East Midlands Cancer Alliance

Personalised Stratified Follow Up (PSFU) Guidelines for people with a Differentiated Thyroid Cancer Diagnosis

East Midlands Cancer Alliance

General Personalised Stratified Follow Up Guidelines for people with a Cancer Diagnosis

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EMCA Living with Cancer / Personalised Care Steering Care Group

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Executive Summary

The number of people living with a cancer diagnosis in the UK is set to double from more than 2 million in 2010 to 4 million by 2030[1]. In England the average general practice has 280 patients living with cancer, 140 diagnosed in the past 5 years. This is set to double by 2040. 70% of people with a diagnosis of cancer are living with at least one other long term condition[2]

The culture of education and rehabilitation seen in other long-term conditions such as respiratory, diabetes and cardiac medicine have not yet been fully embraced in cancer services. Traditional outpatient consultations do not provide the best environment to enable holistic and personalised care planning.

This overarching guideline has been developed to support the redesign of services that embody the whole person, whole pathway personalised care approach in cancer. The clinical team and the person affected by cancer decide about the best form of follow up. Care is tailored according to the severity and complexity of a person's individual and clinical needs, including their knowledge of the disease, their treatment, and their ability to self-manage.

In general:

- People at low risk of recurrence and late effects can be supported to self-manage with remote monitoring for disease recurrence through evidence-based surveillance investigations. Therefore, they only need to attend for follow up clinical review appointments if triggered by their own concern or an abnormal test result. This is called '**supported self-management'** in this document.

- People at high risk of recurrence should continue to receive care from specialist services with routine follow up appointments. Some people through personal choice or other non-clinical reasons or they are on a clinical trial may need to continue with routine follow up. This is called '**professional led'** follow up in this document.

- For some people with metastatic (secondary cancer) disease at presentation in whom surgery is not possible / curative or may be too frail to undergo follow up investigations / surveillance tests then '**best supportive care**' is offered in professional led follow up.

People can move between different levels of care as their needs change and are given a key point of contact for rapid re-entry (Open Access) if required.

Principles underpinning risk stratified follow up

- People living with cancer and professional work collaboratively to form personalised care plans
- There is a programme of appropriate education for people living with cancer, supported by written information and access to online portals for those who are IT enabled
- All clinical evidence-based surveillance investigations continue unchanged
- Robust systems are in place to ensure tracking and monitoring of investigation requests and results
- End of Treatment Review and End of Treatment Summary are provided to people living with cancer and their GP's to support good quality Cancer Care Reviews
- There is fast track re-entry (Open Access) for specialist clinical review if required
- There is a consistent implementation of self-management support interventions

1. Introduction and Purpose of this Guideline

This is a general guideline for personalised stratified follow up for people with a cancer diagnosis. For **specific cancer pathway guidelines** which have been agreed these are on the EMCA website.

This is a guideline for personalised stratified follow up for people with a thyroid cancer diagnosis.

Thyroid cancer is when abnormal cells in the thyroid gland in your neck start to divide and grow in an uncontrolled way.

The purpose of this document is to provide best practice guidelines which span primary and secondary care and covers the care of the individual who has completed their treatment for cancer.

The umbrella term 'personalised follow up care' is used in some settings which covers personalised stratified follow up (PSFU) used for cancer pathways and patient initiated follow up (PIFU) used for non-cancer pathways. PIFU is essentially the 'supported self-management' pathway within PSFU.

Personalised Stratified Follow Up pathways with digital remote monitoring should be in place for all breast, colorectal, prostate and endometrial cancer patients by June 2022.

In 2022/23 another 2-3 other cancer types in 2022/23 (Lymphoma, Skin and Thyroid) to be implemented with the ambition to include a minimum of 8 cancer pathways by 2024/25.

1.1 Background

The NHS Long Term Plan for Cancer[3] states that "after treatment, the person will move to a follow-up pathway that suits their needs, and ensures they can get rapid access to clinical support where they are worried that their cancer may have recurred." Transforming follow-up care by steering individuals with cancer to the best follow-up pathway to address 'what matters to you' rather than 'what is the matter with you'.

The introduction of the Comprehensive Personalised Care Model [4] (NHS England, 2019a) has a focus on promoting wellbeing, recovery and empowerment to provide individuals with the information and confidence to have an active role in their care.

> *"The case couldn't be clearer for joining up and integrating care around people rather than around institutional silos – care that focuses not just on treating particular conditions, but also on lifestyles, on healthy behaviours, prevention and helping people live more independent lives for longer".*
>
> *White Paper: Integration and Innovation: working together to improve health and social care for all (2021)*

Having PSFU pathways in place means that when a person completes their primary treatment, they will be offered a personalised care package including:

- Information about signs and symptoms to look out for
- Rapid re-access to their cancer team, including telephone advice and support, if they are worried about any symptoms, including possible side effects of treatment
- Regular surveillance scans or tests (depending on cancer type), with quicker and easier access to results so that any anxiety is kept to a minimum
- Remote monitoring technology to support their care
- Personalised care and support planning and support for self-management, to help them to improve their health and wellbeing in the long term.

1.2 Increasing Incidence and survival

There is an ageing population, increasing incidence, and improved survival rates for people living with cancer.

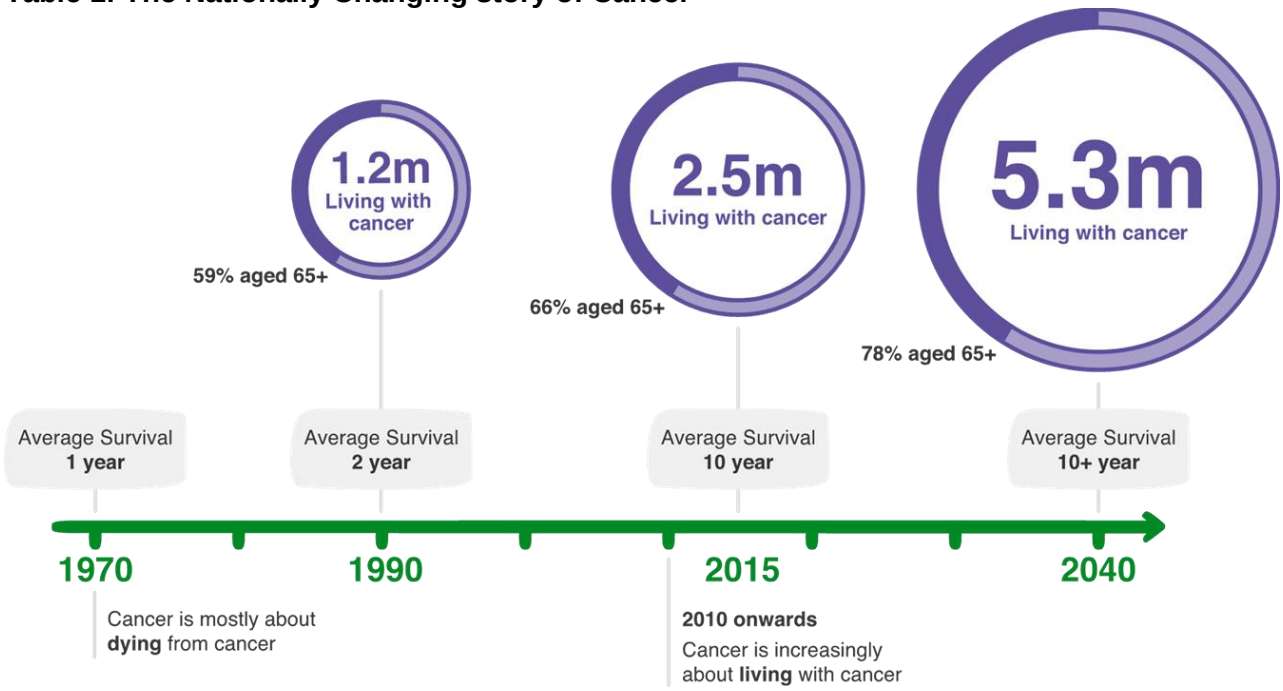
Over the last 25 years, the population of people living with cancer has doubled to 2.5m (2015). The NHS is diagnosing more people with cancer. Looking ahead, Cancer Research UK estimate that 1 in 2 people born after 1960 in the UK will be diagnosed with some form of cancer during their lifetime.

