Personalised Stratified Follow Up (PSFU) Guidelines for People with Haematological Cancer Lymphoma, CLL and MGUS

Report by : West Midlands Cancer Alliance, Haematology Expert Advisory Group

Date : October 2025

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Name	Personalised Care: Haematology Personalised Stratified Follow Up (PSFU)	
Document Title	Personalised Stratified Follow Up (PSFU) Guidelines for People with Haematological Cancer Lymphoma, CLL and MGUS	
Published date	January 2026	
Document Purpose	To provide clinical guidance and support to Trust Haematology Clinical Teams for the management Haematology patients following diagnosis or completing treatment as appropriate. To support the delivery of the national priorities and objectives for cancer.	
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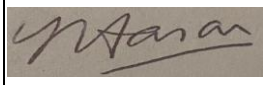
Review Date:	January 2028	
Approval Signatures:	**Dr Yasmin Hasan** **Haematology EAG Chair, West Midlands Cancer Alliance** 	**Clinical Director, West Midlands Cancer Alliance** 

Contents

Version	Date	Revision Author	Status	Description i.e., changes made
0.1	Feb 2023	Debra Palmer	Draft	Draft prepared
0.3	Jan 2025	Haematology EAG Stakeholders	Draft	Review and amended
0.4	Feb 2025	Haematology EAG Stakeholders	Draft	Review and amended
0.5	Mar 2025	Final document	Draft	Review and amended
0.6	Apr 2025	Katherin Stockton Haematology CNS Sandra Smith WMCA	Draft	Review and amended
0.7	Apr 2025	Sandra Smith WMCA	Draft	Review and amended
1.0	June 2025	Haematology EAG Chair	FINAL	Final document
1.0	July 2025	Primary Care EAG	FINAL	Final document
1.0	Sept 2025	Primary Care EAG	FINAL	Final document
1.1	Sept 2025	Haematology EAG	FINAL	Minor amendments to Primary Care segment
1.2	September 2025	Business Support	FINAL	Formatting
1.3	October 2025	Primary Care EAG / Haematology EAG Chair	FINAL	Minor Amendments formatting
1.4	October 2025	Haematology EAG Chair/ WMCA Sandra Smith	FINAL	Minor Amendments formatting

Approved by

This document must be approved by the following people:

Governance	Description	Who	Date
WMCA Haematology EAG Chair	Approved	EAG chair	4.11.2025
WMCA Clinical Cabinet	Approved	Clinical Cabinet	14 January 2026

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Introduction and Context

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

6.5 million people live in the West Midlands, and 600 cancer cases are diagnosed per 100,000 people every year – this is set to increase as our population ages. By 2030 there will be some 135,000 people living with and beyond cancer in the West Midlands. One of the main goals in providing high-quality cancer care is to offer personalised, tailored follow-up and support that empowers individuals to manage their own health and live well.

With the increasing incidence and improved survival from cancer the introduction of personalised stratified follow-up (PSFU), with greater emphasis on personalisation and quality of life, there is a clear benefit to the patient and an opportunity to address capacity issues within pressured pathways ensuring a positive redistribution of resources, workforce, and facilities.

These guidelines are to assist all members of the multi-disciplinary team (MDT) to understand the process and ensure optimum follow-up care is provided to the identified cohort of Haematology patients following diagnosis or completing treatment as appropriate:

1. Lymphoma
2. Chronic Lymphocytic Leukaemia (CLL)
3. Monoclonal Gammopathy of Uncertain Significance (MGUS)

PSFU should be discussed, explained, and planned at the time of diagnosis. The preparation for seamless adaptation and understanding of the transition to living with and beyond cancer should start as early as possible. Demonstrating the message that care is not just about treating the disease but looking after the individual before, during and after treatment regarding both the physical and psychological aspects as some patients will live with long term effects of their disease and/or their treatment that begin soon after treatment ends or many years later.

The clinical team and the person affected by cancer decide about the best form of follow-up through shared decision making. 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 manage.

In general

1. 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, this cohort of patients 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.

2. 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.

3. For some people with metastatic (secondary cancer) disease at presentation for 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 Stratified Follow Up

4. People living with cancer and professionals work collaboratively to form personalised care plans that enable them to live actively and well from diagnosis.
5. There is a programme of appropriate education for people living with and beyond cancer, supported by written information, signposting and access to a range of online portals for those who are IT enabled.
6. All clinical evidence-based surveillance investigations continue unchanged.
7. Robust systems are in place for surveillance, to ensure tracking and monitoring of investigation requests and results and to facilitate timely recall if necessary.
8. End of Treatment Review and End of Treatment Summary are provided to people living with and beyond cancer and their GPs to support good quality Cancer Care Reviews
9. There are fast track re-entry (Open Access) pathways that facilitate specialist clinical review if required.
10. There is a consistent implementation of self-management support interventions.

Purpose of this Guidelines

This document outlines best practice recommendations for the personalised stratified follow-up for individuals diagnosed with Haematology cancer. It encompasses both primary and secondary care settings and is specifically designed for patients who have completed treatment.

Support for patients living with a cancer diagnosis should be focused on the individual to address their specific needs and delivered at the right time, in the right way to both support and empower. There is a fundamental difference between living with a cancer diagnosis and living well.

