0?si=fUlS55egmth88Ji6 |
| Peter Mac | Prehab – oncological | Prep4RT | https://www.petermac.org/patients-and-carers/information-and-resources/preparing-for-radiotherapy-for-patients-with-head-and-neck-cancer-prep-4-rt<br>https://www.petermac.org/patients-and-carers/information-and-resources/preparing-for-radiotherapy-for-patients-with-head-and-neck-cancer-prep-4-rt/preparing-for-radiotherapy-how-do-you-do-it |
| Peter Mac | Throughout pathway | Online exercises for movement | https://www.youtube.com/playlist?list=PLcZoMS6kmE0s7yyq9qj2Zc145qBPCiroZ |
| LIFT Cancer Care Services (Adelaide) | Throughout pathway | General education around services | https://www.liftcancercare.com.au/ |

In Amsterdam UMC this has been taken one step further by using the hospital system to send push notifications and reminders for patients to be proactive in the prophylactic dysphagia exercises, with good adherence. Again, another strength of this study by Dr Van Der Scheer is that it is a multi-centre study (12 out of 14 centres) so increased population numbers can be gathered for feasibility, and it is also investigating professional barriers limiting adherence.

However, Cormie et al. (2025) conducted a study at the Peter MacCallum Cancer Centre (Melbourne, Australia) which found that resources alone are insufficient; engagement only occurs when information is personalised through patient–professional interaction. When promoting exercise, patients valued: tailored discussion of goals and barriers, clear demonstration of relevance to their treatment, reinforcement of progress across multiple contacts.

Cancer patients want the following from their clinicians to adhere with evidence-based exercise guidelines:



*Adapted from Cormie et al (2025): What patients with cancer require from their clinicians to enable uptake of exercise as part of cancer care: A mixed methods study.*

## Digital empowerment: patient portals

- Decision making tool-battling patient regret https://www.keuzehulp.info/maastro/strottenhoofdkanker/1074517/intro
- Patient aid for ongoing follow up https://www.nazorgkeuzehulp.nl/

Peterson et al. (2019) developed a **Patient Decision Aid (PDA)** for advanced laryngeal cancer to support informed, value-based treatment choices. PDAs help patients understand options and clarify preferences; a Cochrane Review (Stacey et al.,2017) found that their use increases knowledge, reduces decisional conflict, and encourages active participation. Both patients and clinicians viewed the PDA as a major improvement to counselling, though feasibility and integration into practice require further study.

Effective decision-making depends on **adequate knowledge, realistic expectations, and clear risk–benefit communication**. When these are lacking, decisional conflict may arise, leading to regret or delayed treatment (Brehaut et al., 2003; Gattellari et al., 2005). Improving **health literacy** – the ability to access, process, and understand health information– is therefore essential.

**Digital tools** can enhance empowerment and engagement but should **complement, not replace**, clinician input. Challenges include inconsistent use of PROMs, variable staff engagement, and infrastructure limitations. Clear guidance on **timing and purpose** is needed to ensure decision tools genuinely support shared decision-making and patient confidence.

## Communication and common messaging

*Aachen Hospital Gym (2025)*

Physiotherapist Mr Uebis (of Aachen Hospital) highlighted the importance of language consistency, advocating for: cancer specific activity groups, goal-orientated sessions, and flexibility to re-enter programmes at any point. As one patient summarised, "*exercise helps me control the situation*" at a time when very often the diagnosis, appointments, and treatment plan are out of the individual's control. Useful phrases to reduce stereotypical expectations and pressure of what is expected in physical activity include:

'Think about making movement not sport'
'Keep moving, let's just change the frequency'
'Let's aim for less rest'
'What do you like?'
'What does your body tell you?'

Without consistent messaging, efforts to promote empowerment and behaviour change falter. Cultural readiness matters, and the impact and benefit on staff should also be considered:

> *"Unless your culture and your people are set right, both seem to suffer."*
>
> (Tim McCallum, 2025)

## Practical integration: "making every contact count"

## Princess Alexandra Hospital and the Royal Brisbane Hospital

An example of this is the physiotherapy teams and optimising pre-operative assessment sessions. Many centres I visited use this opportunity to gather further patient information, baseline measures of physical activity, and risk factors, as well as an opportunity for education. This is important to consider, as often in head and neck cancer there are short turnaround times from diagnosis to treatment, so the earlier AHPs can be involved in the process the more chance there is to repeat that common message of the importance of physical activity. It should also be considered, though, that advanced communication skills are required to not pressurise the patient, and to identify which professional is most needed at any one time, as this may change throughout the pathway.

## Beyond roles: workforce and culture

Internationally, attitudes toward physical activity in head and neck cancer remain mixed. Even in advanced centres, some professionals – from AHPs to surgeons – expressed uncertainty about its feasibility. Comments such as *"I don't want to burden my patients with more things to do when they have to prepare for a life-changing operation"* and *"You have to be realistic; our patient group is complex, and I'd be concerned about airway compromise or malnutrition"* reflect ongoing hesitation about integrating exercise into routine care.

One clinician in Australia observed that *"the timeframe isn't realistic to make enough impact to fitness. We tried introducing physiotherapy and psychology, but patients just didn't want it when first diagnosed."* This highlights a broader challenge: services may have physical activity embedded within them, yet inconsistent professional habits and communication mean these opportunities are not always realised.

As well as attitudes, capacity challenges to achieve changes in the UK should also be considered, with a significant difference in roles and workload of a speech and language therapist (SLT) across Europe versus the UK and Australia. The impact being on time able to focus on exercise principles both in speech therapy rehabilitation but advocating and signposting to relevant teams to promote physical activity.

The SLT role:

| | **VFS** | **FEES** | **Laryngectomy VP change** | **Dysphagia therapy** | **Voice therapy** |
|---|---|---|---|---|---|
| UK | yes | yes | yes | yes | yes |
| Australia | yes | yes | yes | yes | yes |
| Italy | no | no | no | yes | yes |
| Netherlands | yes | yes | no | yes | yes |
| Germany | no | no | no | yes | yes |
| | | | | | |

For individuals following laryngectomy, communication itself becomes a key determinant of engagement. Without appropriate strategies to understand their values and vulnerabilities, attempts to promote behaviour change or physical activity risk falling short. Staff training in alternative communication methods and patient access to suitable communication aids are essential to ensure equitable participation. Meeting the CEO of **Laronix** during my Fellowship reinforced how innovation – such as AI-enhanced electrolarynx technology – may soon transform the communicative landscape for this population, offering new ways to connect and engage.

## Summary

This experience reinforced that promoting physical activity is not only about what we prescribe, but how we communicate and empower. Embedding behavioural science within clinical pathways reveals that motivation is shaped by culture, environment, and professional language as much as by exercise content. Achieving sustainable, flexible services requires a shift in mindset – where workforce education, integrated research, and shared ownership foster a culture that truly values physical activity as part of holistic cancer care.

# Guidelines

## Exercise

Exercise is increasingly recognised as a core component of cancer care, as emphasised by the Clinical Oncology Society of Australia (COSA) 2019 Position Statement and the Exercise and Sports Science Australia (ESSA)  (Hayes et al.,2019) Position Statement. COSA advocates that all members of the multidisciplinary team (MDT) actively promote physical activity and refer patients to accredited exercise physiologists or physiotherapists with oncology experience. This ensures that exercise programmes are safe, evidence-based, and tailored to individual ability and treatment stage. Patients are encouraged to achieve 150 minutes of moderate-intensity or 75 minutes of vigorous aerobic exercise per week, alongside two to three resistance sessions, delivered within a coordinated, survivor-centred care model that extends beyond surveillance to support recovery, wellness, and long-term healthy lifestyles. ESSA complements this guidance by providing a structured framework for personalised exercise prescription, beginning with comprehensive assessment, prioritisation of health issues, and evaluation of individual capacity and suitability. Exercise is then progressively delivered across dose, mode, intensity, frequency, and duration, with ongoing monitoring, education, and behavioural support, and refined through regular reassessment. This approach positions exercise as personalised, adaptive medicine, integrated into multidisciplinary care to maximise adherence and benefit.

In contrast, the UK demonstrates a notable gap. As of May 2024, only 94 registered exercise physiologists were practising nationally, with most cancer patients accessing physical activity via general exercise referral schemes designed primarily for healthy populations. Around 73% of functional assessments are conducted by exercise instructors; this training often does not address the complex physical and psychosocial needs of oncology rehabilitation. The NHS England Position Statement on Physical Activity (2025) recognises physical activity as essential to health and wellbeing, yet many patients do not receive adequate support to remain active. Similarly, while UK Head and Neck Cancer: United Kingdom National Multidisciplinary Guidelines (Homer et al., 2024) acknowledge cancer prehabilitation as a continuum and note the need for exercise and rehabilitation programmes, structured frameworks and integrated MDT approaches remain limited. European Head and Neck Society recommendations (2022) further advocate for regular assessment of long-term and late effects, counselling survivors to engage in at least 150 minutes of moderate or 75 minutes of vigorous aerobic exercise weekly, plus two strength training sessions, highlighting the gap in widespread UK practice.

Reflecting on these differences underscores the importance of systematic, patient-centred approaches combining tailored interventions, behavioural strategies, and multidisciplinary collaboration to support recovery, wellness, and quality of life. Observing international practice offered a lens to consider how these principles could be adapted and implemented in the UK, informing strategies to enhance physical activity, behaviour change, and MDT integration in head and neck cancer care.

## Survivorship

COSA's 2019 Position Statement on Cancer Survivorship Care highlights a fundamental shift from treatment-focused surveillance to a broader, lifelong survivorship perspective, recognising individuals as cancer survivors from diagnosis onwards. Framing cancer as a chronic disease, COSA emphasises the need to establish survivorship as a distinct phase of care, delivered through sustainable MDT approaches. This concept originates from the pivotal report "From Cancer Patient to Cancer Survivor: Lost in Translation., (2005)", which first recommended the prevention of recurrent and new cancers, management of late effects, surveillance for recurrence and secondary cancers, and coordinated care addressing medical and psychosocial needs through collaboration between specialists and primary care.