By 2040, there will be some significant changes to the cancer experience:

- More people will experience cancer - 5.3 million by 2040, driven by increasing number of people being diagnosed with cancer and aging population with increased chances of survival.
- Many will survive their cancer but may live with long term consequences of their cancer or treatment
- 72% of people with cancer with will also have another long-term condition.

In 2018 in East Midlands Cancer Alliance 173,706 people are living with a cancer diagnosis (diagnosed between 1995-2018) [5]

Table 1: The Nationally Changing story of Cancer



Source: Macmillan

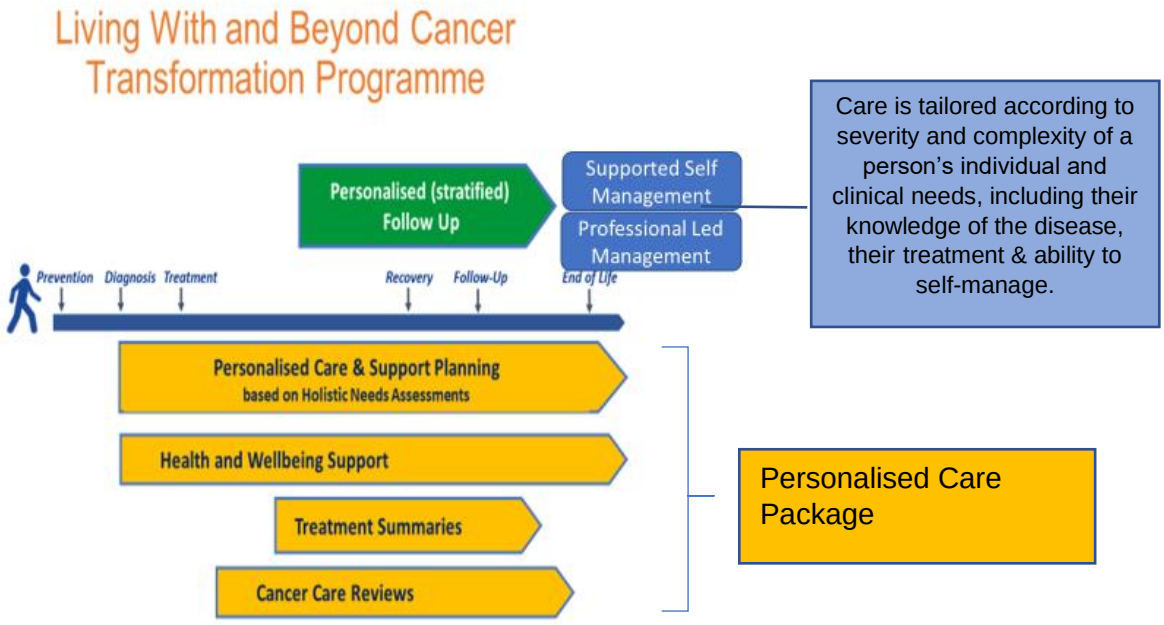
This means that increasing numbers of people are living with a variety of supportive care needs such as coping strategies for symptoms, physical and psychosocial as well as broader emotional, practical and social aspects of the impact of their diagnosis and treatment including late effects. Until recently there has been less emphasis on dealing with the long-term needs of the increasing number of cancer survivors. Side effects of treatment can be missed or overlooked because the current priority of cancer follow-up is to perform surveillance for recurrent cancer.

1.3 Living with Cancer

Cancer Alliances lead transformational programmes to deliver personalised care in cancer and personalised stratified follow-up for individuals to access help and empower them to self-manage and live well with and beyond cancer. These models of follow-up have greater emphasis on quality of life by giving responsibility to the individual on what matters to them than what is the matter with them.

The diagram below illustrates the programme.

Table 2: Personalised Care / Living with Cancer programme



In the East Midlands people living with cancer, have been benefitting from a personalised approach for some years in some areas. It is important that all individuals offered this personalised approach benefit from these changes and variation in service provision that exists across the East Midlands is reduced to ensure equity of access to high quality, safe and sustainable services.

This transformation needs to be supported by IT systems to ensure a safe, quality service ensuring a positive redistribution of resources, staffing and facilities.

This document describes a generic pathway and principles for people with a cancer diagnosis. It defines the levels of follow-up support available to them:

- Supported self-management follow up
- Professional led follow up
    - Including best supportive care

These guidelines recommend:

- All individuals with a cancer diagnosis, including secondary cancer, receive a **Personalised Care and Support Plan** (PCSP) based on a **Holistic Needs Assessment** (HNA) as well as personalised information and appropriate **health and well-being information** and support to encourage them to live actively and well following the end of their cancer treatment in addition to a **Treatment Summary** provided to the person and their GP at the end of active treatment and are offered **Cancer Care Reviews** in primary care.

- Each individual is provided with additional information and signposting to enable them to self-manage and live well with and beyond cancer.

- Each individual is provided with verbal and written guidelines about exactly when and who to contact if they have any concerns in the future.

- Each individual and their GP will receive a Treatment Summary (TS) from the treating hospital outlining the care and treatment received plus any key information regarding consequences of disease and/or treatment required for Primary to facilitate continuity of care in the form of the Cancer Care Review (CCR)

- A safe, robust, user friendly system is available to enable personalised follow-up, which includes appropriate surveillance with timely reporting and recall if required to facilitate a positive individual experience.

- All individuals diagnosed with cancer, irrespective of their risk of recurrence receive co-ordinated supportive care with rapid re-entry (open access) to the specialist cancer team as required.

2. Personalised Follow Up: The Thyroid Cancer Pathway

Personalised follow up care is a broad term that includes Personalised Stratified Follow Up (PSFU) for cancer pathways and Patient Initiated Follow Up (PIFU) for non-cancer pathways. These guidelines are for PSFU for cancer.

Essentially support for self-management should be offered to all.

Things needed for Personalised Stratified Follow Up (PSFU) in cancer but probably not in non-cancer PIFU:

- Ongoing diagnostic surveillance scans/tests
- Remote Monitoring System
- Cancer Support Worker or Clinical Nurse Specialist who may guide/triage callers

2.1 EMCA Cancer Personalised Care Pathway

The referral routes for all individuals with either suspected or secondary cancer are shown in the specific pathway guidance.

Individuals will be offered personalised care when their diagnosis and management plan is discussed at a suitable time for them.

