Head and Neck Cancer Rehabilitation: Care Close to Home Project

Wiltshire Health Select Committee briefing 11 July 2018

1. Introduction

An estimated 9,200 new cases of head and neck cancer are diagnosed each year in England and Wales. Although case numbers are relatively low, a complex range of medical skills contribute to successful outcomes. There are more than 30 areas within the head and neck in which cancer can develop including mouth and lips, voice box (larynx), throat (pharynx), salivary glands, nose and sinuses, the area at the back of the nose and mouth (nasopharynx).

Treatments for these cancers can cause substantial difficulties in speech, swallowing/eating and appearance. Patients require long term follow-up to provide support, rehabilitation, management of consequences of treatment and early identification of recurrence or new primary cancer to allow further effective treatment whenever possible. It is important that patients have access to a full range of health professionals to meet their rehabilitation needs and ensure high quality patient centred care. These include dietitians, speech and language therapists, restorative dentists, physiotherapists, occupational therapists (OTs), clinical nurse specialists (CNS), lymphoedema practitioners and clinical psychologists.

Currently in Swindon and Wiltshire, patients are diagnosed with Head and Neck cancer (HNC) at Great Western Hospital (GWH) in Swindon and then are referred to Oxford University Hospitals (OUH) in Oxford for treatment, rehabilitation and follow up. The latter normally lasts for five years and involves an average of 24 clinic appointments per year in Oxford plus additional appointments with allied health professionals, dentists and clinical nurse specialists. The round trip from Swindon to Oxford can take up to six hours which can have a huge toll on patients' recovery as well as their family and carers as a whole day is lost each time. The financial impact of the cost of travel, parking and potentially time away from work is also significant

2. What is going to change immediately?

From Wednesday 5th September 2018, some patients from Swindon and parts of Wiltshire who currently attend Oxford University Hospitals will be able to receive their follow up rehabilitation appointments at Great Western Hospital in Swindon. The clinic will be run weekly and will be led by a consultant head and neck surgeon and include access to a clinical nurse specialist, speech and language therapist, dietician as well as dentistry and psychology services. Consultants from Oxford University Hospitals will also attend to deliver some of the clinics. This is a pilot project that is due to run initially for three years.

In line with NHS England's best practice, new risk stratified pathways[1] are being developed for the care of those living with and beyond cancer.

Accordingly, the Head and Neck Cancer implementation group have categorised patients according to the level of care they require to determine the appropriate pathway. The factors determining this include:

- level of risk associated with cancer type;
- short and long term effects of treatment;
- other co-morbidities;
- patient's ability to self-manage; and
- level of professional involvement required.

Group 1	T1 – 2 N0. (This is tumour staging shorthand) Single modality of treatment. Minimal input needed, good functional recovery, good social support
Group 2	T2-3 N1. Unilateral Radiotherapy, or limited surgery. Patients with moderate needs, take longer to recover, higher risk of recurrence, less social support
Group 3	T3/4 N1-3 Major reconstructive surgery. Radical radiotherapy +/- chemo to oropharynx or nasopharynx Complex patients who are treated with curative intent and may have tracheostomy, be PEG dependent (feeding mechanism), have laryngectomy, bony reconstruction, obturators (prosthetics within mouth), poor recovery, poor social support.
Group 4	Group 4 Patients with known metastatic disease who need monitoring and palliative care

Follow up care will be determined according to the above groupings. The decision on which grouping and therefore which pathway the patient would follow would be made at the end of initial treatment with input from the whole clinical team and in consultation with the patient. Patients can move between the different levels of care as needs and degree of dependency change. This categorisation enables better understanding of resources required.

Group 1	Group 2	Group 3	Group 4
Discharged to GWH 4-6 months post treatment	Shared care months 6 - 12 and then discharged to GWH	May be shared care months 6-12 but may keep at OUH for 12 months before	May be no treatment at OUH so immediate discharge to GWH or may be palliative

[1] https://www.england.nhs.uk/wp-content/uploads/2016/04/stratified-pathways-update.pdf

		discharge to GWH	treatment then discharge to palliative care team

3. How many people will this affect?

The redesigned patient pathway would affect an estimated 65 Swindon and Wiltshire patients each year. The small group of patients are being informed of the changes by their consultant and there will also be leaflets and printed materials with comprehensive answers to their questions (predicted through work with patient representatives). They will be given a follow up schedule and details of the administrator at GWH. The change is expected to happen gradually over the next two years as patients have their last appointment at OUH and are discharged to GWH.

4. Why is this changing?

The change is a pilot project and the culmination of a significant amount of work completed over the past five years, with the active participation of patients, clinical and managerial staff from Trusts and CCGs, and the Thames Valley Cancer Network and the charity Macmillan. In 2012 a conference organised by Thames Valley Cancer Network highlighted concerns about provider capacity and its ability to deliver a satisfactory service which adhered to national guidelines. This prompted Macmillan to hold a stakeholder day followed by a review of head and neck cancer rehabilitation services in Thames Valley. The publication is available on the following link: http://tvscn.nhs.uk/wp-content/uploads/2016/04/Thames-Valley-SCN-Macmillan-HeadNeck-Scoping-Project-Report-web.pdf.

The service re-design is a result of the report's recommendations. Not only do the changes set out to improve patient experience but also aim to achieve national recommendations on cancer care. These include:

National strategic objectives

• Achieving World Class Cancer Outcomes includes recommendations that people living with and beyond cancer should be fully supported, including approach to reducing and managing long-term consequences of treatment, and that all providers should be incentivised to implement risk stratified follow up pathways of care for cancer patients.