COSA outlines five key recommendations: implementing systematic, integrated care; delivering stratified pathways tailored to risk and need; developing treatment and survivorship care plans during transition to follow-up; ensuring equitable access to timely, tailored services; and using evidence-based tools to identify and manage late effects. By reframing survivorship as a proactive, lifelong phase, COSA positions wellness, prevention, and integrated care at the heart of practice, ensuring that survivors' physical, psychosocial, and functional needs are systematically addressed.
During my professional discussions at NKI Amsterdam, the importance of incorporating expert patient opinion in guideline development was emphasised, mirroring NICE and

National Cancer Alliance approaches in the UK, and reinforcing the value of lived experience in shaping effective, relevant care.

## Occupational and Societal Roles

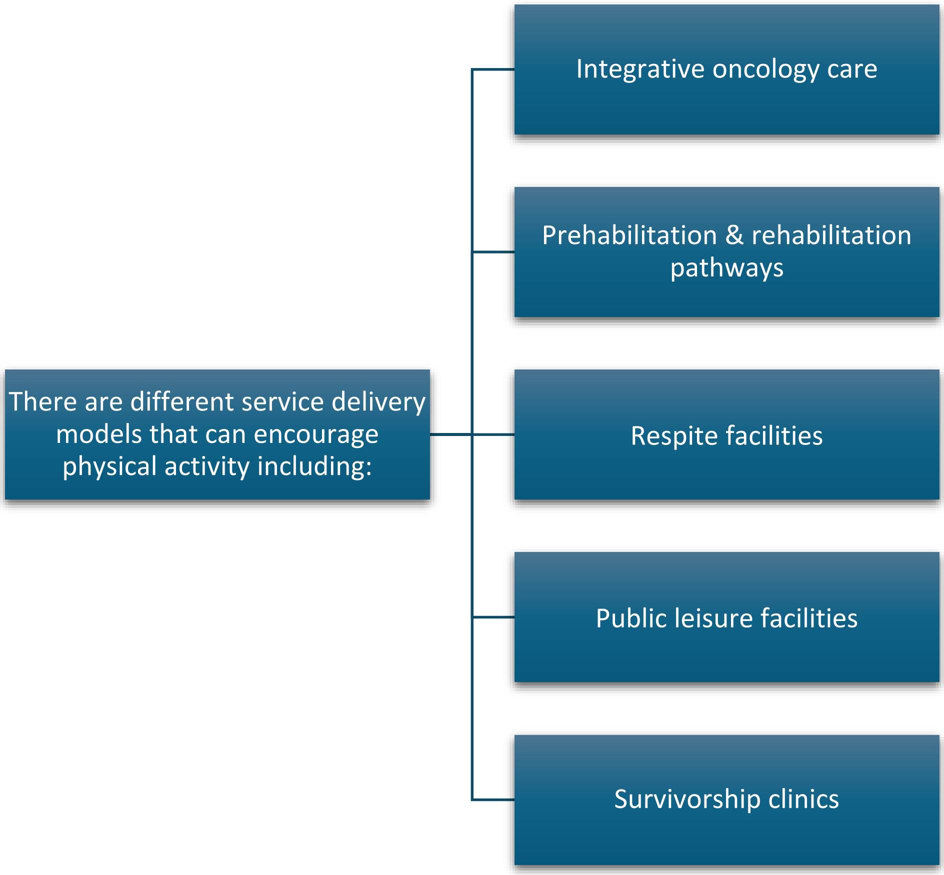
International models, such as Germany's Medical Rehabilitation through German Pension Insurance (2016), highlight the societal dimension of recovery, particularly supporting people with chronic illness to maintain employment and participate fully in society. These guidelines are accessible, culturally sensitive, and emphasise early engagement, stating that patients should proactively seek rehabilitation when needed, with financial barriers minimised. Allied health professionals, psychologists, and social workers provide support tailored to physical and mental health needs, with the ultimate aim of restoring or improving occupational capacity.

In the UK, achieving this is less clear. The Promoting Work as a Health Outcome: Guidance for AHP Leaders (2025) guideline recognises work as a health outcome and the role of all health professionals in supporting employment. However, with 2.8 million people economically inactive due to long-term sickness (March–May 2025), and over 5.6 million disabled employees, implementation remains inconsistent. The Academy of Medical Royal Colleges, Royal College of Nursing, and Allied Health Professionals Federation emphasise AHP's role in promoting work as integral to care, recognising links between physical activity, daily living, and occupational participation.

## Reflections

Collectively, these international guidelines emphasise the integration of exercise, survivorship, and societal participation as core components of cancer care, supported by structured MDT approaches, evidence-based frameworks, and patient-centred strategies. In comparison, the UK demonstrates strengths in guideline development and recognition of physical activity as a health outcome, but gaps remain in specialist workforce availability, structured exercise pathways, MDT integration, and holistic support for occupational participation. Observing international practice highlights opportunities to strengthen UK services by adopting systematic, evidence-based, and patient-centred approaches that prioritise wellness, functional recovery, and quality of life alongside traditional cancer surveillance, while fostering greater equity and accessibility in survivorship care.

# Service Delivery



There are different service delivery models that can encourage physical activity including:

- Integrative oncology care
- Prehabilitation & rehabilitation pathways
- Respite facilities
- Public leisure facilities
- Survivorship clinics

*"Patients are less likely to do it [physical activity] if it is hard to get access to. Need guidance. Patients do own their health, but we have to help them."* (Dr Judith Lacey)

# The Chris O’Brien Lifehouse Hospital: Treating People, Not Just Cancer

## An Integrative Oncological Care (IOC) Model

The **Chris O’Brien Lifehouse Hospital** is a purpose-built, not-for-profit 125-bed cancer centre in Sydney, closely affiliated with the Royal Prince Albert Hospital. It was founded on the vision of the late Professor Chris O’Brien – a head and neck surgeon, oncologist, and cancer patient himself – to *“transform cancer treatment for Australian patients through an environment thriving on discovery, research, and uncompromising care.”* The hospital opened in 2013 with outpatient services, followed by inpatient care two years later. It houses both a clinical trials unit and a psycho-oncology research unit, embedding research into everyday practice.

### The Living Room

A central feature of the hospital is **The Living Room**, an evidence-based supportive care environment designed to help patients live well with and beyond cancer. Accessible before, during, and after treatment, it provides tailored interventions to maintain both physical and emotional wellbeing.

| **Lifehouse Living Room Services** | | |
|---|---|---|
| Individual services | Group-based services | Associated services |
| Holistic medical consultation<br>Acupuncture<br>Oncology massage therapy<br>Reflexology<br>Exercise physiology<br>Physiotherapy<br>Lymphoedema<br>1 on 1 yoga therapy<br>1 on 1 meditation sessions<br>Telehealth sessions | Mindfulness meditation<br>Yoga<br>Qi Gong<br>Exercise classes<br>Survivorship exercise, education and nutrition programme<br>Rehabilitation and prehabilitation programmes | Psycho-oncology<br>Art programme<br>Music therapy<br>Spiritual care<br>Social work<br>dietitian |

Services are also delivered by a comprehensive **Allied Health Professional (AHP) team**, including psycho-oncology, music therapy, physiotherapy, occupational therapy, oncology nutrition, and speech pathology.

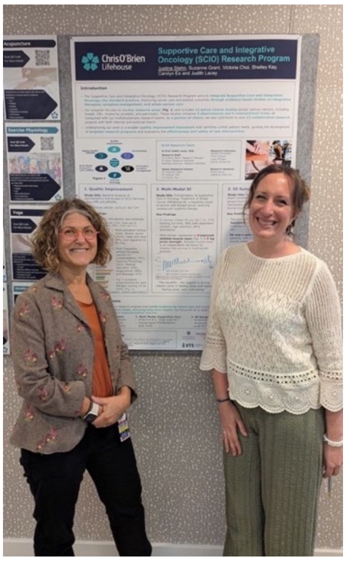
During my visit I observed a 27-year-old patient receiving lymphoedema treatment during week three of unilateral radiotherapy following oral surgery. He described the programme as a *"bootcamp for life, nice to focus not just on post-surgical healing; I just have to show up and it's reduced my self- consciousness."* This demonstrates readiness for behaviour change and engagement with available support and exemplifies how accessible, coordinated environments encourage patients to take ownership of their health and wellbeing.

Another patient perspective highlighted the importance of environment, motivating people to attend appointments:

> *"It doesn't feel or smell like a hospital, it promotes independence and ownership…It feels safe; it [care] is all in one place, I know evidence-based practice occurs and I'm reassured staff have specialist skills and multidisciplinary working. I'm back at work but know I can access what I need when I need it. Cancer messes with you psychologically; it's important I can trust my team."*

## A conversation with Dr Judith Lacey

During my visit, a conversation with Dr Judith Lacey and observations of patient care highlighted the practical impact of this model and how a change in mindset is important from all professionals, strengthening the argument that it is not just patient but staff motivation that impacts quality care.



*"It is no longer about having the treatment, suck it up, go home and you'll be fine. Patients need to be well all the way through treatment. You can intervene proactively; you can potentially change the outcomes, and the perfect example is lymphoedema management. The head and neck surgeons request their patients to have early access to lymphoedema treatment, three weeks post operatively; and the head and neck department will pay. If you start later, especially during adjuvant chemoradiotherapy, it's hard to differentiate between post operative or treatment toxicity."*

## Summary

- Dr Judith Lacey states “*Implementation of IOC requires a demographic and mindset shift. The currency of commissioning has to change.”*
- The Lifehouse model raises important questions for UK cancer care.
    - How can we achieve this level of safety and specialised support while pursuing local, place-based care?
    - How do we demonstrate value within current commissioning frameworks, balancing location with expertise?
    - How can services meet this standard amidst workforce pressures and financial constraints, given many AHP services are currently below recommended staffing levels according to cancer guidelines and GIRFT (getting it right first time) reviews?
    - How can we better measure outcomes such as social reintegration and return to work?