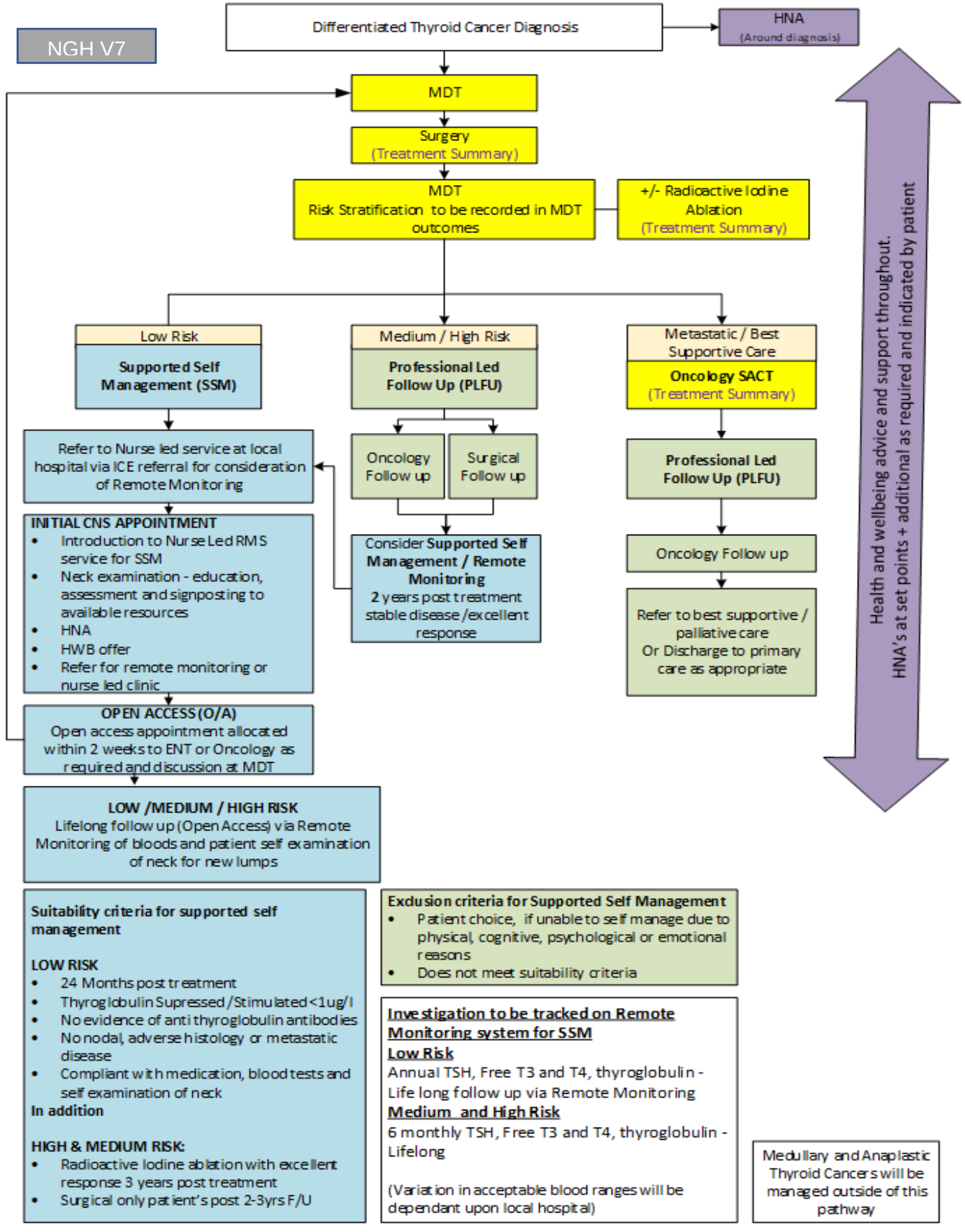
Individuals with secondary cancer (including palliative) who are seen in oncology clinics will also be offered personalised care.

All people living with cancer continue to be supported by primary care including the offer of a cancer care review at 3 months and 12 months of diagnosis.

Supporting Documents: East Midlands Cancer Alliance (2019) **Cancer Personalised Care Glossary of Terms** (Appendix A)

THYROID CANCER – PERSONALISED STRATIFIED PATHWAY

NB: Allied Health Professionals such Speech and Language therapy support can be reflected in the pathway below.



2.2 Diagnosis and Treatment

All individuals will have been offered a personalised care package consisting of:

- Personalised Care and support plan (**PCSP**) based on a Holistic Needs Assessment (**HNA**)
- Health and wellbeing support and information (**HWBSI**)
- Treatment Summary (**TS**)
- Cancer Care Review (**CCR**)

Individuals with secondary cancer will be offered personalised care based around the professional-led pathway follow up model.

At diagnosis, individuals will be informed, at a suitable time for them, about supported self-management and professional-led follow up pathways; Open Access; and Health and Wellbeing support and information.

The Multidisciplinary Team (MDT), following the decision on treatment recommendation, will record the clinically stratified risk decision in the individual's notes as defined in the Table 3.

Table 3 THYROID CANCER - EMCA Defined Clinical Risk Stratification Decision for Follow Up

	Stratification	**Supported Self-Management** (No routine follow up + Remote Monitoring testing)	**Professional Led Management** (Routine follow up + Remote Monitoring testing)
1	Low Risk	• 12 months post treatment • Thyroglobulin Supressed / Stimulated <1ug/l • No evidence of anti-thyroglobulin antibodies • No nodal, adverse histology or metastatic disease • Compliant with medication, blood tests and self-examination of neck	For those who do not meet criteria for Supported Self-Management
2	Medium / High Risk	• Radioactive Iodine ablation with excellent response 3 years post treatment • Surgical only patients' post 2-3 years follow up	
4	Metastatic	N/A	Supported by (Oncologist / CNS) prior to transfer to best supportive care or primary care as appropriate

NB: Medullary and Anaplastic Thyroid Cancers managed outside of this pathway

Examples of clinical criteria agreed for breast, prostate and colorectal can be found within these EMCA guidelines Living With and Beyond Cancer - East Midlands Cancer Alliance

Individuals may be deemed clinically suitable for supported self-management **unless**:

- There is mutual agreement not to enter the self-managed follow up pathway.
- The individual is unable to self-manage due to physical, cognitive, communication or emotional reasons.

- The individual has co-morbidities that may require closer monitoring.
- The individual is deemed inappropriate by the MDT because of oncological concerns.

The follow up pathway agreed should be recorded in the individual's clinical notes by a member of the Multi-Disciplinary Team.

Individuals may move between supported self-management or professional led follow-up pathways if it is appropriate and mutually agreed at any point.

2.3 Personalised Care Package

There are four elements to the personalised care package:

- Personalised Care and Support Plan (PCSP) based on a Holistic Needs Assessment (HNA)
- Health and Wellbeing Support and Information (HWBSI)
- Treatment Summary (TS)
- Cancer Care Review (CCR)

2.3.1 Personalised Care and Support Plan and Holistic Needs Assessment

The **Holistic Needs Assessment** (HNA) informs the development of a **Personalised Care and Support Plan** (PCSP) for the individual following discussions with their specialist nurse (often a Clinical Nurse Specialist) or key worker, highlighting the most important issues at that time that need to be addressed during or after treatment.

PCSPs should be completed and agreed by the specialist nurse and the individual. A review of this plan will occur following subsequent HNAs, e.g. at the end of treatment.

An on-line version of the HNA is known as an eHNA (electronic Holistic Needs Assessment).

It is recommended there is real time recording of the point HNA's are offered and completed in the person's pathway Eg: at diagnosis, at end of treatment, and number (% of all people diagnosed) of HNAs undertaken.

An HNA, also known as a 'concerns checklist' or 'Health MOT', is a simple assessment completed by the person affected by cancer that assesses the physical, practical, emotional, spiritual and social needs of the person and ensures these needs are met in a timely and appropriate way.

The HNA requires consideration of the timing of the assessment in relation to the person's journey, enough time to reflect and consider their own needs and feelings and an appropriate environment to undertake the questionnaire. This environment may be at home, in their GP surgery or at the hospital they have been attending for cancer treatment.

HNA's should not be used a tool for identifying side effects of cancer treatment.

All individuals will be offered an HNA as a minimum as part of the normal assessment process from diagnosis through to the end of treatment. An HNA should also be offered at any point in the pathway where there is a change in treatment, including at the end of treatment, or issues identified by the individual or healthcare professional and the PCSP updated accordingly and agreed with the individual. HNA's can also be offered to individuals undergoing surveillance tests.

The HNA can be undertaken by the individual with support from any HNA trained member of the team, often this is a clinical nurse specialist, cancer support worker, radiographer or allied health care professional. Support can also be provided by other healthcare professionals. Appropriate time should be allocated to staff to enable time for reviewing HNAs and managing the findings.

Common areas of concern identified through HNA's by individuals diagnosed with cancer can vary according to the type of cancer however they can often include concerns shown in the table below:

Table 4: Common HNA Concerns

Tired, exhausted or fatigued	Eating, appetite or taste	Loss of interest in activities
Sleep problems	Worry, fear or anxiety	Anger or frustration
Diet and nutrition	Pain or discomfort	Partner, Children, Taking care of others
I have questions about my diagnosis, treatments or effects	Thinking about the future	Sex, intimacy or fertility
Uncertainty	Hot flushes or sweating	

2.3.2 Health and Wellbeing Support and Information (HWBS&I)

All individuals will have access to health and wellbeing support and information at suitable points in the pathway. This support may be in the form of an event, face to face or on line, where there is education and support sessions aimed to provide individuals with the information and reassurance to build the confidence they require to enable them to lead as normal and active life as possible after their cancer treatment.