This is a guideline for PSFU for people with a Haematological cancer diagnosis or a pre-malignant condition that would benefit from Self-Management and Remote Monitoring. This guidance is to assist all members of the multi-disciplinary team to understand the process and ensure optimum follow-up care is provided to the identified cohort of Haematology patients following diagnosis or completing treatment as appropriate. This includes-

- Gammopathy of Uncertain Significance (MGUS)
- The umbrella term 'personalised follow up care' is used in some settings which covers PSFU this may also be referred to as PIFU Patient Initiated Follow Up (PIFU) PIFU is the 'supported self-management' pathway within PSFU.

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 into 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 consequences/side effects of their disease and/or treatment that are to be expected.
- Information about signs and symptoms to look out for - red flags' that could indicate possible recurrence.
- 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.

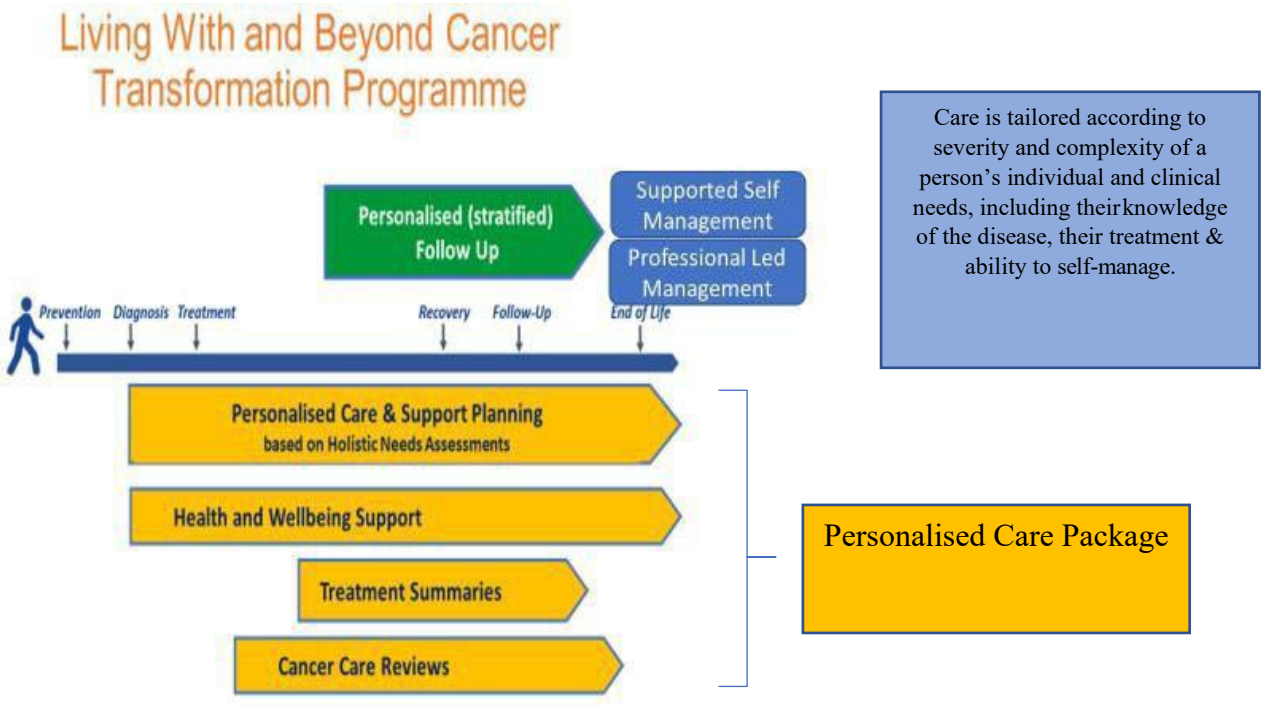
Living with and Beyond Cancer

Cancer Alliances lead transformational programmes to deliver Personalised Care and PSFU for people diagnosed with cancer to enable them to self-manage, seek help when necessary and live well with and beyond cancer. These models of follow-up have greater

emphasis on quality of life through empowerment and focus on what matters to the person rather than what is the matter with them.

- The diagram below illustrates the programme

Figure 1



It is important that all individuals are offered this personalised approach and can benefit from these changes and that variation in service provision that exists across the West Midlands is reduced to ensure equity of access to high quality, safe and sustainable cancer services.

This transformation needs to be supported by robust 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 Holistic Needs Assessment(s) (HNA) as well as personalised information and appropriate Health and Well-Being Information and Support (HWBiS) to encourage them to live actively and well following the end of their cancer treatment in addition to a Treatment Summary (TS) provided to the person and their GP at the end of active treatment and are offered Cancer Care Reviews (CCR) in primary care

- Everyone is provided with additional information and signposting to enable them to manage and live well with and beyond cancer.
- Everyone 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 Care to facilitate continuity of care in the form of the Cancer Care Review (CCR) or ongoing care and support.
- 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 coordinated supportive care with rapid re-entry (open access) to the specialist cancer team as required. (PSFU protocol development: Outline pathway see appendix 10).