• The Five Year Forward View has encouraged efforts to deliver more healthcare out of acute hospitals and closer to home, with the aim of providing better care for patients, cutting the number of unplanned bed days in hospitals and reducing net costs. This project aims to move patients closer to home albeit to another acute setting. However, the relationships between the team at GWH and the community providers will make it more likely that care can be moved to the community at an earlier point.

Local CCG and Trust objectives

• Achievement of targets: At present neither OUH nor GWH are meeting the 14 day and 62-day cancer treatment targets. The average for HNC over 2016 was 46% of cases treated in 62 days

• The new pathway would release clinical time and clinic capacity at OUH, which could be used to expedite HNC treatment and diagnosis and reduce waiting times.

• This proposal supports achievement of several of the objectives in the Swindon CCG 5-year plan, notably the local objective to co-locate cancer services as far as possible within the current estate at the Great Western Hospital and to improve patient experience of cancer care.

This project meets the objectives of the Wiltshire Health and Wellbeing Strategy which advocates that "care should be personalised and delivered in the most appropriate setting, wherever possible in the community and at, or closer to home. We want the people of Wiltshire to be supported and empowered to live independently, healthily and for longer. We aim to be in the top ten percent of local authority areas on these measures." http://www.wiltshire.gov.uk/adult-care-joint-health-and-wellbeing-strategy.

5. Why is this change happening now?

We would have liked the change to have happened sooner but ensuring that everything is in place for a smooth transition, staff are recruited and trained and clinical space made available has taken time.

6. Why is this change not going through formal consultation?

- Head and Neck cancer remains relatively uncommon (though the incidence is increasing) and the number of patients affected by the service change is small. In addition to a patient centred conference, a patient representative, Nick Crowson-Towers, has been involved since 2012 to reflect the views of patients. Clinicians including consultants, nurses, speech and language therapists, dietitians, psychologists from both OUH and GWH have been consulted throughout the process.

- This change is required in order to ensure compliance with national guidance.

7. Why hasn't the Health Select Committee heard about this change sooner?

We sent notification of the change to the Health Select Committee in January 2018 a month before the proposal was formally approved by Wiltshire CCG. We apologise that we are unable to attend the Health Select Committee in person in advance of the service commencing but will be presenting an update at the September committee meeting.

8. What impact will this have on patients?

There are numerous benefits including:

• Improved patient experience through reduction in frequent long journeys

• Improved quality of service for patients from Swindon and Wiltshire, with an innovative stratified pathway that stretches across their input at GWH and OUH, ensuring patients are managed by the most appropriate service for their needs but in a local setting where appropriate.

• Improved capacity in Oxford University Hospital NHS FT (OUHFT) Head and Neck cancer follow up clinics, thereby aiding attainment of the 62 day standard, improving access for patients and reducing current delays in the diagnosis of recurrence and treatment. Also improved capacity for Speech and Language therapy, Dietitian support, Clinical Nurse Specialist support and Restorative dentistry.

• Development of local expertise in Swindon which can be built on in the future

• Ensuring the long-term sustainability of the whole networked service, with a pathway that has the resilience to cope with increasing referrals including the projected rise in incidence of oral cancer and expected increases in population in both Swindon and Wiltshire. The current service is stretched and unable to absorb additional referrals.

• Reduction in number of breaches of the 62 day standard at OUHFT. Approximately 50% of Head and Neck Cancer patients currently breach the 62-day target at OUH. (54% in 2016).

•Completion of more Holistic Needs Assessments to enable patients to be referred for appropriate support

• Increased patient education and focus on prevention of recurrence to enable patients to feel more in control of their own health and wellbeing.

• Reduction in unplanned emergency presentations at GWH by patients who are unable or unwilling to travel to Oxford for support.

• Development of a blueprint for localised follow- up which can be replicated across the Thames Valley

9. What is happening longer term?

We will be collecting data to assess the impact of the pilot project with a view to continuing it after three years and replicating the model elsewhere.

10. Clinical information

• Head and Neck Cancers (HNC) are a range of cancers that arise principally in the oral cavity, oropharynx, nasopharynx, hypopharynx, larynx and nasal sinuses.

• Head and Neck Cancer is the 4th most common cancer in the UK in males and 12th most common cancer in females in 2014, with 50% of all cases occurring in people aged 65 and above. [2]

• Incidence of HNC is increasing, with a 30% increase in incidence of HNC since the early 1990s. The number of people living with HNC continues to grow due to the ageing population, improvements in treatment and changes in patient characteristics. The incidence of human papillomavirus (HPV) is also changing the typical patient demographic with a growing cohort of younger patients.

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[2] http://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/oral-cancer/

• The risk of recurrence for H&N patients is relatively high, with one study showing a recurrence rate of 50% over five years, and NICE evidence showing that 90% of recurrence develops within the first two years of initial diagnosis. [3]

• Treatment for head and neck cancer can include surgery, radiotherapy, chemotherapy, or a combination of treatments. Treatment options are considered carefully with the patient as they may change the way the patient looks, talks, eats or breathes.

• In England, there are over 50,000 people living with and beyond a HNC diagnosis (NCIN, 2015)[4]

• Rehabilitation is a very important part of the process to help the patient return to normal activities as soon as possible after treatment and will depend on the extent of the cancer and the treatment the patient has received. It may include speech therapy to help patient with swallowing and speech, dietitian input including tube feeding, restorative dentistry, psychological support, physiotherapy and education to help the patient understand how to self-care and reduce risks of recurrence.

11. **Who do I contact if I have any comments or questions?**

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[3] National Institute for Health and Care Excellence. 2004a. Improving Outcomes in Head and Neck Cancers. Available from: https://www.nice.org.uk/Guidance/CSGHN
[4] National Cancer Intelligence Network. 2015. Cancer Prevalence UK Data Tables. Available from: http://www.ncin.org.uk/item?rid=2954