These sessions may also aim to increase awareness of the local facilities, supportive care and opportunities that are available to them and their families.

Signposting to other existing known local health and wellbeing support services for cancer and other long-term conditions can also be offered as health and wellbeing interventions and will promote collaboration between service providers to ensure sustainability of this essential element of supported self-care.

In summary, health and wellbeing support and information may be delivered face to face or virtually as:

- 1:1 appointments
- Rolling programmes
  E.g. The 6-weekly Macmillan HOPE Programme[28] also delivered as an iHOPE course. The Help to Overcome Problems Effectively (HOPE) course concentrates on focusing and rediscovering inner strengths and resilience to help individuals cope emotionally, psychologically and practically. Table 5 shows what the HOPE course covers:

Table 5: HOPE Course Content

Goal setting and action planning	Looking for solutions to problems
Stress management (e.g. mindfulness and relaxation)	Fatigue management
Identifying your strengths	Becoming more positive, grateful and appreciating life more
Healthy lifestyles (e.g. eating more healthily and physical activity)	Prioritising the important things in life
Fear of cancer recurrence	Body image and sexuality and intimacy
Communication skills	

Source: Macmillan HOPE Programme[6]

- **Group events** which are scheduled at regular intervals, face to face or online, throughout the year and which individuals may have an open invitation to attend if they choose to do so. They may be specific to individuals who have had a cancer diagnosis or open to all who have had a

cancer diagnosis. The events provide opportunities for interaction between individuals, carers, clinicians, clinical nurse specialists, allied health professionals, and complementary therapists. These might also include market stalls and/or videos (depending if face to face or online) of local health promotion services or voluntary agencies. Common area covered in these events include:

Information about local groups
Finances
Exercise
Emotional support
Healthy eating

- Signposting and access to local services for cancer as a long-term condition health and wellbeing management.
- Online support groups
- Online tools and support– examples include:
  https://www.cancercaremap.org/
  https://www.macmillan.org.uk/
  Cancer Research UK
  British Thyroid Foundation
  Butterfly Thyroid Cancer Trust
  Association for Multiple Endocrine Neoplasia Disorders (AMEND)

These are in addition to locally developed apps. And other local online resources.

A national checklist of health and wellbeing services is available so healthcare systems can identify gaps in provision across cancer pathways and thus to support them in providing consistent information across the health system in different formats. See Appendix B for details.

2.3.3 Treatment Summary (TS)

A Treatment Summary (TS) is a document produced by a healthcare professional after a significant phase of an individual's cancer treatment. It is designed to be shared with the person living with cancer and their primary care team, to enable them to manage their health and wellbeing. The TS are important to help inform and support effective Cancer Care Reviews in primary care.

TSs are essential for good quality and safe open access follow up. Personalised stratified follow up should not be undertaken without treatment summaries being completed. It should include:

- A personal plan for **future surveillance** such as blood tests and scans.
- **Possible treatment toxicities/consequences** of disease and/or treatment and late effects.
- **Late Effects** cancer survivors might experience late effects of cancer treatment years later.
- **Symptoms Checklist** - highlighting symptoms that should trigger obtaining advice from the specialist CNS.
  People living with cancer and clinicians may differ as to what constitute significant symptoms. People who experience these symptoms may require follow up by trained staff to support them.
- **Key symptoms (red flags) that require re-access** flags' to the specialist secondary care team
- **Contact Details:** name, phone number and working hours of the specialist team.
- Include whether the individual is eligible or not for **free prescriptions**
- Information that the individual will receive a national '**quality of life' survey** 18 months after their cancer diagnosis

An end of treatment review (see section 2.5) is when the final TS is drawn up by secondary care and will include information including side effects of treatment and how to access help.

There should enough detail in the treatment summary to enable GP practices to add codes/ information, so they can set alerts on their systems if follow up surveillance tests are required. If

there is a change in responsibility for ordering and reviewing the results of investigations local guidelines may need to be drawn up.

Treatment summary codes shown below are recommended to go at the top of Treatment Summaries when people diagnosed with cancer have finished an active treatment (eg: Surgery, radiotherapy):

Table 6: Treatment Summary coding

Snomed code: 413737006	Cancer hospital treatment completed (situation)
Read code: 8BCF.00	Cancer hospital treatment completed

2.3.4 Cancer Care Review (CCR)

The CCR is a holistic conversation between the individual and their healthcare professional in their GP practice. It is aided by the HNAs, PCPS and TS. It allows an opportunity for the individual to raise any concerns that may be affecting their quality of life, taking into account their existing conditions and medication and enables individuals to discuss their cancer experience and supports them to manage their own health and wellbeing. The GP Practice can support individuals expressing concerns during their review and signpost them to services such as social prescribing.

National Quality Outcome Framework indicators for primary care in 2021/22 for people diagnosed with cancer specify that a individual's GP practice offers those diagnosed with cancer:

- An opportunity for a discussion and to inform them of the support available from primary care within 3 months of diagnosis.
- Offers a Cancer Care Review (CCR) within 12 months of diagnosis.

2.4 Open Access in Secondary Care

All individuals can continue to access their GP practice in primary care as before as well as having Open Access to secondary care specialist team (without necessarily involving the GP). Open Access (this could be via telephone, e-mail etc according to local systems) may have a triage process to enable clinical prioritisation.

Low risk patients will be offered open access to the service for 5 years post treatment, medium and high-risk patients will have lifelong open access to the service unless specified otherwise for individuals by the specialist team. After Open Access finishes, people will be discharged to primary care for ongoing support and would be referred back to secondary care if there are red flag symptoms or side effects of treatment that require specialist support as outlined in their Treatment Summary.

During Open Access run by secondary care the clinical governance responsibility for the individual lies with the specialist team. The clinical responsibility moves to primary care once the individual is discharged to the care of their GP.

Any discharge letters and treatment summaries should be shared with the individual and their GP as soon as possible after their last appointment. Contact numbers and guidelines on how to contact the specialist team must be made clear in this information.

The individual will be reviewed via secondary care Open Access and will receive advice and may either have an appointment made for specific surveillance, one-stop clinic, virtual or face to face appointments with either a surgeon, specialist nurse, oncologist, specialists in side effects of

treatment or be recommended to see their GP (GP access times can vary up to 4 weeks in advance). Once an individual has contacted the secondary care Open Access service, they can expect to receive a response to their query as soon as possible, best practice is that this is within 1 working day however this may be within 2 working days. Experience has shown that the majority of queries can be resolved over the telephone. If someone needs to be seen (face to face or virtually) and are clinically urgent, they should be seen within 2 weeks of contacting the open access service.

It is recommended that:

- Hospitals identify a triage clinic for these individuals to ensure rapid access when required
- An alternative code is used for OAFU appointments to enable differential data collection for these groups of patients unless alternative methods already capture this data.
    - An updated Outpatient Commissioning Dataset is due to be introduced from April 2022 which will include Personalised stratified follow up / Patient Initiated Follow Up.

2.5 End of Treatment Review

This is a key decision point, at the end of treatment, all individuals will receive an end of treatment review with a clinician. It may be an individual or group appointment (E.g. a health and wellbeing information and support event). Each person will have the opportunity to meet with a healthcare professional individually and will receive personalised information about their planned follow-up and surveillance.

At a suitable time and place appropriate to the individual, they will be invited to complete a Holistic Needs Assessment. Their personalised care and support plan can then be updated accordingly.

All newly diagnosed and secondary cancer individuals will receive information about their diagnosis, treatment options and subsequent follow-up pathway at the end of treatment. This will include a description of the re-entry process, the support and tools available to enable self-management and explanation of the ongoing surveillance and screening that will occur during the defined follow up period according to their treatment pathway.

All individuals will be transferred onto the jointly agreed follow-up pathway, supported self-management or professional led, at the end of treatment.