Personalised Stratified Follow Up process for patients with Lymphoma

PSFU should be discussed, explained, and planned at the time of diagnosis. All newly diagnosed Lymphoma patients within the inclusion criteria for PSFU should be offered information about the PSFU options available to support them at the end of treatment. This will include information on the potential follow up pathways with the emphasis that the patients can move at any time if the patients' needs change.

Patients will receive surveillance after cancer treatment along one of two pathways:

1. Scheduled follow up appointments face to face or by phone with either their consultant or clinical nurse specialist (CNS)

2. Supported self-management pathway (SSM) via remote monitoring.

The key consideration for entry into the supported self-management follow-up pathway is the patient's ability and desire to self-manage. All patients who have completed treatment for high grade lymphoma, Classical Hodgkins lymphoma and low-grade non-Hodgkins's lymphoma should be considered for entry into supported self-management. Supported self-management should be considered first and offered to all patients that meet the inclusion criteria.

Figure 2 (United Hospital Birmingham NHS Foundation Trust (UHB PSFU protocol)

Profession led/ Scheduled follow up appointments	Patient initiated follow up/supported self-management
• Patients **will** have routine follow up surveillance with outpatient appointments that are individualised to their diagnosis/needs. • Appointment may be consultant or CNS led. • Appointments may be face-to-face or telephone. • Patients may be subsequently transferred to a self-managed pathway at any point if appropriate and mutually agreed. • Patients will have access to health and wellbeing interventions. • All patients should have an end of treatment summary. • This pathway involves the provision of supportive interventions and education to increase patient's knowledge, skills, and confidence to manage their health condition. • It is essential that patients can recognise and report signs and symptoms of potential cancer recurrence or consequences of cancer treatment and not wait for their next clinic appointment. • Patients should be supported to improve their overall health and wellbeing (e.g., managing fatigue, fear, and anxiety). • Details of who the patient will contact, if signs of recurrence or concerning symptoms arise will be provided.	• Patients will be transferred onto the supported self-management pathway. They will be transferred to the remote monitoring system. • Patients will not have routine follow up appointments. • Patients may move to professional lead follow up at any point in time if it is appropriate and mutually agreed. • Have access to health and wellbeing interventions. • All patients should have an end of treatment summary. • This pathway involves the provision of supportive interventions and education to increase patient's knowledge, skills, and confidence to manage their health condition. • It is essential that self-management interventions empower patients to recognise and report signs and symptoms of potential cancer recurrence or consequences of cancer treatment. • Patients should be supported to improve their overall health and wellbeing (e.g., managing fatigue, fear, and anxiety). • Details of who the patient will contact, if signs of recurrence or concerning symptoms arise will be provided. • Patients may be contacted to be offered access to relevant clinical trials or new treatments.

Personalised Stratified Follow Up process for patients with Lymphoma

Figure 3 (United Hospital Birmingham NHS Foundation Trust (UHB PSFU)

Type of lymphoma	PSFU/ Supported self-management	Professional lead follow-up
High Grade Lymphoma - Diffuse large B-Cell Lymphoma & - Burkitts Lymphoma - Primary mediastinal B cell lymphoma	In Complete Metabolic Remission (CMR) by PET or Complete Remission (CR) by CT post R-chemo. Continue face to face follow up as per local policy for at least 12 months post treatment. Option to move to PSFU in 12 months if remains in a remission. **Discharge** 2 years post treatment	For those who do not meet criteria for Supported Self-Management, Including: - Not in remission - Evidence of relapses - Clinical Trials patients - Patients choose to stay on profession lead follow up. - Patients unable to safely self-manage - Patients with complex co-morbidities
Classical Hodgkins Lymphoma - post first line chemotherapy who are In CMR on end of treatment PET scan.	Patients in a CMR at the end of treatment PET scan and who remain in complete remission following 12 months of routine follow up (usually three-monthly appointments) can consider moving to PIFU. Discharge from 2 years post treatment.	For those who do not meet criteria for Supported Self-Management, Including: - Not in remission - Evidence of relapses - Clinical Trials patients - Patient chooses to stay on profession led follow-up. - Patients unable to safety Self-manage. - Patients with complex co-morbidities
Nodular Lymphocyte predominant Hodgkins Lymphoma in CMR following completion of treatment and have been in remission for at least **2**	Patients who remain in CMR for at least 2 years post completion of chemotherapy can be considered for patient initiated follow up/ PSFU.	For those who do not meet criteria for Supported Self-Management, Including: - Not in remission - Evidence of relapse - Clinical Trials patients

years from end of treatment.	<u>Not for discharge from PSFU</u>	- Patient chooses to stay on profession led follow up - Patients unable to safely self-manage. - Patients with complex co-morbidities
<u>Follicular Lymphoma –</u> Patients in remission for a minimum of 2 years from end of treatment OR on watch and wait for a minimum of 2 years. Low risk patients as agreed with named consultant	Patients in remission for a minimum of 2 years from end of treatment OR on watch and wait for a minimum of 2 years or more o can be considered for patient initiated follow up/ PSFU. <u>Not for discharge from PSFU</u>	For those who do not meet criteria for Supported Self-Management, including: - Not in remission - Evidence of relapse - Clinical Trials patients - Patient chooses to stay on profession led follow-up. - Patients unable to safely self-manage - Patients with complex co-morbidities
<u>Marginal Zone Lymphoma</u> – Patients in remission for a minimum of 2 years from end of treatment OR on watch and wait for a minimum of 2 years. Low risk patients as agreed with named consultant	Patients in remission for a minimum of 2 years from end of treatment OR on watch and wait for a minimum of 2 years or more can be considered for patient initiated follow up/ PSFU. <u>Not for discharge from PSFU</u>	For those who do not meet criteria for Supported Self-Management, including: - Not in remission - Evidence of relapse - Clinical Trials patients - Patient chooses to stay on profession led follow up - Patients unable to safely self-manage - Patients with complex co-morbidities