This experience was both inspiring and challenging. It highlighted the gaps in current UK provision: IOC and supportive therapies are not widely implemented in the NHS despite existing governance frameworks. Patients often seek private services, creating inequality and compromising safety and MDT integration. In head and neck cancer care specifically, physiotherapy, occupational therapy, and psychological support are frequently underutilised.

Embedding IOC in UK cancer services could enhance treatment completion, patient empowerment, and long-term quality of life. Surgical and oncological interventions are only as effective as the multidisciplinary team supporting patients to live well beyond treatment. Additionally, the Lifehouse’s use of research-embedded dashboards demonstrates how evidence can guide service provision, monitor needs across specialties, and support continuous improvement.

In summary, the Chris O’Brien Lifehouse illustrates how an integrative, patient-centred model – where supportive care is accessible, coordinated, and research-informed – can transform cancer care. Translating these principles to the UK requires investment in workforce, coordinated multidisciplinary practice, and embedding supportive care as a core component of cancer treatment.

# Sargood on Collaroy: Translating Spinal Rehabilitation Concepts to Head and Neck Cancer Care

An impromptu visit to **Sargood on Collaroy**, a spinal rehabilitation and wellness facility near Sydney, offered unexpected inspiration for how we might rethink rehabilitation for people living with and beyond head and neck cancer. The visit followed a recommendation from a wheelchair user who spoke passionately about how the facility had enabled him to regain independence and confidence at a particularly stressful time – his wife was in intensive care and they were from out of area, so had limited local support available. He described his experience not as respite, but as a *holiday*, where he could engage in adaptive sports such as surfing while maintaining his wellbeing and sense of self.

What struck me most was how **non-clinical the environment felt**. Sargood is not designed like a hospital or standard rehabilitation centre; instead, it feels welcoming and restorative. Subtle ergonomic features – adjustable work surfaces, varied table heights, wide-access pathways, and ceiling hoists – enable inclusivity without drawing attention to disability. The site itself has a rich history, having once been a polio hospital; its current lease ensures the land remains dedicated to healthcare.

Facilities are **adapted for all ages** and cater to both individuals and families, reinforcing a sense of normality and community. The gym is fully equipped with accessible technologies, including ceiling hoists, muscle-stimulating pads, and wristband scanning systems that tailor exercises to each user. Guests can also engage in recreational and social programmes such as adaptive tennis or sailing through partnerships with the National Disability Insurance Scheme (NDIS).

What emerged from this visit was the power of **designing rehabilitation around independence, empowerment, and dignity**. Sargood allows individuals to focus on living well rather than feeling like patients. This environment nurtures self-care and resilience, enabling people to sustain their physical and emotional health even during life's most challenging circumstances.

## Summary

From a head and neck cancer perspective, this model invites us to **think differently** about survivorship and supportive care. Could we envision a similar environment in the UK – one that accommodates the unique challenges faced by people with **dysphagia, neck stomas, or altered airways**, while offering access to safe physical activity and evidence-based complementary therapies? Could partnerships between the NHS, charities, and rehabilitation specialists create such holistic spaces for recovery?

Sargood demonstrates that with innovation and cross-sector collaboration, rehabilitation need not feel clinical or temporary – it can feel like life continuing, confidently and independently.

# Sydney Cancer Survivorship Centre: A Model of Multidisciplinary Excellence

The **Sydney Cancer Survivorship Centre (SCSC)**, led by **Professor Vardy** and supported by **Nurse Kim** and **Dietitian Cindy**, exemplifies compassionate, evidence-based multidisciplinary care. Their programme seamlessly integrates medical, physical, psychological, and social support, creating a robust model of survivorship that extends well beyond clinical surveillance.

The centre offers a **12-week structured programme**, delivered in person or remotely, which supports patients through recovery and guides their reintegration into community-based physical activity. Central to its success is collaboration between clinicians, **exercise physiologists**, and **academic institutions**. By partnering with university programmes, SCSC not only delivers high-quality exercise rehabilitation but also trains the next generation of exercise physiologists – ensuring workforce sustainability and advancing best practice.

A key learning point was understanding the complementary roles of **physiotherapy** and **exercise physiology**. While physiotherapists typically focus on restoring function after injury or surgery, exercise physiologists provide tailored, long-term programmes to improve endurance, strength, and overall health. This partnership model could inform UK practice, demonstrating how physiotherapy services might be enhanced through collaboration rather than duplication.

## Evidence of Impact

Research from SCSC demonstrates the tangible benefits of this model. In Vardy et al's study (2021) of **206 survivors (2013–2019)**, moderate-intensity aerobic exercise increased by **63–68 minutes per week**, and resistance training by **26 minutes per week**, with the proportion meeting exercise guidelines doubling from **20% to 41%**. Participants reported improvements in **pain, fatigue, and energy**, and those experiencing five or more moderate–severe symptoms fell from **35% to 26%**. These outcomes underline the value of structured exercise, supported by skilled professionals, in improving post-treatment wellbeing.

Importantly, patients rated the SCSC highly for its ability to address **psychological and physical concerns** – reflecting earlier findings that cancer survivors experience persistent symptoms long after treatment, which are best managed through coordinated MDT care (Tan et al., 2019).

## Embedding PROMS into Practice

The use of **Patient Reported Outcome Measures (PROMs)** is central to how the clinic individualises care. Patients complete a range of validated questionnaires, including distress thermometers, diet and exercise measures, food diaries, and quality-of-life scales. Between 2013 and 2023, completion rates remained impressively high (up to **99% on paper** and **92% electronically**), suggesting strong patient engagement and acceptability (Tan et al., 2025).

These PROMs enhance communication between patients and clinicians, ensuring consultations are guided by individual concerns rather than solely clinical indicators. They also serve as valuable data sources to monitor outcomes and continually refine service delivery – an approach that could be transformative within NHS survivorship pathways.

## Survivorship Care Plans and Communication

The SCSC also employs **Survivorship Care Plans (SCPs)** to improve continuity and communication between secondary care, general practice, and patients. While healthcare professionals valued SCPs for their educational benefit, research found variable use among cancer specialists, emphasising the need for tailored, accurate, and timely implementation

(Tan et al., 2024). This highlights the importance of embedding SCPs as living documents that support shared care, rather than static records.

## Workforce and Education

The SCSC model demonstrates the power of **investing in workforce development** and **education**. Its collaboration with university exercise physiology programmes strengthens both service capacity and clinical research, embedding a culture of physical activity within cancer care. This forward-thinking approach ensures patients benefit from evidence-based interventions while students gain real-world experience in oncology rehabilitation.

## Summary

The Sydney Cancer Survivorship Centre provides a clear vision for how **survivorship clinics** could complement **traditional surveillance clinics** within the UK. Rather than focusing solely on recurrence monitoring, survivorship services can proactively address quality of life, function, and self-management.

Key takeaways include:

1. **Embed MDT working** – Integrate exercise physiologists, dietitians, nurses, and allied health professionals into survivorship care.
2. **Invest in workforce development** – Partner with academic institutions to train future specialists and expand service capacity.
3. **Incorporate PROMs systematically** – Use patient-reported outcomes to personalise care and track progress.
4. **Enhance continuity through SCPs** – Develop practical, patient-friendly survivorship plans that facilitate communication with GPs.
5. **Offer flexible models of care** – Combine in-person, online, and community-based options to improve access and long-term engagement.

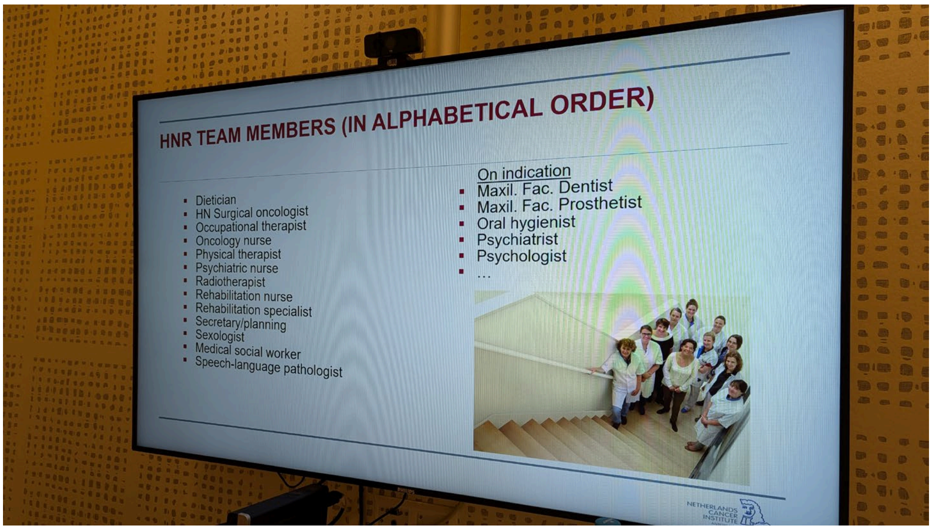
In the UK, survivorship clinics have an important role in service delivery as they align with **preventative health strategies** outlined in current policy. They support people returning to work, maintaining independence, and ageing well after cancer. While initial setup may require investment in specialist workforce and facilities, these services have the potential to generate **long-term savings** by reducing unplanned hospital visits, mitigating long-term complications, and promoting sustained health and wellbeing.

This model epitomises **person-centred care** – where compassion, collaboration, and evidence meet to support patients in truly *living well after cancer*.

The **Sydney Cancer Survivorship Centre (SCSC)**, led by Dr Vardy and supported by a multidisciplinary team, exemplifies best-practice, patient-centred care. Its 12-week programmes integrate exercise physiology, nutrition, nursing, and psychological support, with flexible in-person and online delivery, enabling patients to safely re-engage with community activities post-treatment. Evidence demonstrates increased physical activity, improved symptom management, and enhanced quality of life, while systematic use of **Patient-Reported Outcome Measures (PROMs)** ensures personalised care and strengthens clinician–patient communication. Collaboration with university programmes builds workforce capacity and ensures sustainable, evidence-based practice. **Survivorship Care Plans (SCPs)** further support continuity between specialists, GPs, and patients, although tailored implementation is key.