During this appointment, it is expected that the individual will be provided with verbal information and have access to either on-line or printed information as shown below.

- A personal plan for **future surveillance** such as blood tests and scans. This will include an explanation of the process for receiving appointments for these and the results.

- **Possible treatment toxicities/consequences** of disease and/or treatment and late effects.

- **Late Effects** are side effects of cancer treatment that become apparent after treatment has ended and can impact on someone's quality of life. Cancer survivors might experience late effects of cancer treatment years later. Common problems include:
    - pain
    - nerve damage and neuropathy
    - mental and emotional changes, including anxiety, depression,
    - chemotherapy-related cognitive impairment
    - changes to self-perception
    - social identity

- **Advice** on the following is also recommended:
    - adapting physical activity to maintain their quality of life

- diet
- weight management, physical activity and healthy lifestyle choices (for example stopping smoking and reducing alcohol use)
- how long their recovery might take
- how, when and where to seek help if side effects become problematic.

- **Symptoms Checklist** - It is recommended that this is given to all people diagnosed with cancer as a means of highlighting symptoms that should trigger obtaining advice from the specialist CNS. Much of this can be assessed over the phone, with the person being asked a detailed history, regarding onset duration, exacerbating and relieving factors and any action already taken, then given advice and/ or signposted to their GP or late effects services. However, some of these symptoms combined with telephone triage may necessitate an outpatient appointment.

  People living with cancer and clinicians may differ as to what constitute significant symptoms. People who experience these symptoms may require follow up by trained staff to support them.

- **Key symptoms that require re-access** to the specialist secondary care team
  - Development of a new lump/bump in the neck;
  - Noisy breathing;
  - Worsening voice quality;
  - Rise in thyroglobulin levels;
  - Increased difficulty swallowing.

- **Contact Details:** name, phone number and working hours of the specialist team for **Open Access.**

- **Health and Wellbeing information and support** and how to access relevant services. This may include any local self-help groups and useful phone numbers (e.g. https://www.cancercaremap.org/ https://www.macmillan.org.uk/ and cancer tumour specific charities

- Include whether the individual is eligible or not for **free prescriptions**

- Information that the individual will receive a national '**quality of life' survey** 18 months after their cancer diagnosis

At the conclusion of the end of treatment review, individuals, will choose with help from a health professional within the specialist team to transfer onto either the **supported self-management** or the **professional led pathway**. The type of follow up pathway agreed will be recorded by the healthcare professional in the individual's hospital notes.

A **Treatment Summary** will be generated following this end of treatment review meeting covering many of the points above and be sent to the individual, their GP as soon as possible following their review and held within the individual's hospital notes.

Examples of Treatment Summaries for chemo/immunotherapy, radioactive iodine, surgery and best supportive care are shown below

Northants TS-HAN - Thyroid - Radioactive

Northants TS-HAN - Thyroid - Chemo +- Ir

Northants TS-HAN ONC NGH Best Suppc

2.6 Personalised Follow Up Pathways

2.6.1 The Benefits of Personalised Stratified Follow Up

For Patients:

Access to higher quality care that:
• Is personalised and tailored to people's specific needs and conditions
• Is based on what matters to people and their individual strengths, needs and preferences
• Helps to detect and manage cancer-related psychosocial problems
• Provides more support for those with complex needs
• Helps people find services that meet their individual needs, and
• Increases the proportion of people continuing to have surveillance tests (i.e. fewer 'lost to follow up').

Support for self-management that:
• Provides information enabling earlier self-detection of recurrence, progression, or long-term side effects
• Encourages people to contact their healthcare team at any time with any worries or concerns
• Increases people's knowledge and understanding of their condition and situation
• Increases people's overall confidence, health and wellbeing, and
• Encourages lifestyle changes which can help to reduce the risk/impact of cancer recurrence (or new cancers), treatment consequences and comorbidities.

Improves patient experience by:
• Reducing travel to hospital (if on remote monitoring)
• Reducing anxiety through more timely access to results.

For professionals:

• Enhanced continuity of care
• Better triage of queries by support staff
• More responsive access to specialist teams if problems occur
• Improved communication and links with primary care teams (e.g. via End of Treatment Summaries)
• Improved knowledge of management of acute and long term side effects, and
• Improved knowledge of pathways for referral/ signposting to services and third sector support.

For systems:

• Improves productivity through the redeployment of professionals' time, outpatient capacity* and reduced duplication of surveillance tests
• Supports greater integration of care
• Supports better communication across different care settings
• Reduces demand for unplanned care
• Increases the transparency around costs of cancer follow up, allowing resources to be targeted at patients

Source: NHS Living with and Beyond Cancer – Implementing Personalised Stratified Follow Up Pathways. A Handbook for local health and care systems. March 2020

2.6.2 Types of Personalised Follow Up

The follow up schedule broadly revolves around two central tenets:

I. Oncological risk of recurrence (pathological / radiological staging)

II. Method of Delivery (See Table 7)
- Supported self-management
- Professional led
    - Best Supportive Care

Table 7: Types of Personalised Follow-Up Pathways – Method of delivery

Supported Self-Management Pathway	**Professional Led Pathway / Best Supportive Care**
Individuals will not have scheduled outpatient appointments after initial post-operative follow up appointment with the surgeon. Surveillance test results will be communicated by phone/e-mail/ letter unless results indicate the person needs to be seen. • HNA can be offered when test requests are sent. It may be valuable for the individual to have an annual review with their GP Practice team.	Individuals will have scheduled outpatient appointments (virtual or face to face): At these appointments/reviews there will be a review of: • Test and other scan results as appropriate and available • Medication review where appropriate • HNA can be offered. The cancer MDT will decide the frequency and responsibility of follow ups for the professional led pathway.
At the end of Open Access, individuals will be discharged to the care of their GP. A letter from the specialist team will be sent to the individual and their GP confirming this.	At the end of Open Access, following a review, individuals will be discharged to the care of their GP. A letter from the specialist team will be sent to the individual and their GP confirming this.
Individuals may move to professional led follow-up if it is appropriate and mutually agreed at any point.	Individuals may move to supported self-management follow-up if it is appropriate and mutually agreed at any point.
All Personalised Follow Up Pathways	
All individuals should have a **Cancer Care Review** undertaken with their GP practice within 12 months from diagnosis and offered the opportunity for discussion and informed of the support available in primary care within 3 months of diagnosis.	
Individuals will have re-entry to secondary care **Open Access** (appointment within 2 weeks if clinically urgent) for the length they are on remote monitoring with the specialist team from diagnosis (Eg: 5 years) for both Supported Self-Management pathway or Professional Led pathway. An individual can contact their specialist team as needed with any concerns via a dedicated contact number and or e-mail address advised in the **Treatment Summary.**	
Individuals will be invited to their surveillance tests, by their specialist team. This will be clearly documented in the **Treatment Summary** clearly stating who is responsible for ordering and reviewing the investigations and when they should be started and stopped.	
At any point during the secondary care **Open Access** individuals may be contacted to be offered access to any relevant clinical trials or new treatments that may become available.	
If recurrent or metastatic disease is found at any time along the pathway the persons results will be discussed with the consultant, referred to the MDT meeting and referred as appropriate.	

To ensure effective personalised follow up systems are in place each NHS Trust will have **Remote monitoring systems** (section 4) to enable the following to happen:

- There should be a designated member of the specialist cancer team who is responsible for ensuring the following takes place:
    - The scheduling, monitoring and communication of surveillance tests and subsequent results
    - Scheduling systems to ensure appropriate individuals are contacted with the test results and no individual is 'lost to follow up'

a Eligibility for Entry - Personalised Supported Self-Management Pathway

Individuals suitability for entering the supported self-management pathway will be considered at the end of treatment review, if not before at the cancer MDT, according to the clinical criteria. Those eligible will be recorded as appropriate for supported self-management follow-up on their MDT proforma within the cancer IT system. A copy will be placed in the individuals notes as appropriate.