Exclusion Criteria

- Patients who are unable to self-manage. This may be due to physical, cognitive, communication or emotional reasons. This will be a joint decision between the patient and health care professional.
- Patients who are not in complete metabolic remission determined by the MDT at the end of treatment.
- Patients on clinical trials. For patients participating in clinical trials, follow-up will be determined by the clinical trial protocols. Patients taking part in trials will still access and benefit from the end of treatment clinical review and Health and Wellbeing information and support.
- Patients with complex co-morbidities may require closer monitoring.
- There is mutual agreement between patients and clinicians not to enter the self-managed follow-up pathway.
- Patients deemed inappropriate by the MDT because of oncological concerns or non-engagement.

- It is recommended that the decision for entry into supported self-management should be confirmed and agreed by the patients named Haematology consultant or Clinical Nurse Specialist.

Note - 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 the Professional Led Follow-Up Pathway. A copy will be placed in the individuals notes as appropriate.

Resources needed for Personalised Stratified Follow Up PSFU

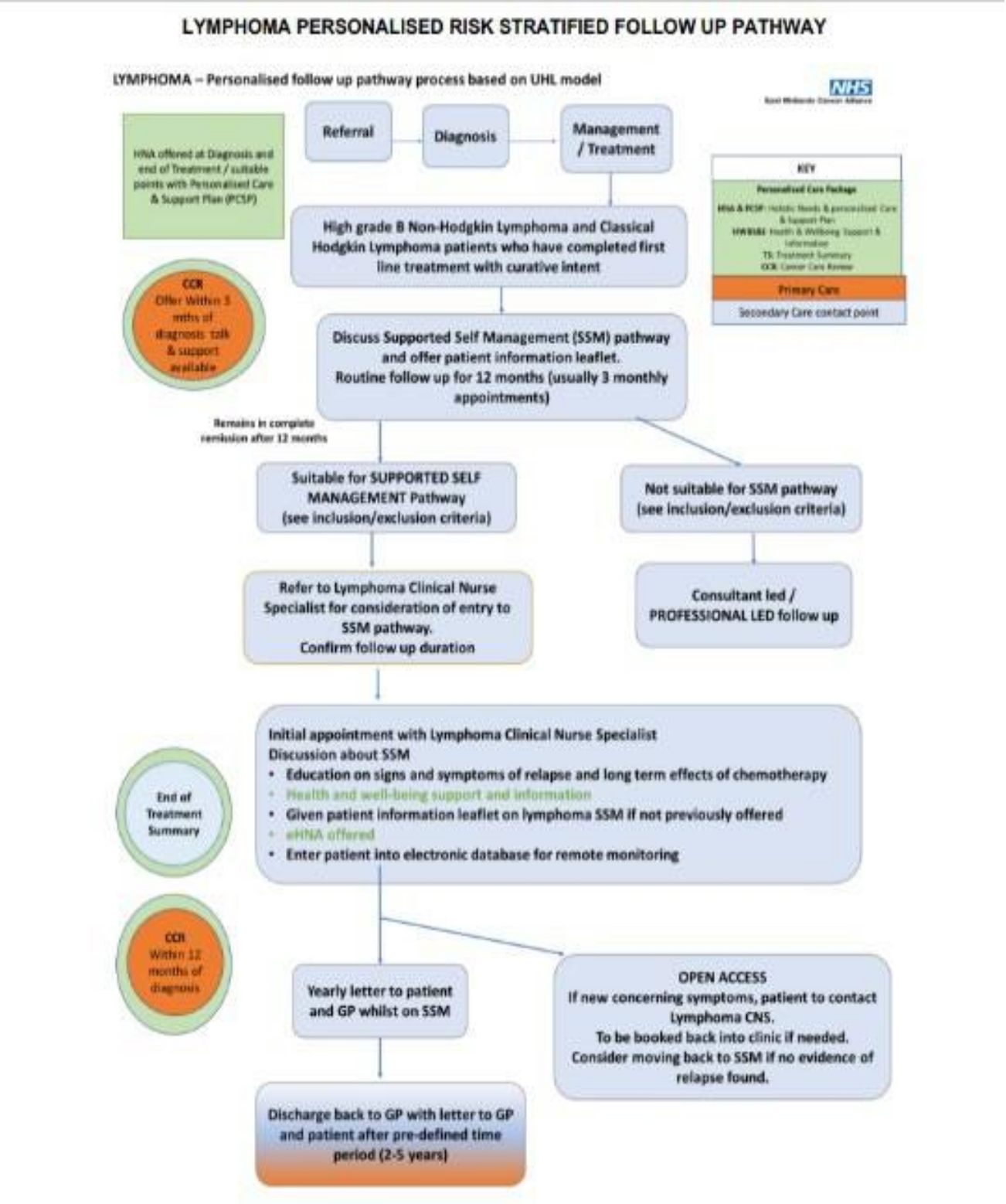
To ensure effective personalised follow up systems are in place each NHS Trust will have **Remote monitoring systems** to enable the following to happen.