For the UK, survivorship clinics could complement traditional surveillance services, reflecting preventive health policies, supporting return to work, promoting independence, and aiding long-term wellbeing. While workforce investment is required, these clinics offer potential **long-term savings** by reducing complications and improving patient outcomes. The SCSC model highlights how multidisciplinary, evidence-based, and flexible survivorship care can transform post-cancer recovery, placing patient empowerment and quality of life at the centre.

# Netherlands Cancer Institute – Head and Neck Cancer Rehabilitation



HNR TEAM MEMBERS (IN ALPHABETICAL ORDER)

- Dietician
- HN Surgical oncologist
- Occupational therapist
- Oncology nurse
- Physical therapist
- Psychiatric nurse
- Radiotherapist
- Rehabilitation nurse
- Rehabilitation specialist
- Secretary/planning
- Sexologist
- Medical social worker
- Speech-language pathologist

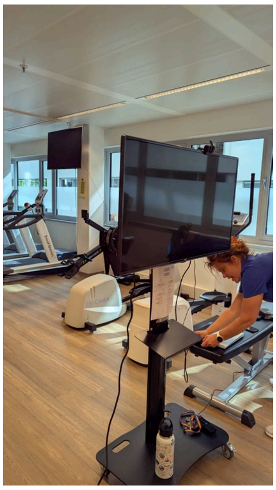
On indication
- Maxil. Fac. Dentist
- Maxil. Fac. Prosthetist
- Oral hygienist
- Psychiatrist
- Psychologist
- …

## Overview

The Netherlands Cancer Institute (NKI) has provided head and neck cancer (HNC) rehabilitation since 2011, combining state-of-the-art facilities with a strong culture of research, multidisciplinary collaboration, and patient-centred care. Its unique model allows clinical practice and research to overlap seamlessly, ensuring interventions are evidence-based and directly translatable to patient care. A key ethos of the institute is empowering patients to self-manage and understand what is normal during recovery, reducing the need for onward referrals.

The Integrated Head and Neck Rehabilitation (HNR) programme is a tailored, multidisciplinary initiative designed to restore functioning, optimise health-related quality of life (HRQoL), and support societal participation for HNC patients. Its aims are to evaluate programme effectiveness, generate evidence for modular interventions, and improve access to rehabilitation and survivorship care across the Netherlands.

An observational prospective study has demonstrated that HNR positively impacts HRQoL and may accelerate recovery compared to mono-disciplinary usual care. A multicentre cost-effectiveness analysis is underway, comparing HNR with standard supportive care across six Dutch HNC centres. Parallel work includes an online survey to assess guideline implementation nationally and identify barriers and facilitators to rehabilitation integration. Recognising gaps in evidence, the programme also explores exercise interventions during chemo-radiation for advanced HNC and develops participation-focused patient-reported outcome measures aligned with the WHO-ICF framework.



**Key Features of the NKI Rehabilitation Model**

- **Integrated Social and Clinical Support:** Combines social counselling with a multidisciplinary rehabilitation programme addressing both physical and psychosocial needs.
- **Structured Assessment:** Screening tools and the ICE framework enable baseline evaluation and outcome measurement for tailored interventions.
- **Flexible Physical Activity Programs:** Face-to-face and remote exercise programmes allow continuity of care, personalised to treatment toxicity and individual tolerance.
- **Patient-Centred and Motivational Approach:** Personalised exercises, educational videos, and motivational strategies encourage patients to “keep moving” even during treatment.

- **Referral Pathways:** Patients can self-refer or be referred from other centres; approximately 100 patients per year participate for six months.

**Research and Evidence-Based Interventions**

- **Expiratory Muscle Strength Training (EMST):** Demonstrates high compliance and improved vocal and respiratory outcomes for laryngectomy patients.
- **MOVEit Study:** Combines supervised physiotherapy with home-based exercise during chemoradiotherapy, supporting habitual movement and good adherence accounting for treatment peak side effects.
- **McNeil Swallow Bootcamp:** Enhances patient confidence and goal achievement; flexible delivery via online or in-person sessions.
- **Guideline Alignment:** Practices follow ESCO 2023–2024 recommendations, emphasizing movement throughout treatment and challenging assumptions that patients are too unwell to participate.

## Summary

My visit to NKI exceeded expectations; what was scheduled as a two-hour meeting turned into a four-hour session, rich with knowledge sharing, publications, and practical insights. Staff displayed a deep passion for understanding their patient population and improving outcomes. The ongoing research projects, many at PhD level, highlight the centre’s dedication to evidence-based rehabilitation despite funding challenges. Notably, investment in rehabilitation outside HNC has been reduced, emphasising the need to carefully consider long-term sustainability and value for money. The experience highlighted how a well-integrated, patient-centred model can translate evidence into impactful care and offered practical lessons for the UK on multidisciplinary collaboration, flexible exercise delivery, and embedding rehabilitation into care pathways.

# Novel ways of working

## Singing-Based Pulmonary Rehabilitation – “Singing Cords” Pilot, Australia

**https://youtu.be/QO-JIOJ02cs?si=eu-_oNYgvgoRK0pG**

During my visit to Australia, I had the opportunity to interview **Tim McCallum**, who leads the innovative **“Singing Cords”** programme. This pilot project explored group singing as a form of pulmonary rehabilitation for people with spinal cord injury (SCI), conducted over three months in a ward-based spinal rehabilitation unit. The study included **five community participants**, who achieved 100% attendance, alongside **five inpatients**, whose attendance was less consistent. Singing was run alongside usual therapies including physiotherapy, occupational therapy, speech and language therapy, hydrotherapy, and social work, demonstrating that it can be integrated seamlessly into existing rehabilitation schedules.

The programme targets **respiratory muscle function, voice control, and overall well-being**, with objective outcome measures including respiratory function, mood, emotional health, and general wellbeing. Tim highlighted that the intervention also created a positive, engaging atmosphere for both patients and staff, producing **secondary gains** in staff mood, team cohesion, and ward environment. As he described, it is about *“creating the atmosphere and creating a space for people to use the music as a means of fun and a way of expressing yourself… a way of forgetting about some of the stuff that goes on in here too.”*

The approach is highly relevant to populations with compromised respiratory mechanics, such as laryngectomy patients. Singing exercises train accessory respiratory muscles, improve breath control, and support voice projection, while offering psychosocial benefits including increased confidence, social participation, and motivation to engage in rehabilitation. By combining peer leadership with clinical oversight, the programme encourages sustained participation through a meaningful and enjoyable activity.

In the UK, **choir groups for laryngectomy patients already exist**, demonstrating that the foundational elements for this approach are in place. What is needed is to **utilise these groups more effectively** as structured pulmonary rehabilitation interventions, linking them to clinical care pathways and evidence-informed exercises to maximise both respiratory and psychosocial outcomes. Tim reflected that **inpatient adherence may be challenging**, suggesting the intervention may have greatest impact in the community, though the **benefit of music in the inpatient setting** remains important and raises a broader question about the role of music therapy within the NHS. From my time at the **Chris O'Brien Lifehouse**, I observed the value of music therapy in providing patients with alternative ways to express mood and emotions, particularly for those not yet ready to access formal psychological support.

For the UK laryngectomy population, this model offers several practical benefits:

- A **motivating, patient-centred intervention** that enhances respiratory muscle training beyond conventional physiotherapy.
- Support for **voice rehabilitation and communication confidence**, central to identity and social participation.
- A **group-based, peer-supported format** that reduces isolation and improves adherence.
- Broader **psychosocial benefits** that improve mood, quality of life, and engagement with care.

## Summary

The **Singing Cords** pilot demonstrates how a creative, evidence-informed rehabilitation approach can produce both physiological and psychosocial gains. While inpatient adherence may be limited, the programme appears particularly effective in the community, with important motivational and environmental benefits for ward settings. Combined with insights from music therapy at the Chris O'Brien Lifehouse, this highlights the broader potential of music-based interventions to support rehabilitation, emotional well-being, and patient engagement. For the UK, leveraging existing choir groups as structured pulmonary rehabilitation interventions offers a **novel, holistic approach** to improving survivorship care for laryngectomy patients, while raising important questions about integrating music therapy more widely into NHS practice.

# The Role of Yoga Therapy in Head and Neck Cancer Care

The benefits of yoga are well established across several cancer populations – particularly breast cancer – for improving peripheral neuropathy, respiratory function, stress control, inflammation, flexibility, and strength. However, its application in head and neck cancer (HNC) remains underexplored.

A recent randomised controlled trial by **Milbury et al. (2024)** examined the feasibility and efficacy of *dyadic yoga* – delivered to patients undergoing chemoradiotherapy alongside their caregivers. Participants were offered 15 sessions across treatment; on average, 12.5 sessions were completed by 37 dyads. Findings demonstrated that yoga therapy was **acceptable and potentially effective** as a supportive care strategy, with participants reporting **reduced symptom severity and interference** and **improved quality of life**.

In discussion with **Georgina Green**, a yoga therapist at the Chris O'Brien Lifehouse Hospital, several key insights emerged regarding safe and effective delivery. Yoga therapy differs from general yoga by being **highly individualised**, informed by **access to medical notes**, physical assessment, and the patient's treatment context. Interventions address both physical and psychological dimensions – such as limited range of motion, breath capacity, neuropathy, and treatment-related anxiety. Green emphasised that "*learning how to relax the nervous system is probably the greatest thing I can teach.*"

Her approach includes brief, tailored video sessions (up to 20 minutes) to encourage continuity and empowerment, with patients often integrating these into radiotherapy sessions or mask fittings. Group classes enhance motivation and adherence, while early referral – ideally before treatment – appears to improve engagement and outcomes, including reduced lymphoedema.

Collectively, these insights suggest that **yoga therapy offers a safe, flexible, and evidence-based approach** to managing both the physical and emotional side effects of head and neck cancer. Early, individualised integration into care pathways could enhance self-efficacy, symptom management, and overall quality of life.