At the end of treatment review the supported self-management and professional led follow up pathways and the support available is discussed with the individual to help them decide what works for them. People may change between supported self-management and professional led pathways in discussion between their specialist team and themselves.

Section 2.5 describes the end of treatment review and what is offered including open access to secondary care.

For those individuals on the supported self-management follow up pathway no further scheduled follow up appointments in secondary care are required after the end of treatment review except for undergoing planned surveillance tests.

b Eligibility for Entry - Personalised Professional Led Pathway

Individuals suitability for entering professional led pathway will be considered at the end of treatment review, if not before, according to the clinical criteria and agreed at the MDT at which their results are discussed.

Individuals with secondary cancer (metastatic disease) will be supported on this pathway. They may receive non curative treatment and be followed up on the professional led pathway for a period of time before being counselled for referral to palliative care / enhanced supportive care and also discharged to their GP. This is called **Best Supportive Care.**

Some individuals who meet the clinical criteria for supported self-management may not be appropriate for supported self-managed care and will join the professional led pathway. These can include:

- The individual who is unable to self-manage due to physical, cognitive, communication or emotional reasons.
- The individual who has co-morbidities that may require closer monitoring.
- Following discussion between the individual and the healthcare professional there is mutual agreement not to enter the self-managed follow up pathway.
- The individual is deemed inappropriate by the MDT because of oncological concerns.
- The individual is in a clinical trial

Any need for the provision of language services for people diagnosed with cancer whose first language is not English will need to be considered locally depending upon the demographic served by each hospital to enable them to have access to a self-managed option.

Individuals who are not eligible will be recorded as not appropriate for self-managed follow-up on their MDT proforma within the cancer IT system and will continue on the professional led follow-up pathway. A copy will be placed in the individuals notes as appropriate.

2.6.3 Clinical Trials

For individuals participating in clinical trials, follow-up will be determined by the clinical trial protocol.

It is recommended that at any point during the 5-year follow-up pathway in secondary care, individuals may be contacted to be offered access to any relevant clinical trials that may become available.

All individuals taking part in trials will still access and benefit from the end of treatment review and updated holistic needs assessment, updated personalised care and support plan, a treatment summary, open access to secondary care and health and wellbeing support. Information must include who, how and when individuals can access support (E.g. written advice, online, telephone support etc) including open access to secondary care in addition to their scheduled appointments.

2.7 Personalised Supported Self-Management Pathway

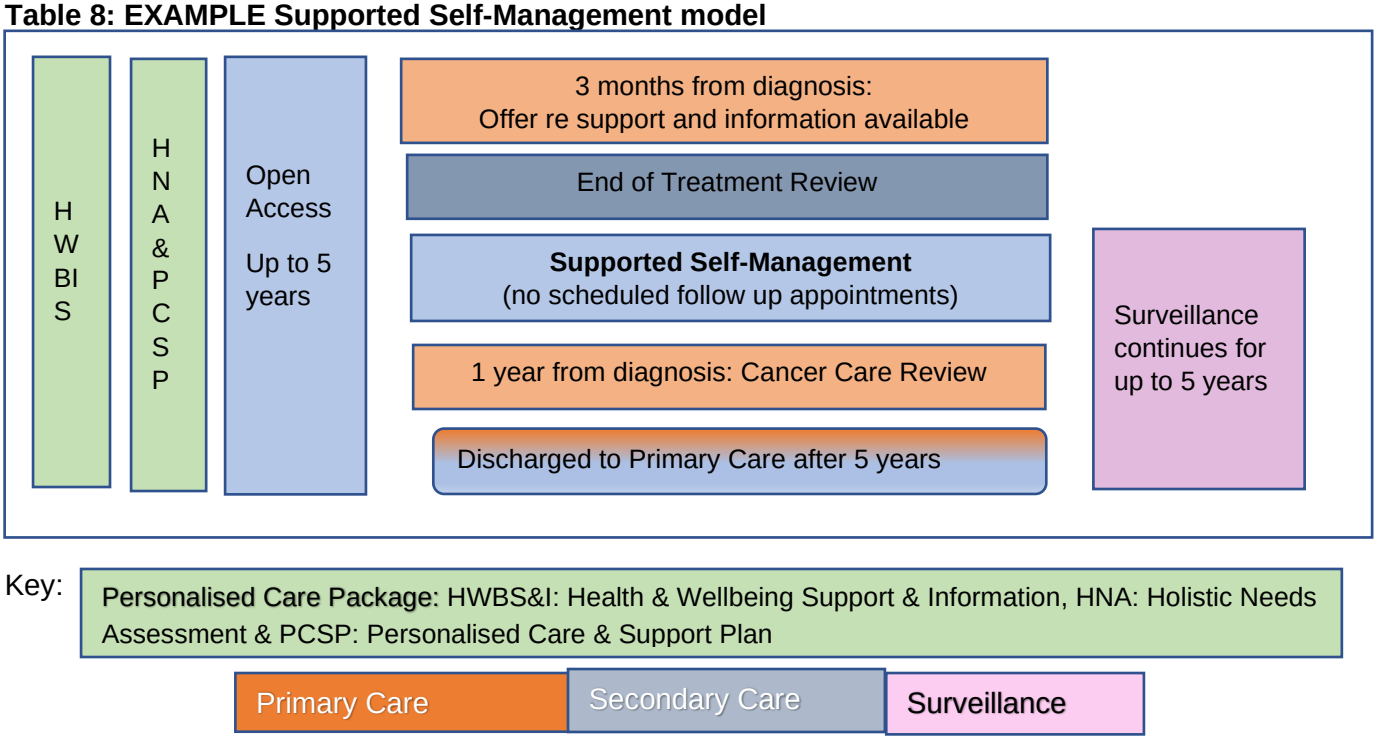
Non-Scheduled Appointments

Individuals on the supported self-management pathway including those, where it has been mutually agreed between the person affected and their clinician, who have moved from professional led will not have scheduled outpatient appointments after their end of treatment review as shown in Table 8. They will continue to be supported by the personalised care package, open access service and surveillance tests specific to them and their treatment pathway.

An appointment may be subsequently scheduled (face to face or virtually) because the individual has contacted the open access service.

A review (virtual or face to face) may take place when the individual is discharged from personalised stratified follow up at the end of the surveillance period to inform both the individual and their GP that follow up is complete and they have been discharged from secondary care.

Table 8: EXAMPLE Supported Self-Management model



2.8 Professional Led Follow Up Pathway

Scheduled Review Appointments

The specialist MDT will decide the frequency and responsibility of scheduled follow up appointments including individuals who have moved from a supported self-management pathway.

Those on the professional led pathway will also be supported by the personalised care package, open access service and surveillance tests specific to them and their treatment pathway.

At discharge individuals have a review, virtual or face to face, with a healthcare professional.