There should be a designated member of the specialist cancer team such as a Cancer Navigator/Support Worker or Clinical Nurse Specialist who may guide/triage callers 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.'

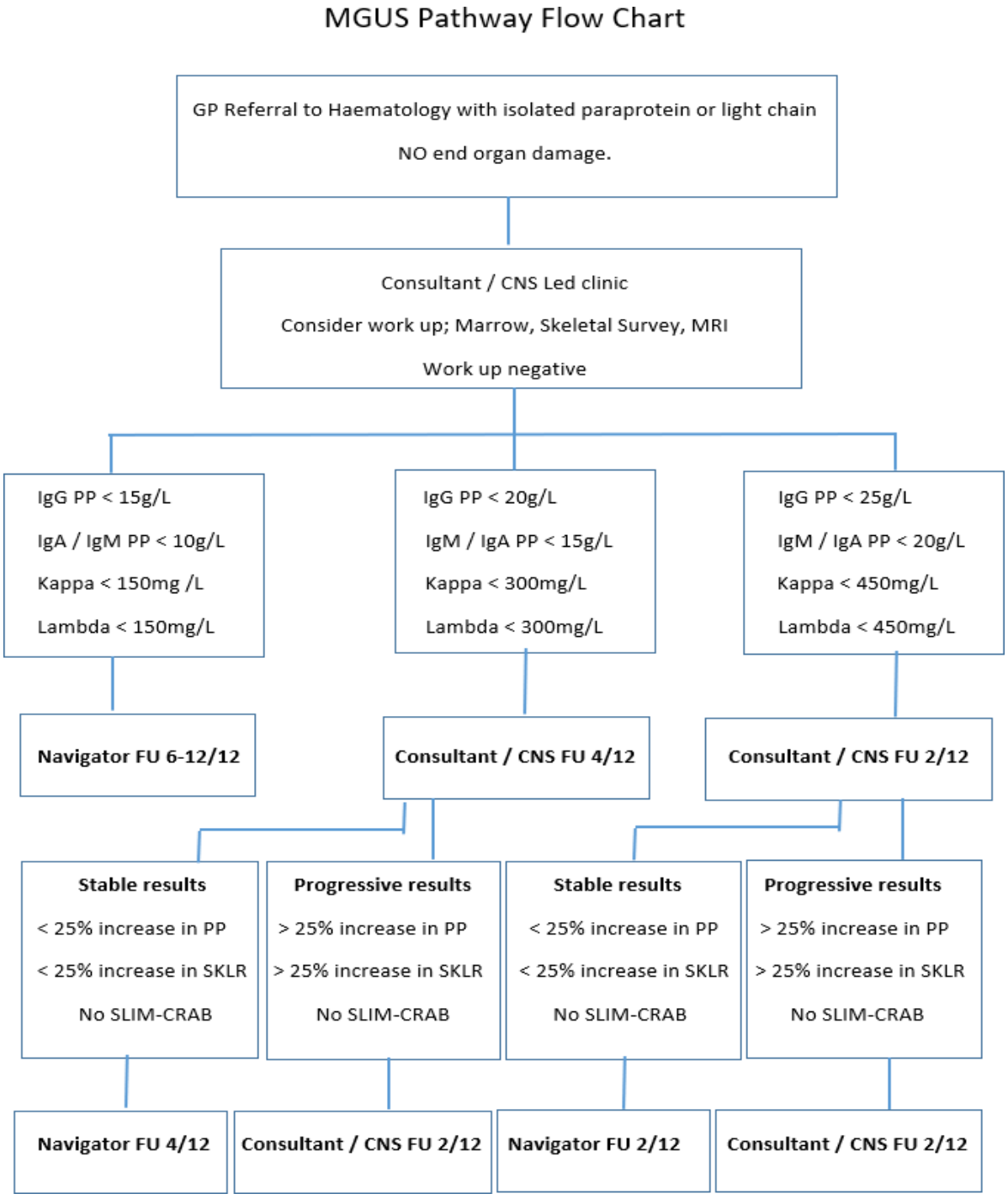
Flowchart of Lymphoma Pathway

Figure 4 (University Hospitals of Leicester NHS Trust Example)



MGUS Pathway

Figure 5 (Shrewsbury and Telford Hospital NHS Trust Royal Shrewsbury Hospital example)