## Summary

Recommendations for UK practice highlight the importance of integrating yoga therapy early in cancer care pathways to improve adherence and outcomes. Approaches should be personalised and evidence-based, tailored to each patient's diagnosis, treatment phase, and comorbidities, with yoga therapists granted appropriate access to clinical information to ensure alignment with medical and rehabilitation goals. Hybrid delivery models – combining brief in-person or virtual sessions with online resources – can support self-management and continuity, while group-based programmes help foster motivation and social connection. Multidisciplinary collaboration between yoga therapists and clinical teams such as physiotherapists, speech and language therapists, and oncologists is essential for holistic care. Developing UK-specific training, accreditation standards, and competency frameworks will ensure consistent and safe practice, while implementing robust research and evaluation strategies will help build evidence on yoga therapy's impact on quality of life, lymphoedema, fatigue, and psychological wellbeing in people with head and neck cancer.

# Community Leisure Facilities: Learning from “Ballet After Breast Cancer”

Dance is increasingly recognised for its wide-ranging health benefits, with UK initiatives such as *Move, Dance, Feel* highlighting its potential to support physical, emotional, and social wellbeing after cancer. However, its feasibility in head and neck cancer rehabilitation remains largely unexplored.

While in Sydney, I met with **Dr Rachel Ward**, an exercise physiologist and ballet teacher, to learn from her pioneering work on the *Ballet After Breast Cancer* feasibility study. Her research involved offering **two one-hour ballet classes per week over 16 weeks**, assessing enrolment, attendance, and participant feedback, alongside secondary measures including **quality of life (QOL), shoulder range of motion (ROM), upper-body function, strength, aerobic capacity**, and **physical activity levels**.

Of the 29 women who commenced the intervention, attendance averaged **77.6%**, with participants reporting **significant improvements in shoulder mobility, reduced sedentary behaviour**, and enhanced **physical, psychological, social, and cognitive wellbeing** (Macdonald et al 2022). The physical demands and creative, social nature of ballet appear to promote improvements across multiple domains, supporting long-term engagement in health-promoting activities after cancer.

During my visit, it was striking that participants attended regularly – often more than once per week – and expressed strong emotional attachment to the classes. When asked why, many described the sessions as *joyful*, *liberating*, and *a space to feel like themselves again*, reflecting the importance of social connection and identity in recovery. Rachel also disclosed that although people were initially frustrated about their initial ability, ultimately it enabled people to let go and move forward, build strength and adapt to their current function, increasing their awareness of what their current ability is and what the body is capable of.

Dr Ward's dual expertise in exercise physiology and ballet ensures a **safe, evidence-based environment** for participants to explore movement beyond clinical settings. This highlights a potential model for the UK – **upskilling dance teachers** and partnering with health professionals to ensure classes are both creative and clinically informed.

From a head and neck cancer perspective, the implications are significant. Many patients experience challenges with **body image, self-perception, lymphoedema**, and **post-surgical disfigurement**, particularly women who may struggle with **reduced femininity** and **psychological distress** after treatment. Given the shared symptoms between breast and head and neck cancers – including **fatigue, reduced strength, neck and shoulder stiffness, and cognitive changes** – dance could offer a meaningful avenue for rehabilitation and reconnection.

Future research should explore the **feasibility of adapted dance**, such as **seated or modified ballet**, both during and after treatment, and assess its impact on long-term engagement, mood, and social wellbeing. Ethical considerations would need to be addressed, but the opportunity to combine physical activity with creativity and self-expression makes dance a promising and holistic approach to survivorship care.

## Summary

All these novel ways of working promote movement and repetitive exercises but in a way that that person has chosen to do and is therefore likely to enjoy more, leading to them being more likely to be compliant in it, rather than repeating shoulder roles in isolation, where there is no translation to overall goal.

## Recommendations for UK Practice

1. **Explore Dance-Based Rehabilitation for Head and Neck Cancer**
   - Develop feasibility studies on adapted dance or ballet programmes to assess safety, engagement, and outcomes in this population.
2. **Foster Cross-Sector Collaboration**
   - Partner NHS trusts, cancer charities, and dance organisations to co-design programmes that bridge community leisure and clinical rehabilitation.

3. **Upskill Dance and Movement Practitioners**
    - Provide targeted education on cancer treatment side effects (e.g., dysphagia, lymphoedema, fatigue) to ensure evidence-based, safe delivery.
4. **Prioritise Accessibility and Inclusivity**
    - Offer options such as seated dance, shorter sessions, or smaller group formats to accommodate differing physical capabilities.
5. **Promote Social and Psychological Recovery**
    - Recognise dance as a means of improving self-image, confidence, and social connection alongside physical rehabilitation.
6. **Encourage Long-Term Engagement**
    - Integrate community-based classes within cancer survivorship pathways to support sustained participation in physical activity.

# Water Therapy and Rehabilitation in Germany:

## A conversation with water therapist Marie and head and neck article review

*'Going back to water was like going back to life.'*

## Government Support and Access

In Germany, patients are entitled to 3–4 weeks of rehabilitation through statutory health or pension insurance, with the option to renew every two years based on individual need. This system emphasises reintegration into work and society, aiming to reduce early retirement and unemployment following cancer. Rehabilitation can be accessed either from hospital-based programmes or at home, highlighting a flexible, patient-centred approach.

## Role of Charities and Patient Organisations

Charities, such as the Bundesverband Kehlkopf- und Kopf-Hals-Tumore e.V., play a crucial role in training water therapists and supporting patients. Access to therapy often requires referral by a consultant or membership, ensuring clinical oversight. These organisations emphasise self-help, physical activity, and holistic recovery, integrating emotional and social wellbeing alongside physical rehabilitation.

*All leaflets have a focus on self-help: physical activity and water therapy.*

The website https://netzwerk-onkoaktiv.de/ highlights where people can go for rehabilitation.

## Benefits of Water Therapy

Water therapy offers a combination of physical, emotional, and social benefits. Cardiovascular fitness, muscular strength, and overall mood improve through aquatic exercises, while patients experience enhanced confidence and reintegration into family and social life. Swimming and water aerobics provide a sense of freedom and emotional restoration.

## Case Example: Parksanatorium Aulendorf

At Parksanatorium Aulendorf, patients participated in structured water therapy programmes designed for safety and effectiveness. Training included the use of assistive devices, such as the Larchel®, along with progressive water-based exercises. Beyond physical benefits, the programme fostered community, peer support, and psychological empowerment, illustrating the holistic value of aquatic rehabilitation.

*Given with thanks by the charity Bundesverband Kehlkopf- und Kopf-Hals-Tumore e.V (2025)*

## The Larchel® Device

This device enables safe water activity for laryngectomees. Patients require medical clearance and a prescription, with insurance covering the cost (~€700). Training is progressive, beginning in shallow water with breathwork before advancing to swimming. Notably, patients often take on peer-mentor roles, promoting long-term engagement and community-led support.

## Multidisciplinary Collaboration

The success of water therapy is underpinned by strong collaboration between speech and language therapists (SLTs), consultants, and physiotherapists. Programmes prioritise patient-centred care, safety, and long-term empowerment. SLTs are particularly encouraged to advocate for access, ensuring inclusion of patients with complex needs.

## Reflections and Relevance to the UK

This German model demonstrates a well-resourced, patient-centred approach to post-cancer rehabilitation, combining clinical oversight, charity involvement, and innovative assistive technology. Key reflections for the UK include:

- **Structured access and insurance support** enable consistent participation, something currently limited in NHS-funded rehabilitation.
- **Multidisciplinary integration**, particularly the role of SLTs in water-based therapy, highlights gaps in UK services for patients with laryngectomy and other head and neck complications.
- **Use of assistive devices** such as Larchel® shows how safety and independence can be enhanced, providing confidence to engage in physical activity.
- **Peer support and social engagement** reinforce psychological wellbeing, an aspect often missing in standard UK rehabilitation programmes.

## Learning Points for UK Practice

1. Water therapy could be integrated as part of head and neck cancer rehabilitation, complementing traditional physiotherapy and occupational therapy.
2. Collaboration with charities and patient organisations may enhance access and community engagement.

3. Progressive, structured programmes with medical oversight ensure safety for patients with altered airways or stomas.
4. Investment in workforce and training (including SLTs and physiotherapists) is essential to implement such programmes effectively.
5. Early integration into survivorship care plans could support reintegration into work and social life, mirroring preventative health and wellbeing policies.

## Conclusion

The German model illustrates how water-based rehabilitation can restore physical capacity, confidence, and social engagement in head and neck cancer patients. While current UK provision is limited, adopting similar approaches – tailored, multidisciplinary, and supported by charitable networks – could significantly enhance survivorship care and long-term patient outcomes.

# Lymphoedema Management and the Role of Physical Activity in Head and Neck Cancer Care

International frameworks such as the *World Health Organization (WHO) Global Action Plan on Physical Activity 2018–2030* (WHO, 2018) and UK initiatives including *Macmillan's Move More* campaign (Macmillan Cancer Support, 2020) and *Moving Medicine* (Faculty of Sport and Exercise Medicine UK, 2019) advocate embedding physical activity into routine healthcare delivery. These frameworks emphasise that encouraging movement and reducing sedentary behaviour can mitigate treatment-related side effects, enhance recovery, and improve quality of life for people living with and beyond cancer. Within this broader agenda, lymphoedema management provides a salient example of how physical activity and rehabilitation intersect to support functional outcomes and long-term wellbeing.

Lymphoedema is a recognised and relatively common side effect following surgery and radiotherapy in the head and neck cancer population. Despite its prevalence, debate continues around the optimal timing of intervention, and which professional group is best placed to deliver care. The rationale for the commonly cited three-month delay before intervention remains unclear and lacks an evidence base. Within the NHS, lymphoedema services are often provided by specialist nurses, frequently working separately from the core head and neck oncology team. However, growing recognition of the prevalence of internal lymphoedema and its correlation with dysphagia severity has led to an expansion of interest within speech and language therapy (SLT) to extend scope of practice in this area.