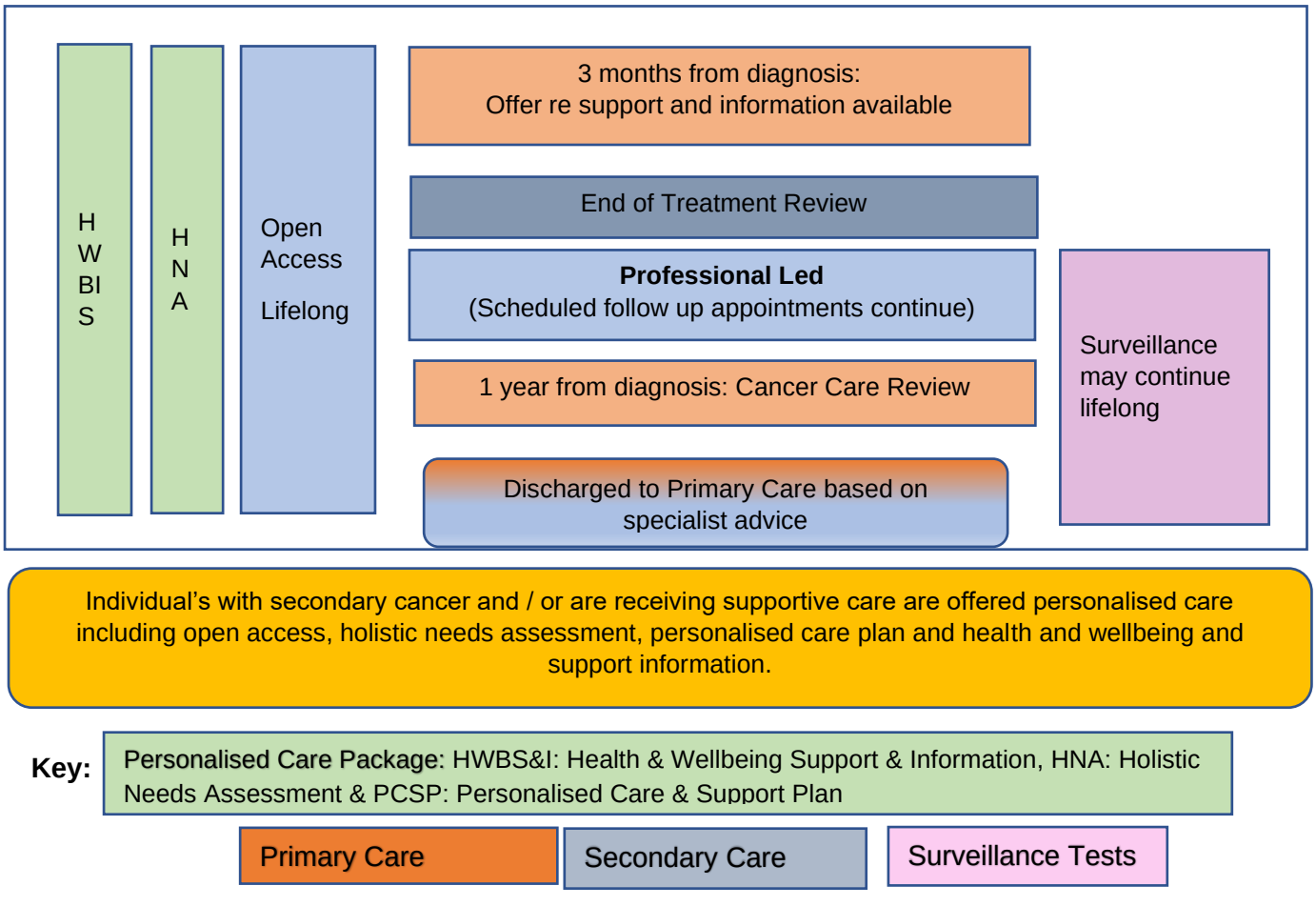
There needs to be a safe, robust system in place to ensure all individuals are booked appropriately onto a virtual review at the appropriate time.

The purpose of the review is:

- To identify and inform individuals that their treatment is complete.
- To identify and inform individuals of any ongoing surveillance tests such as colonoscopies and who will order and communicate the results to them.
- To define when the individual is discharged from professional led follow-up care and open access so both the individual and their GP are notified that the follow up is complete and they have been discharged from secondary care.

Individuals will receive confirmation of the outcome, with a copy sent to their GP.

Table 9: **EXAMPLE Professional Led Management model summary**



2.8.1 Best Supportive Care

Some individuals may decline treatment, or their clinical condition such as complex symptomatic advanced disease or frailty, means it is inappropriate to offer full follow up surveillance tests and non-curative treatment is being considered.

A couple of six-monthly follow up appointments with a member of the specialist team may be appropriate to review and support the individuals before offering transfer to their GPs care and /or palliative care /enhanced supportive care as appropriate

2.9 Discharge from Personalised Follow-up Pathways to Primary Care

Generally, after 5 years (this will vary by tumour site) from diagnosis individuals on supported self-management and professional led review are eligible for discharge from the secondary care open access service unless the specialist clinical team agree to continue surveillance tests.

2.9.1 Discharge from Supported Self-Management Follow Up Pathway to Primary Care

After 5 years individuals, on a supported self-management follow up pathway, and their GP, will be informed by letter that they are being discharged from the secondary care open access service to their GP with recommendations for their long-term plan.

The letter will include advice on what to do if the individual has any **new** cancer treatment related problem, including late effects (self-referral available), so they can see their GP who can refer them back to the relevant hospital service.

Any surveillance required after 5 years from diagnosis will be considered and organised by secondary care and individualised.

Table 10 lists some resources available to help primary care clinicians with possible cancer symptoms and long-term consequences.

Table 11 lists some support to help individuals around health and wellbeing support and information. Good practice would be to remind individuals of the support available to them nationally and locally.

2.10.2 Discharge from Professional Led Follow Up Pathway to Primary Care

Individuals within the professional led pathway will have a final review scheduled appointment. This appointment may be face to face or virtual with a member of the specialist cancer team.

Individuals on the professional led follow up pathway, following the final review, and their GP, will be informed by letter of the outcome and recommendations for their long-term plan.

Outcomes include:

- Individuals are discharged from the secondary care open access service to their GP with recommendations for their long term plan and any queries around their cancer in future can be discussed with their GP practice. This will include advice on what to do if the individual has any **new** cancer treatment related problem, including late effects (self-referral available), so they can see their GP who can refer them back to the relevant hospital service.

Table 10 lists some resources available to help clinicians with possible cancer symptoms and long-term consequences.

Table 11 lists some support to help individuals around health and wellbeing support and information. Good practice would be to remind individuals of the support available to them nationally and locally.

Table 10: Resources for clinicians to help with possible cancer symptoms

Gateway C	https://www.gatewayc.org.uk/gwc-cancer-map/
RCGP Toolkit – Consequences of Cancer	https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/consequences-of-cancer-toolkit.aspx
CRUK interactive Desktop Easel	https://www.cancerresearchuk.org/health-professional/diagnosis/suspected-cancer-referral-best-practice/nice-cancer-referral-guidelines#NICE_implementation1
CRUK Infograph Poster	https://www.cancerresearchuk.org/sites/default/files/nice_infographic_poster_march2016.pdf Or can be ordered: https://publications.cancerresearchuk.org/search?p=7)
Macmillan Rapid Referral Guidelines	https://www.macmillan.org.uk/_images/rapid-referral-toolkit-desktop_tcm9-291864.pdf Also versions for desktop/ mobile/ laptop or can order in print)
Macmillan Clinical Decision Support	https://www.macmillan.org.uk/about-us/health-professionals/programmes-and-services/prevention-early-diagnosis-programme/cancer-decision-support-tool.html#280141

Table 11: National Resources for individuals around health & wellbeing support

Good practice: Remind individuals of health and wellbeing support and information available nationally such as websites, and in their local community including support groups in addition to local GP practice resources E.g.: Social prescriber	
Cancer Care map directory	https://www.cancercaremap.org/ Can help individuals living with cancer to find local cancer care services in their area.
Macmillan Cancer Support	https://www.macmillan.org.uk/ Provides advice and patient information on bowel cancer. Includes an online community and support line.

3. Workforce Planning

Workforce planning is essential to the implementation and delivery of a successful personalised follow-up pathway. The impact on staff health and wellbeing should not be underestimated as a result of this transformational shift.

"The NHS achieves extraordinary things for patients, but safety and health and wellbeing matter just as much for our people. If we don't look after ourselves, and each other, we cannot deliver safe, high-quality care."

Source: NHS People Plan 2020

Organisations should demonstrate an understanding of the potential increase in emotional labour that this change will bring, ensure workforce planning is prioritised and opportunities for staff to build resilience are embedded within their work.

Staff should have IT and remote monitoring system knowledge, so they can be confident in using and navigating systems and processes accurately and effectively.

Cancer support worker/ Cancer coordinator/ Cancer navigator role:

This role in secondary care may be employed to release and appropriately realign CNS clinical time and will require specific support, training and development. It is expected that this role will require some clinical knowledge, have a level of communication skills and coordinating the re-entry process and any other contact point within the service.

- Examples of clinical knowledge could include NVQ Level 3 / 4 in health-related subject / equivalent knowledge and experience.
- In addition to clinical knowledge is the ability to show empathy and understand difficulties faced by people affected by cancer, to communicate both verbally and non-verbally on a daily basis with people at all levels as well as accurate written communication and ability to motivate self and others.