MGUS - WMCA Defined Clinical Risk Stratification Decision for Follow Up

Figure 6

Stratification	**Supported Self-Management** (No routine follow-up + Remote Monitoring testing)	**Professional Led Management** (Routine follow up + Remote Monitoring testing)
All Patients following a diagnosis of MGUS	Annual Full Blood Count, Paraprotein Level, Serum Free Light Chains (SFLC), Calcium, Renal function, NT-Pro-BNP Urine for Albumin-Creatinine Ratio (ACR) Refer via Open Access if evidence of: • Unexplained anaemia (drop in Hb of 20g/L from baseline or to <100g/L) • Unexplained thrombocytopenia (drop in platelets to <100) • Unexplained low neutrophil count (<1.5) • Rapid rise in paraprotein level or serum free light chains (if 2 consecutive readings show >50% rise in paraprotein readings or SFLC (absolute rise should be >5g/lt for paraprotein or >100 for SLFC) • Unexplained localised pain in the back, ribs or long bones • Unexplained deterioration in renal parameters (significant rise in creatinine from patients baseline or if creatinine >115 when previously normal without other obvious cause) • Unexplained elevated calcium • If lambda light chain MGUS Unexplained rise in NT-Pro-BNP >400 ng/lt • If lambda light chain MGUS Unexplained rise in ACR >70 mg/mmol	N/A

CLL - WMCA Defined Clinical Risk Stratification Decision for Follow Up

Figure 7

Stratification	**Supported Self-Management** (No routine follow-up + Remote Monitoring testing)	**Professional Led Management** (Routine follow up + Remote Monitoring testing)
Stage A CLL	Annual Full Blood Count Refer via Open Access if: • Anaemia • Thrombocytopenia • Troublesome lymphadenopathy or splenomegaly • There is a rapid doubling of the white count (within 6 months) • If develops night sweats or weight loss (B symptoms)	N/A

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.

Clinical Trials

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

Some individuals may decline treatment, or their clinical condition such as complex symptomatic advanced disease or frailty, these patients should remain on clinician led follow up and be discharged when clinically appropriate.

Personalised Care and Holistic Needs Assessment

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 Information and Support (HWBiS)
- Treatment Summary (TS)
- Cancer Care Review (CCR)

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.

See Appendix 9 for more details.

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:

Common HNA Concerns
Figure 8

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	

Health and Wellbeing Information and Support (HWBiS)

All individuals will have access to health and wellbeing information and support at suitable points in the pathway. This support may be in the form of an event, face to face or online, 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.

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 ongoing health and wellbeing. The TS is important to help inform and facilitate 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:

1. Their cancer diagnosis
2. An end of treatment review is when the final TS is drawn up by secondary care.
3. There should be enough detail in the treatment summary to enable GP practices to add codes/information, so they can set alerts on their systems if/when follow up surveillance tests are required. If
4. There is a change in responsibility for ordering and reviewing the results of investigations, local guidelines may need to be drawn up. This will need further discussion at ICB/PCN level.
5. 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 (e.g.: Surgery, radiotherapy):

Treatment Summary coding
Figure 9

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

Cancer Care Review (CCR)

CCR is a holistic conversation between the person and their healthcare professional in their GP practice. It is enabled by the HNAs, PCPS and TS. It allows an opportunity for

- A discussion to inform patients of the support available from primary care and other health professionals.
- The individual to raise any concerns that may be affecting their quality of life,
- Consider their existing conditions, medication and importantly discuss their cancer experience,
- Helping them to manage their overall health and wellbeing.
- The health care practitioner to support individuals expressing concerns during their review and signpost them to others within the practice such as social prescribers or beyond into the third sector.

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.

All patients will be offered open access to the service for the designated period post treatment which will be specified for individuals by the specialist team. After Open Access finishes, people will be discharged to primary care for ongoing support and would be referred 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 advised to see their GP. 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 one working day however this may be within two working days. Experience has shown that most queries can be resolved over the telephone. If someone needs to be seen (face to face or virtually) and is clinically urgent, they should be seen within 2 weeks of contacting the Open Access service.

It is recommended that:

1. Trusts identify a triage clinic for these individuals to ensure rapid access when required.
2. An alternative code is used for Open Access Follow Up (OAFU) appointments to enable differential data collection for these groups of patients unless alternative methods already capture this data.

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. 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 those who are newly diagnosed and/or have secondary cancer 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 online 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 of receiving appointments for these and the results.
- **Possible treatment toxicities/consequences** of disease and/or treatment.

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:

1. Lymphoedema.
2. Infectious complications, if Splenectomy has taken place, or following Radiotherapy.
3. Specific effects on the heart, lungs, bones, bowel, bladder.
4. Nerve damage and neuropathy.
5. Psychological and emotional changes, including anxiety and/or depression.
6. Changes to self-perception.
7. Sex and fertility.
8. Second Cancers.

Advice on the following is also recommended:

9. adapting physical activity to maintain their quality of life.
10. Diet.
11. Weight management, physical activity, and healthy lifestyle choices (for example stopping smoking and reducing alcohol use).
12. How long their recovery might take.
13. 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 team. 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 and beyond 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.