Internationally, multidisciplinary models highlight the value of shared professional responsibility in lymphoedema management. At centres such as the Peter MacCallum Cancer Centre (Peter Mac) and Chris O'Brien Lifehouse, as well as the Princess Alexandra Hospital in Australia, both physiotherapists (PTs) and occupational therapists (OTs) are actively involved in lymphoedema care, integrating this work within broader rehabilitation frameworks. These models illustrate that effective management is not the remit of one profession alone but is best achieved through multidisciplinary collaboration, drawing on the diverse expertise of allied health professionals (AHPs) to address complex patient needs.

| **Case Study A** | **Case Study B** | **Case Study C** |
|---|---|---|
| • 27 year old unilateral radiotherapy post partial glossectomy<br>• Week 3 on radiotherapy<br>• Conducted by occupational therapist (OT)<br>• Combination of infra-red therapy (Thor-2 device) and massage<br>• Benefits: OT able to discuss managing fatigue too | • Palliative patient with neck recurrence and accessory nerve damage leading to reduced shoulder movement from prior radiotherapy<br>• Still accessing ROM exercises for shoulder and lymphoedema to maintain function during treatment and know staff are monitoring him<br>• He reported feeling safe<br>• Conducted by physiotherapist (PT)<br>• Combination of massage and infra-red (Thor 2 device) therapy<br>• Benefits: PT able to provide shoulder exercises too | • Post RT, neck lymphoedema<br>• Known dysphagia<br>• SLT began initial assessment of lymphoedema scale<br>• General advice and massage and introduced bands<br>• Bridged gap until physiotherapy able to see patient<br>• Benefits: SLT able to conduct dysphagia assessment and recommendations |

Central to best practice is the adoption of a flexible, patient-centred approach. Lymphoedema management cannot follow a “one size fits all” model; interventions must be tailored to each individual’s presentation, treatment phase, and personal priorities. Understanding what motivates a patient – such as improving swallowing, reducing facial swelling, or restoring appearance – can guide which professional should lead the intervention and how physical activity can be appropriately incorporated. Such an approach aligns with the principles of personalised care advocated in UK cancer rehabilitation policy (NHS England, 2019).

For SLTs, integrating lymphoedema management into therapy programmes requires thoughtful consideration of clinical priorities and service capacity. It is essential to ensure that the inclusion of lymphoedema intervention does not compromise delivery of dysphagia or communication therapy, which remain core to the SLT role. Nevertheless, all AHPs share responsibility for early identification, patient education, and referral to specialist services. Lymphoedema care should be proactive and guided by the public health principle of “making every contact count” (Public Health England, 2016), ensuring that every clinical encounter reinforces the value of movement and self-management in recovery.

Embedding lymphoedema care within a wider framework of promoting physical activity is consistent with international and national recommendations to reduce sedentary behaviour and support active living across the cancer care continuum. Gentle, regular movement not only facilitates lymphatic drainage but also contributes to improved energy levels, psychological wellbeing, and functional independence. This integrative, multidisciplinary, and patient-centred model reflects a contemporary vision for oncology rehabilitation – one that recognises physical activity as both a therapeutic and preventative intervention essential to long-term recovery and quality of life for individuals living with head and neck cancer.

# Research, Education, and Speech and Language Therapy

International visits highlighted the critical role of **integrating research within clinical services** to improve patient outcomes and embed evidence-based practice. Hospitals such as Amsterdam UMC, NKI (Netherlands), Milan and Turin (Italy), and German centres, as well as Australian sites including Chris O'Brien Lifehouse, Prince of Wales, Royal Melbourne, Peter Mac, and Princess Alexandra Hospital, demonstrate robust research infrastructures integrated within service delivery. These centres combine **dedicated SLT researchers and clinician-researchers**, allowing staff at multiple levels to engage in research according to their capacity and interest.

From a university perspective, leaders such as Professor Liz Ward actively coordinate and encourage SLTs to pursue research projects that optimise clinical application, while accounting for demographic pressures and caseloads at each hospital. As one clinician observed, *"Why do something if it's not evidence-based?"* This ethos ensures that **service pressures do not erode quality care**. Safe staffing, evidence-based practice, and protected research time are considered essential pillars for delivering high-quality rehabilitation and optimising patient outcomes. This approach contrasts with the UK, where research is often fragmented and dependent on local university affiliations. Lessons from international models highlight the importance of **national networks or working groups**, which can build consensus, standardise practice, and facilitate the rapid translation of research into clinical care.

## Speech and Language Therapy: Principles and Practice

Speech and language therapy (SLT) is pivotal in supporting **swallowing, communication, and overall functional recovery** for head and neck cancer patients. Therapy draws on principles similar to those used in physical activity interventions. For example, **prehabilitation for dysphagia and trismus** emphasises the principle of "keep moving, keep swallowing," maintaining muscle function and reducing functional decline. This overlap between exercise science and SLT rehabilitation demonstrates how structured, activity-based approaches can be applied across multiple domains of recovery.

International centres emphasised that therapy should be **evidence-based and responsive**, supported by ongoing research embedded within clinical practice. However, reliance on **case studies and small cohort studies** remains a limitation, and efficacy data for many interventions – particularly for trismus and swallowing – are limited. In the UK, the variation in SLT and allied health research is significant; a local review showed that 0% of job time is formally allocated to research, limiting opportunities for evaluation, innovation, and integration of evidence into practice. Strengthening the **link between research and service delivery** is therefore essential to support sustainable, high-quality SLT interventions that are both patient-centred and feasible within NHS pressures.

## Reflection: Integrating Research, Service Structure, and SLT Practice

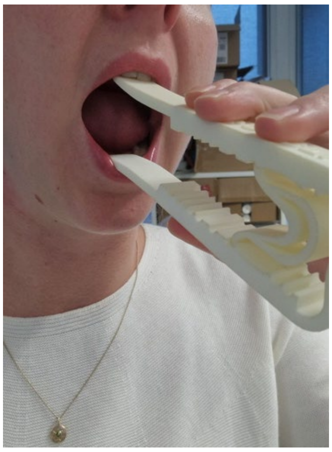
The international experience demonstrates that **high-quality rehabilitation depends on the integration of research, service structure, and clinical expertise**. Where research is embedded within service structures, clinicians – particularly SLTs – are empowered to apply evidence-informed interventions while simultaneously contributing to the evidence base. This supports patient-centred care by ensuring therapies, such as dysphagia and trismus exercises, are tailored to individual goals, treatment timing, and physical capacity.

SLT practice exemplifies this interconnection: therapy draws on exercise principles to maintain swallowing and communication function, mirroring approaches used in broader physical activity interventions. Yet reliance on case studies and small sample sizes highlights the need for **structured evaluation within clinical services**. Embedding research into everyday practice enables teams to generate meaningful data, adapt interventions, and justify innovations despite service pressures.

For the UK, the lessons are clear. Strengthening links between universities, NHS services, and professional networks can support **research-active multidisciplinary teams**, ensuring that SLTs and allied health professionals have protected time and infrastructure to evaluate interventions. This alignment fosters a culture where **evidence underpins care**, patient outcomes are optimised, and service pressures do not compromise quality. Integrating research, service structure, and therapy principles provides a sustainable pathway to

**improve physical activity, functional recovery, and quality of life** for people living with and beyond head and neck cancer.

# Case Study: Restorabite™ Device for Trismus Rehabilitation – Sydney, Australia



The **Restorabite™ device** was piloted in Sydney, Australia, through excellent multi-disciplinary work between speech therapy and maxilla-facial teams, to address **trismus**, a condition characterised by restricted mouth opening commonly seen in patients undergoing treatment for head and neck cancer (HNC). Trismus can significantly impact speech, eating, and overall quality of life. Severity is typically measured using **Maximal Interdental Opening (MIO)**, with MIO <35 mm indicating trismus, and classified using the **Dijkstra system**.

Traditional therapy includes passive methods such as stacking tongue depressors and active devices like TheraBite®, supplemented by warm/cold compresses and massage. The Restorabite™ pilot focused on **early postoperative intervention**, enrolling patients within six weeks of curative surgery and prior to radiotherapy, aiming to prevent radiation-induced fibrosis and accelerate functional recovery.

Participants in the study by Charter's et al (2024) completed a **10-week structured exercise programme** incorporating warm-up, active and passive exercises, cyclical routines, and maintenance strategies for ongoing or resolved trismus. Adherence was evaluated using the **Hawley-Hague framework**, tracking completion, attendance, duration, and intensity. Outcomes were measured at baseline, 10 weeks, and six months using validated tools, including the Gothenburg Trismus Questionnaire, MD Anderson Dysphagia Inventory (MDADI), EAT-10, Speech Handicap Index (SHI), McGill Pain Questionnaire (short form), TheraBite Jaw Range of Motion Scale, and adherence ratings.

All **nine participants completed the programme**, with high initial adherence and minor mid-programme drop-off. Most returned to recommended exercise levels by week 10. MIO improved in all patients, and gains were maintained at six months. No adverse effects were reported, even when exercises commenced as early as three weeks post-surgery. Patient feedback highlighted the programme's **ease of use and integration into daily life**, with family support enhancing engagement.

The Restorabite™ programme aligns with **evidence-based rehabilitation principles**, emphasising preventative care, patient-centred motivation, consistency, progression, and the use of the **OMNI exertion scale** within the ICF framework to monitor effort and function.

## Reflections and Insights for UK Clinical Practice

The Restorabite™ device and structured exercise programme offer clear opportunities for **UK head and neck oncology services**. Early intervention could reduce long-term complications, improve quality of life, and integrate seamlessly into NHS care pathways. Multidisciplinary collaboration between SLTs, physiotherapists, oncologists and radiographers is essential for optimising patient outcomes and adherence.

Implementation strategies include:

- **Integration into care pathways:** Early screening for trismus and embedding Restorabite™ exercises into post-operative care protocols, particularly prior to adjuvant radiotherapy.
- **Multidisciplinary coordination:** Use of MDT meetings to plan and monitor rehabilitation, aligning with shared decision-making principles.
- **Training and education:** Standardising training for SLTs and allied health professionals on device use, exercise principles, and OMNI exertion monitoring.
- **Patient-centred delivery:** Tailoring exercises to individual goals and lifestyle, providing verbal feedback, and supporting adherence through remote or weekend options where necessary.
- **Outcome monitoring:** Tracking progress using standardised measures and auditing adherence and clinical impact.
- **Research and innovation:** Piloting Restorabite™ in UK settings with support from NIHR or local innovation funding, potentially complemented by digital resources for exercise guidance and telehealth support.