This role in primary care may be employed within a practice or across a primary care network E.g.: a social prescriber to support individuals making best use of the treatment summary to inform cancer care reviews, coordinating the re-entry process and any other contact point within the service.

Clinical Nurse Specialists: Will need to have the correct time agreed in their job plans to allow the necessary time to be trained and be competent in undertaking HNA's, PSCPs and end of treatment reviews.

Open Access follow up (OAFU) helpline: Trusts may wish to consider a helpline, with without e-mail access, where people can access advice, support and be triaged to virtual or face to face CNS, oncology or surgical clinics if new symptoms develop.

4. Surveillance Pathway

Surveillance tests are important because the recurrence of cancer is usually detected through surveillance monitoring undertaken by secondary care

Where ongoing surveillance tests are required the responsibility for organising the surveillance tests resides with the individual's treatment hospital.

All individuals will have their secondary care-initiated surveillance investigations recorded on a remote monitoring system (RMS) in secondary care. This system will hold the information required for secondary care to manage follow-up investigations - ordering, checking and recording of results.

In secondary care unexpected results will be discussed by the MDT to formulate a plan and the individual then contacted (preferably by phone). Any missing results will be followed up to ensure all individuals receive their surveillance.

If an individual is required to have further investigations following their routine surveillance tests, they will be recalled for further tests or an outpatient appointment and, if clinically urgent, should be seen within 2 weeks

The development of a patient portal for individuals to directly access their results will be a requirement as part of remote monitoring going forward.

It is recommended that the Trust RMS has clear standard operating procedures outlining which team members will have the responsibility:

- To minimise the risk of losing individuals
- To resolve issues regarding missed surveillance tests such as CEA blood test
- To not contact individuals who have died or moved out of area
- To contact newly registered individuals who qualify for surveillance monitoring
- It makes clear what other healthcare professionals should do with an abnormal result in the absence of the responsible clinician.

Generally, it is recommended that the RMS is:

- Easy to use and compatible with a Trusts current IT system.
- Secure and safe (regularly backed-up etc.).
- Accessible throughout a Trusts IT system.
- Able to record and distribute the metrics needed for comparison of other sites.
- Easily adaptable to future changes in care.
- Suitable for other cancer living with cancer programmes in the Trust.
- Able to support a patient portal going forward

Further information with examples of suppliers of digital remote monitoring systems, patient portals, including NHS Digital clinical risk management requirements for health IT systems is shown below.

Digital RMS supplier case studies are contained and referenced here:

Cancer follow up
Digital RMS guide V1.

The required functionality of remote monitoring is listed below

1)	To pull patient data set information from PAS via the local cancer information system
2)	To pull test results from local diagnostic IT systems
3)	To store key diagnostic and key patient history data
4)	To store log any relevant treatment history during monitoring period including a log of patient contacts
5)	To set individual patient range/tolerances for specific tests
6)	To schedule tests based on user definable follow up schedules
7)	To hold a range of template letters to enable communication of results to patients and GPs by post or electronically
8)	To include an alert system that identifies test results for review, due dates exceeded or test results that exceed tolerance
9)	To provide a summary history and treatment page with test results shown numerically and graphically
10)	To record the outcome of any event or test
11)	To provide standard and ad hoc reporting and routine monitoring function and be amenable to clinical audit
12)	To be NHS and HL7 compliant with secure access
13)	To use a common file format for all data export to be able to import the data into local IT systems if required.

Source: Page 15: https://www.slideshare.net/NHSImprovement/effective-followup-testing-risk-stratfied-pathways-cancer

System implementation should comply with the NHS Digital clinical risk management requirements for health IT systems shown below:

- Compliance with standards DCB0129 and DCB0160 is mandatory under the Health and Social Care Act 2012
- DCB0129: Clinical Risk Management: its Application in the Manufacture of Health IT Systems - more information here
- DCB0160: Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems - more information here

The standards relate to clinical risk management and comprise:

- a specification, which defines the requirements and conformance criteria to be met by the user of the standard - how these requirements are met is the responsibility of the user, for example the NHS Trust implementing digital RMS
- implementation guidance, which provides an interpretation of the requirements and, where appropriate, defines possible approaches to achieving them.

4.1 Surveillance Test Schedule - Secondary Care Setting

It is the responsibility of secondary care to arrange, review and communicate results for these evidence-based surveillance tests with the person living with cancer.

The exception to this is if primary care is commissioned with a clear specification to contact the person to arrange these tests in secondary care with clear governance around communication of results and follow up.

For those people on the supported self management pathway communication of normal test results does not routinely require a routine booked follow up appointment (virtual or face to face). Results of HNA's offered and undertaken at the time of the tests may indicate further key worker (often a specialist CNS) support is required resulting in an appointment.

For those people on the professional led pathway follow up appointments may be booked as part of their test surveillance schedule.

Overall Points of Note for all surveillance tests:

- Surveillance tests should be delivered irrespective of whether the person with cancer has a scheduled follow up
- Where appropriate to the tumour site people of screening age should be encouraged to participate in the relevant national screening programmes in addition to these surveillance tests
- Follow-up should stop when MDT agree the risks of more tests outweigh the potential benefits and best supportive care offered
- If recurrent or metastatic disease is found at any time along the pathway the persons results will be discussed with the consultant, referred to the MDT meeting and referred as appropriate and best supportive care offered.
- In general after 5 years of surveillance tests (or as specified for the pathway) and there is no cause for concern people living with cancer can be discharged to primary care with advice on how to access services for late effects (including self-referral) as appropriate and red flag symptoms.
- However, in some cases the specialist team may require further surveillance tests.
  It would be the responsibility of secondary care to arrange for these tests with the person unless there is a clear specification for primary care to contact the person to arrange these tests in secondary care.

For Thyroid Cancer as illustrated in 2.1 the schedules a shown below:

LOW RISK	**MEDIUM & HIGH RISK**
Annual TSH	Annual TSH
Free T3 and 4	Free T3 and 4
Thyroglobulin - 5 years monitoring	Thyroglobulin – lifelong monitoring

5 Equality and Health Inequalities Impact Assessment

The purpose of an EHIA is to assess the potential impact of a policy, practice or programme of work on groups with a protected characteristic, and whether and to what extent our equality duties and duties in relation to health inequalities are affected and facilitate legal compliance. A template for the assessment for personalised stratified follow up which can be adapted and adopted locally is in Appendix C including reference to the impact of COVID19.

6 References

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NHS Living with and Beyond Cancer – Implementing Personalised Stratified Follow Up Pathways. A Handbook for local health and care systems. March 2020

NICE Interim Guidelines, https://www.nice.org.uk/guidance/indevelopment/gid-ng10150.

8. APPENDICES

APPENDIX A EMCA - Cancer Personalised Care Glossary of Terms

EMCA Personalised Care Glossary of term

APPENDIX B National Health & Wellbeing Checklist

Word and excel versions are available on request from england.emca@nhs.net or direct from FutureNHS

HWBIS_SelfAssessment_Checklist_v1.0_Aug2

APPENDIX C Equality & Health Inequalities Impact Assessment Template

EHIA Provider template.docx

Abbreviations

ANP	Advance Nurse Practitioner
CCR	Cancer Care Review
CNS	Clinical Nurse Specialist
CPES	National Cancer Patient Experience Survey
ECAG	Expert Clinical Advisory Group
EMCA	East Midlands Cancer Alliance
HCP	Healthcare Professional
HNA	Holistic Needs Assessment
HWBSI	Health and Wellbeing and Support Information
HOPE	How to Overcome Problems Effectively
MDT	Multidisciplinary Team
NICE	National Institute of Clinical Excellence
OAFU	Open Access Follow Up
OPFA /OPFU	Outpatient Follow Up Appointment
PIFU	Patient Initiated Follow Up
PCSP	Personalised Care and Support Plan
PSFU	Personalised Stratified Follow Up
TS	Treatment Summary