Lymphoma

1. B-symptoms (fevers/drenching night sweats and/or unexplained weight loss)
2. New unexplained widespread itch
3. New lymph gland swelling
4. Falling blood counts
5. Rising LDH

MGUS

1. Unexplained anaemia (drop in Hb of 20g/L from baseline or to <100g/L)
2. Unexplained thrombocytopenia (drop in platelets to <100)
3. Unexplained low neutrophil count (<1.5)
4. Rapid rise in paraprotein level or serum free light chains (if 2 consecutive readings show >50% rise in paraprotein readings or SFLC (absolute rise should be >5g/lt for paraprotein or >100 for SLFC)
5. Unexplained localised pain in the back, ribs or long bones
6. Unexplained deterioration in renal parameters (significant rise in creatinine from patients' baseline or if creatinine >115 when previously normal without other obvious cause)
7. Unexplained elevated calcium
8. If lambda light chain MGUS Unexplained rise in NT-Pro-BNP >400 ng/lt
9. If lambda light chain MGUS Unexplained rise in ACR >70 mg/mmol

CLL

10. Anaemia
11. Thrombocytopenia
12. Troublesome lymphadenopathy or splenomegaly
13. There is a rapid doubling of the white count (within 6 months)
14. If develops night sweats or weight loss (B symptoms)

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 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.

Discharge from Personalised stratified follow up Pathways to Primary Care

After the designated follow up period 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 agrees to continue surveillance tests for clinical reasons. This should be documented and communicated with both the individual and their GP.

After the designated period of times 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 beyond discharge if the individual develops any **new** cancer disease and/or treatment related problem, including late effects so the individual is clear to first see their GP who can refer them back to the relevant hospital service.

Following completion of treatment for a Haematological cancer and completion of the Personalised Stratified Follow-Up (PSFU) pathway the patient is discharged back to Primary Care. If there are any clinical concerns suggestive of disease recurrence this should trigger an immediate referral back to the Haematology Cancer Team. This referral must be made via the urgent suspected cancer referral route.

Discharge from Professional Led Follow Up Pathway to Primary Care

Individuals within the Professional Led Follow Up 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, their GP, will be informed by letter of the outcome and recommendations for their long-term plan.

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.

The letter will include advice on what to do beyond 5 years if the individual develops any **new** cancer disease and/or treatment-related problem, including late effects so the individual is clear to first see their GP who can refer them back to the relevant hospital service.

Following completion of treatment for a Haematological cancer and completion of the Personalised Stratified Follow-Up (PSFU) pathway the patient is discharged back to Primary Care. If there are any clinical concerns suggestive of disease recurrence this should trigger an immediate referral back to the Haematology Cancer Team. This referral must be made via the urgent suspected cancer referral route.

Equity and Health Inequalities Impact Assessment

The purpose of an EIA 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.

There is an impact assessment within the general PSFU guidelines. People who are non-English speakers are at particular risk of being marginalised 17 (Kumarakulasingham et al 2019), Kumarakulasingham goes on to indicate this can be reduced through:

1. Education sessions with their family/carers and
2. Availability of interpreting services can enable people to participate in PSFU.
3. Knowledge of the local community and its demographics can be helpful in planning services. Each Trust should have available language support in place.

Surveillance Pathway

More specific CLL MGUS

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, reviewing, 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 and subsequent results and no patient is lost to follow up.

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.

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

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 HNAs offered and undertaken at the time of the tests may indicate further key workers (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:

4. Surveillance tests should be delivered irrespective of whether the person with cancer has a scheduled follow-up.
5. Where appropriate to the cancer pathway, people of screening age should be encouraged to participate in the relevant national screening programmes in addition to these surveillance tests.
6. Follow-up should stop when MDT agrees the risks of more tests outweigh the potential benefits and best supportive care offered.
7. If recurrent or metastatic disease is found at any time along the pathway the person's results will be discussed with the consultant, referred to the MDT meeting and referred as appropriate and best supportive care offered.
8. In general, after 5 years of surveillance tests (or as specified for the pathway) and there is no cause for concern, people Living with and Beyond Cancer can be discharged to primary care with advice on how to access services for red flag symptoms and late effects as appropriate
9. However, in some cases the specialist team may require further surveillance tests.

It is recommended that the Trust Remote Monitoring System (RMS)has a clear standard operating procedure:
(See appendix 1 for more information regarding RMS).

References cross ref this to ensure that it aligns.

1. Macmillan (Nov 2012) People living with cancer (general survivorship)
2. Macmillan: The burden of cancer and other Long-Term Health Conditions (April 2015) https://www.macmillan.org.uk/documents/press/cancerandotherlong-termconditions.pdf
3. NHS (2019) The NHS Long Term Plan. NHS, https://www.longtermplan.nhs.uk/online-version/
4. NHS England (2019) Comprehensive Personalised Care Model
5. Macmillan (2019) How to Overcome Problems Effectively. https://learnzone.org.uk/courses/course.php?id=111
6. Figure 2 United Hospital Birmingham NHS Foundation Trust (UHB PSFU Protocol)
7. Figure 3 United Hospital Birmingham NHS Foundation Trust (UHB process for patients with Lymphoma)
8. (University Hospitals of Leicester NHS Trust (example flowchart of Lymphoma pathway)
9. Figure 5 Shrewsbury and Telford Hospital NHS Trust Royal Shrewsbury Hospital (Example MGUS Pathway flowchart)

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National Cancer Survivorship Initiative (2011) *Evaluation of adult cancer aftercare services.*
Ipsos MORI.