## Key Performance Indicators (KPIs)

- **Clinical effectiveness:** Improvements in MIO ≥5 mm at 10 weeks, maintained at six months; changes in Dijkstra classification; validated questionnaire scores.
- **Adherence and engagement:** Programme completion rates, exercise frequency, intensity adherence, and OMNI scale feedback.
- **Patient experience:** Ease of use, perceived benefit, and continuation into maintenance phase.
- **Service delivery:** Time from surgery to rehabilitation, MDT planning documentation, SLT/AHP training.
- **Research and quality improvement:** Inclusion in audits, completeness of outcome data, and participation in multi-site pilot studies.

## Summary

The Restorabite™ pilot demonstrates that a **structured, early intervention programme** can safely and effectively improve jaw mobility, function, and patient experience following HNC surgery. Its integration into rehabilitation pathways highlights the importance of **multidisciplinary collaboration, patient-centred care, and evidence-based practice**. For the UK, the programme offers a practical model to enhance trismus management, reduce long-term complications, and embed consistent outcome monitoring and audit within head and neck oncology services. The use of structured exercises, combined with patient motivation and family support, illustrates how rehabilitation interventions can be **both clinically effective and adaptable to patients' daily lives**, ensuring sustainability and meaningful impact.

# Voice and Swallow Rehabilitation Following Open Partial Horizontal Laryngectomy (OPHL): International Perspectives

## Turin: Professor Succo and Milan: Professor Schindler: Multisensory Rehabilitation and Exercise-Based Recovery

A conversation with laryngologist Marco Fantini and speech therapist Michela Gallia.

The **PROEL method**, originally developed by **Giovanna Borragan**, provides the theoretical and practical foundation for Turin's approach to voice rehabilitation after Open Partial Horizontal Laryngectomy (OPHL). PROEL – **Progressive and Resistance Exercises for the Larynx** – applies exercise-science principles to restore laryngeal neuromuscular control.

In **Fantini et al. (2022)**'s study of *substitution voice rehabilitation after OPHL using the PROEL method*, patients demonstrated **significant improvements** between pre-operative baseline and three months of structured rehabilitation across **acoustic, aerodynamic, perceptual, and self-assessment domains**. Moreover, at **six months**, the experimental group undergoing PROEL therapy continued to show **significant gains** over the control group in **aerodynamic, perceptual, and self-assessment measures**, underscoring the sustained and progressive nature of this rehabilitation model. These findings confirm that structured, exercise-based interventions can deliver measurable and enduring improvements in both objective voice parameters and patient-perceived function following complex partial laryngectomy.

The collaboration between the laryngologist and speech-language therapist is particularly strong, ensuring continuity between surgical design and functional rehabilitation.

The **PROEL method** – originally designed for functional dysphonia – has been successfully adapted for OPHL patients. It combines **semi-occluded vocal tract exercises**, **laryngeal manipulation**, **postural instability tasks**, and **resistance-based phonation** to enhance vibration and coordination in the neoglottis. These exercises serve as the equivalent of physiotherapy for the larynx: progressive, repetitive, and tailored to stimulate neuromuscular adaptation. Therapy also incorporates "sensory bombardment" through pressure, vibration, temperature variation, and stretch to reawaken receptors within the mucosal and muscular systems. This mirrors exercise training principles – intensity, variability, and recovery – to promote gradual gains over time.

Patients undergo a structured six-month rehabilitation programme, with **voice and swallow assessed pre-operatively, and again at three and six months** post-surgery using acoustic and perceptual measures such as jitter, shimmer, and signal-to-perturbation ratio (SPR). Surgical classification follows the **European Laryngological Society OPHL types (I–III)**, where the extent of resection dictates expected outcomes. Types II and III, which involve more extensive resection and substitution voice, are associated with greater initial dysphonia, but longitudinal data from Turin demonstrate that improvement often continues **years after surgery**, emphasising the long-term potential of targeted exercise-based therapy.

Professional discussion recognises that swallow and voice outcomes are influenced not only by surgical technique, but also by the patient's **baseline physical fitness, comorbidities, and motivation for rehabilitation**. Swallow management begins with saliva control, then progresses through graded consistencies – from sterile gel to pureed foods and eventually thin liquids – guided by endoscopic evaluation. Rather than discouraging micro-aspiration, clinicians view it within a functional context, prioritising safety, awareness, and progressive confidence.

This approach reframes OPHL as a functional reconstruction rather than a compromise, emphasising physical adaptation, and patient empowerment. The iterative use of acoustic measures and real-time biofeedback ensures that even subtle improvements are identified and reinforced, nurturing patient motivation and adherence.

In Milan, my discussions with the Dr Selvagio and Dr Pizzorni revealed a therapeutic culture grounded in **patient-specific biofeedback**, **expectation management**, and **psychological readiness** for behaviour change.

Therapy sessions often begin with simple motor activations such as throat clearing, breath-hold strategies, or abdominal breathing – techniques that bridge awareness and control. Real-time visual feedback via endoscopic imaging allows patients to observe glottic closure and understand how tongue movement or postural shifts affect phonation. This process mirrors motor learning theory, where visual and sensory cues help refine technique and reinforce progress.

Milan's clinicians highlighted that **patient motivation and values strongly predict compliance**. For instance, individuals who understood the purpose behind exercises or could connect therapy to meaningful goals were more likely to persist. Caregiver support was also identified as a key determinant of success, echoing wider evidence from behaviour change frameworks.

From a physiological standpoint, discussions reinforced that **improvement is not limited to the early postoperative window**. In some cases, gains in both swallow safety and voice quality continued to evolve for years, particularly where patients maintained active engagement with tailored exercise programmes. The integration of outcome measures – such as the **MDADI**, **GRBAS**, and **VHI for a-laryngeal voices** – enabled objective tracking and supported patient reflection. The use of **biofeedback and video coupling** enhanced self-efficacy, helping patients visualise improvement and regain a sense of agency in their recovery.

Importantly, both teams underscored that OPHL outcomes are multifactorial. The extent of arytenoid preservation, patient age, radiotherapy exposure, and surgical skill all influence long-term function, but none determine it absolutely. Instead, the therapists' emphasis on **habit formation, consistency, and motivational alignment** showed that recovery is a product of both anatomy and behaviour.

## Critical Reflection and Learning for the UK

The Italian experience offers valuable insights for UK practice, where OPHL remains relatively uncommon and rehabilitation protocols vary. Both centres demonstrate that speech and swallow therapy after OPHL should be approached as a **form of physical training**, not merely compensatory technique teaching. The application of exercise science principles – progressive loading, repetition, feedback, and rest – drives neurofunctional gains even years post-surgery.

However, successful implementation requires clinicians to assess and foster **behavioural readiness** and **patient motivation** from the outset. Understanding an individual's values, physical fitness, and willingness to engage in activity-based recovery predicts adherence far more than surgical variables alone. Moreover, the close collaboration between head and neck surgeons, laryngologists and SLTs observed in Italy exemplifies an integrated model that could enhance outcomes in the UK.

While OPHL can offer voice and swallow preservation without a permanent stoma, it demands substantial postoperative commitment. Thus, candid preoperative discussions about effort, expectation and motivation are essential. A critical challenge for the UK is ensuring service capacity and continuity that allow the long-term, exercise-based rehabilitation seen in Turin and Milan to be replicated sustainably.

## Summary

The Italian OPHL centres demonstrate that recovery of voice and swallow is an adaptive, exercise-driven process rather than a fixed surgical outcome. Speech therapy functions as laryngeal physiotherapy – combining repetition, sensory feedback, and behavioural reinforcement. Gains can continue for years when therapy is consistent and person-centred. For UK practice, this highlights the importance of embedding exercise science into SLT frameworks, strengthening multidisciplinary collaboration, and integrating motivational assessment into prehabilitation and postoperative care.

# Conclusions

This Churchill Fellowship has highlighted that improving access to **physical activity for people living with and beyond head and neck cancer – including those post-laryngectomy – requires a holistic, multi-dimensional approach**. International models demonstrate that meaningful change is achievable when workforce development, patient values, research, education, service delivery, IT, and robust guidelines are integrated into a unified strategy.

### Workforce Development

A well-trained, multidisciplinary workforce is essential. Internationally, exercise physiologists, physiotherapists, dietitians, SLTs, occupational therapists, psychologists, and specialist nurses contribute to improved patient outcomes. Upskilling health professionals to confidently promote and support physical activity –through motivational interviewing and behaviour change techniques – is crucial. Protected time for research and service development is needed to close existing workforce gaps.

### Patient-Centred Care

Successful programmes prioritise understanding individual patient values, goals, and readiness for change. Empowerment, self-efficacy, and social support drive engagement. Resources and interventions should be co-designed with patients, emphasising abilities rather than limitations and providing clear, consistent messaging throughout the care pathway.

### Research and Education

Embedding research within clinical services ensures interventions are evidence-based and responsive to evolving needs. International centres excel where research teams are integrated into service delivery, enabling rapid translation of findings. Education for staff and patients – through leaflets, digital platforms, and interactive tools – supports informed decision-making and sustained engagement.

### Service Delivery

Innovative models, including survivorship clinics, integrative oncological care, and community-based rehabilitation, demonstrate the value of **accessible, flexible, and holistic**

**support**. These models advocate for broader inclusion of allied health professionals and seamless transitions between hospital and community care. Welcoming, non-clinical environments that combine physical and social rehabilitation foster participation and wellbeing.

### IT and Digital Resources

Digital platforms – including patient portals, online exercise programmes, and telehealth – support self-management, access to specialist advice, and ongoing monitoring. However, technology must be user-friendly, inclusive, and integrated with face-to-face care to avoid widening inequalities.

### Guidelines

Evidence-based guidelines and national/international frameworks standardise care and reduce variation. Physical activity should be a **core component of cancer care**, with recommendations tailored to head and neck populations. Regular review, informed by patient feedback and outcomes data, ensures continued relevance.

## Practical Implications for the UK

To transform physical activity provision for head and neck cancer patients, the UK should:

- **Adopt a whole-system approach:** Integrate workforce development, patient-centred care, research, digital innovation, and robust guidelines.
- **Invest in multidisciplinary teams:** Ensure all relevant professionals are empowered and resourced to contribute fully.
- **Prioritise patient empowerment:** Co-design services and resources with patients, focusing on strengths and goals.
- **Embed research and quality improvement:** Make research a routine part of service delivery with dedicated support and funding.
- **Leverage digital tools:** Use IT to enhance, not replace, personal care while ensuring accessibility.
- **Standardise and innovate:** Use guidelines to drive consistency while adopting international best practice.

## Reflections from International Case Studies

Evidence from international initiatives underscores that physical activity interventions are **safe, feasible, and effective** when tailored to patient readiness and treatment timing. For example:

- **MOVEIT Study (NKI, Netherlands):** Patients can engage in structured exercise before and during radiotherapy, provided interventions account for peak treatment effects.
- **Restorabite™ Pilot (Sydney, Australia):** Patients adhered to mouth-opening exercises when supported by consistent professional guidance.

These examples reinforce the importance of staff promoting movement as a standard component of care, recognising individual motivation, readiness, and accessibility.

International experiences highlight that sustainable service delivery requires:

- **Robust multidisciplinary teams**, supported by clinical research infrastructure
- **Expanded roles for AHPs and nurses**, including specialised training in exercise prescription and motivational techniques
- **Patient-centred design**, reflecting individual goals such as independence, social participation, and return-to-work.

## Current UK Progress

Several actions have been implemented locally to support these aims:

- **Workforce Training:** PACC (Physical Activity for Cancer Care) training delivered to SLT and Clinical Nurse Specialist teams.
- **Multidisciplinary Collaboration:** Engagement with the Oncology ERAS team to align early mobilisation and rehabilitation pathways.
- **Innovation and Technology:** Ongoing evaluation of the Larchel® device and other rehabilitation technologies post-laryngectomy.

# Recommendations and Next Steps

**1. Research and International Collaboration**

- Establish partnerships with Restorabite™ and Laronix teams.
- Expand multicentre SLT and AHP-led studies to strengthen evidence.
- Embed research job plans to integrate PROMs and evidence-based practice.

**2. Workforce Development and Training**

- Continue PACC collaboration to enhance training on exercise and altered airway management.
- Develop interprofessional placements and student research opportunities.
- Promote AHP and SLT leadership and visibility within the NHS.

**3. Service Delivery and Integration**

- Conduct a comprehensive pathway gap analysis to identify unmet rehabilitation needs.
- Liaise with Cancer Alliance Networks to develop survivorship and late effects clinics.
- Embed early mobilisation across pre-treatment, treatment, and survivorship phases.

**4. International and Cross-Sector Partnerships**

- Maintain dialogue with German water therapy centres, charities, and suppliers.
- Evaluate new rehabilitation devices in partnership with FAHL and other international collaborators.
- Review UK legislation for medical devices relevant to HNC rehabilitation.

**5. Digital Transformation and IT Enablement**

- Integrate digital patient portals and self-management platforms.
- Use technology as preparatory or supplementary tools to enhance engagement and efficiency.
- Ensure accessibility and support for digital literacy to prevent inequalities.

### 6. Patient-Centred and Value-Based Care

- Embed patient motivations and readiness for change into all interventions.
- Create shared messaging across MDTs to cultivate a culture of movement.
- Advocate commissioning models recognising long-term rehabilitation benefits.

### 7. Education, Guidelines, and Policy Alignment

- Align service development with WHO Global Action Plan on Physical Activity, Macmillan Move More, and NHS Long Term Plan.
- Develop educational modules incorporating behavioural change techniques.
- Promote inclusion of physical activity competencies in SLT and AHP professional frameworks.

Promoting physical activity in head and neck cancer and laryngectomy care offers a **critical opportunity to integrate clinical practice, research, and public health priorities**. By combining international evidence, workforce development, patient-centred approaches, digital innovation, and robust service models, the NHS can deliver rehabilitation that is **flexible, empowering, and sustainable**, enhancing survival, wellbeing, and social participation for people living with and beyond head and neck cancer.

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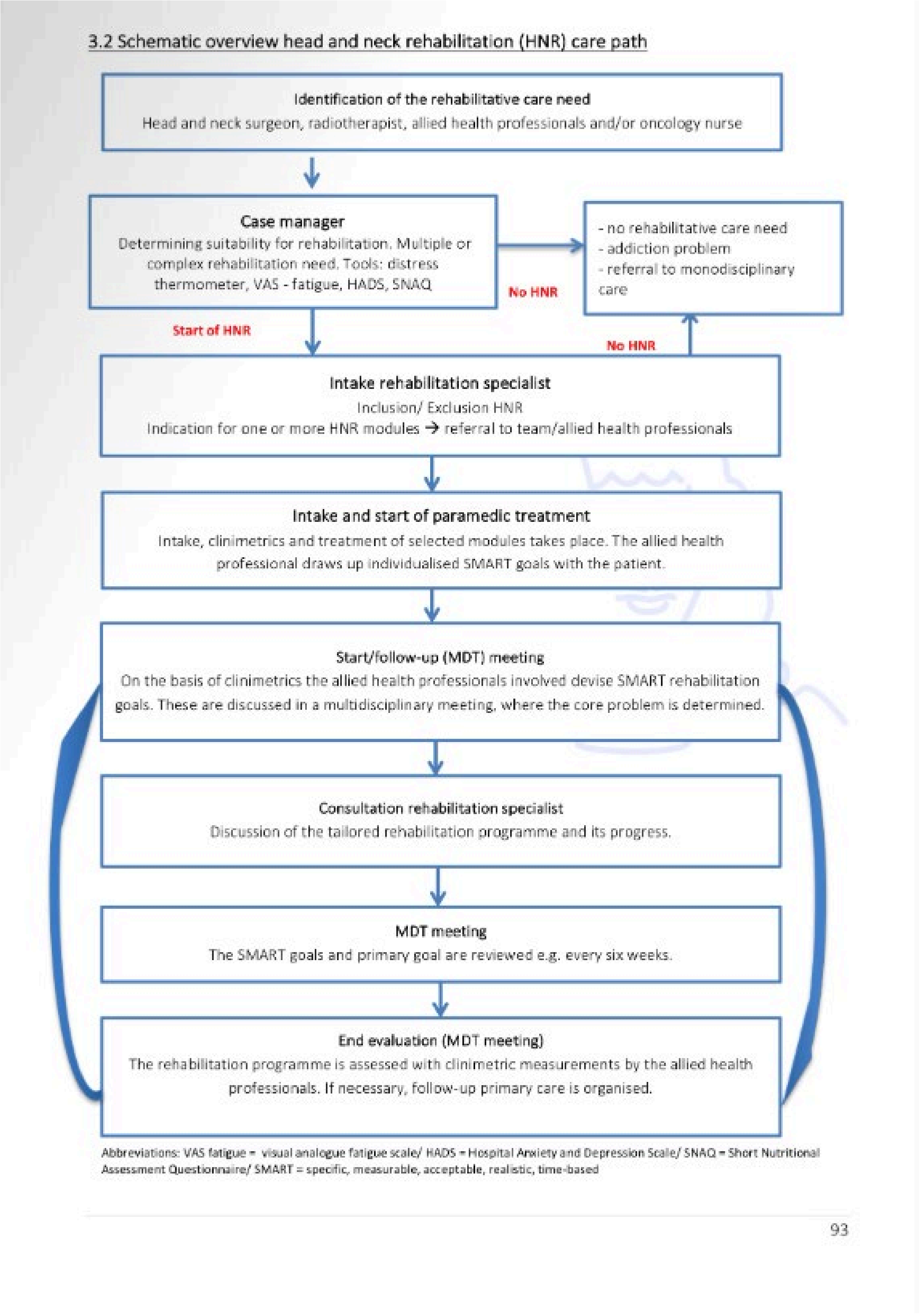
# Appendix 1: HNR Pathway



3.2 Schematic overview head and neck rehabilitation (HNR) care path

**Identification of the rehabilitative care need**
Head and neck surgeon, radiotherapist, allied health professionals and/or oncology nurse

**Case manager**
Determining suitability for rehabilitation. Multiple or complex rehabilitation need. Tools: distress thermometer, VAS - fatigue, HADS, SNAQ

No HNR

- no rehabilitative care need
- addiction problem
- referral to monodisciplinary care

Start of HNR

No HNR

**Intake rehabilitation specialist**
Inclusion/ Exclusion HNR
Indication for one or more HNR modules → referral to team/allied health professionals

**Intake and start of paramedic treatment**
Intake, clinimetrics and treatment of selected modules takes place. The allied health professional draws up individualised SMART goals with the patient.

**Start/follow-up (MDT) meeting**
On the basis of clinimetrics the allied health professionals involved devise SMART rehabilitation goals. These are discussed in a multidisciplinary meeting, where the core problem is determined.

**Consultation rehabilitation specialist**
Discussion of the tailored rehabilitation programme and its progress.

**MDT meeting**
The SMART goals and primary goal are reviewed e.g. every six weeks.

**End evaluation (MDT meeting)**
The rehabilitation programme is assessed with clinimetric measurements by the allied health professionals. If necessary, follow-up primary care is organised.

Abbreviations: VAS fatigue = visual analogue fatigue scale/ HADS = Hospital Anxiety and Depression Scale/ SNAQ = Short Nutritional Assessment Questionnaire/ SMART = specific, measurable, acceptable, realistic, time-based

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*Taken from the free framework for head and neck cancer rehabilitation offered by the NKI Netherlands (2016) available online*:

https://www.franshilgers.nl/HHrehab2/index.html