NHS England (2016) *Implementing the cancer taskforce recommendations: commissioning person centred care for people affected by cancer*. NHS.

NHS Improvement Cancer (2012) Innovation to implementation: Stratified pathways of care for people living with or beyond cancer. A 'how to guide.' NHS.

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.

Definitions

Cancer IT System: The local cancer database (Somerset, Infoflex or Dendrite).

Cancer Care Review (CCR): A CCR is a conversation that is carried within Primary Care with the cancer patient.

Co design: Collaborative method of design engaging with all key stakeholders involved in service provision and those using the service.

Eligibility Criteria: An agreed description of the safety and appropriateness of entry onto the supported self-management pathway for individuals with a haematology cancer.

End of Treatment: The end of treatment is defined as the conclusion of all active treatment required by an individual following a diagnosis of cancer, this may be after surgery alone or following a combination of therapies (excluding adjuvant endocrine therapy) but precedes the period known as 'follow-up'.

The patient will be presented with a Treatment Summary – see definition below.

Health & Wellbeing Information and Support (HWBiS): Health and Wellbeing Information and Support offers enable the transition from diagnosis to treatment for cancer to supported self-management. They can range from one-to-one information sessions to group sessions, educational events or programmes on a variety of topics designed to help with the emotional and practical aspects of life with and beyond cancer.

Holistic Needs Assessment (HNA): A Holistic Needs Assessment is a checklist of concerns that cover physical, emotional, practical, spiritual and financial issues ensuring each area is addressed and a care plan created for those identified as needing specific support. The care plan offers suggestions to manage the concerns including signposting to other services or information services that can help.
An HNA can be offered at key points during the pathway to meet the needs of the individual.

Personalised Follow Up: A model of follow-up in which the clinical team and the person living with cancer make a shared decision about the best form of aftercare based on the individual's clinical and personalised needs. Individuals enter either a professional led or self-managed follow up pathway. The Personalised Follow Up pathway extends 5 years from the point of diagnosis.

Personalised Approach: A personalised approach means that any person that receives care or support will have choice and control in determining the shape of that support based on what is important to and for them.

Professional Led Follow Up Pathway: The follow-up pathway in which individuals with cancer continue to have face to face, phone, or email contact with the specialist team as part of continuing follow up.

Self-managed Follow Up Pathway: The follow-up pathway in which patients are empowered with the knowledge and skills to self-manage their condition. They are given information about the symptoms to look out for and who to contact if they notice any of 'red flag' symptoms, future scheduled tests, and how to contact the specialist team if they have any concerns. They do not receive any further OPA unless further investigations or support is required.

Shared Decision Making: Shared decision making is a collaborative process that allows the

individual and the responsible health care professional to make health care decisions together in the person's best interest, based on evidence-based practice – considering the person's values and preferences.

Stratified Follow Up: A model for managing how an individual is followed up after completion of treatment; depending on their risk of disease recurrence.

Treatment Summary (TS): A Treatment Summary is a document produced by the Clinician or Specialist Nurse at the end of active treatment for cancer. The TS details the diagnosis, stage and any relevant pathology information. It also includes any surgery, chemotherapy, radiotherapy or any other therapies that the person may have received during the treatment phase. It is followed by specific information on signs and symptoms of recurrence as well as significant consequences of disease and/or treatment. This is important as this information may be needed at a later date by those who may develop issues. A TS and a HNA enable the Cancer Care Review.

The document is shared with the Patient and the Primary Care team to facilitate ongoing supported self-management.

Appendices

Appendix 1 RMS

It is recommended that the Trust RMS has clear standard operating procedures outlining:
The minimizing of risk to losing individuals
The resolution of issues regarding missed surveillance test
That safety netting is in place to ensure contact is not made with individuals who have died or moved out of area.

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- stratified-pathways-cancer

10. System implementation should comply with the NHS Digital clinical risk management requirements for health IT systems shown below:
    11. Compliance with standards DCB0129 and DCB0160 is mandatory under the Health and Social Care Act 2012
    12. DCB0129: Clinical Risk Management: its Application in the Manufacture of Health IT Systems - more information here
    13. DCB0160: Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems - more information here

Appendix 2 National Health & Wellbeing Being Checklist

(Insert Embedded Doc)

Appendix 3: Equality & Health Equity Impact Assessment

(Insert Embedded Doc)

Appendix 4: Example Content for Trust PSFU Patient Information

14. System implementation should comply with the NHS Digital clinical risk management requirements for health IT systems shown below:
15. Compliance with standards DCB0129 and DCB0160 is mandatory under the Health and Social Care Act 2012
16. DCB0129: Clinical Risk Management: its Application in the Manufacture of Health IT Systems - more information here
17. DCB0160: Clinical Risk Management: its Application in the Deployment and Use of Health IT Systems - more information here

Appendix 5
Workforce Planning

1. The standards relate to clinical risk management and comprise:
2. 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
3. Implementation guidance, which provides an interpretation of the requirements and, where appropriate, defines possible approaches to achieving them. 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.
4. “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.”
5. 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.
6. Staff should have IT and remote monitoring system knowledge, so they can be confident in using and navigating systems and processes accurately and effectively.
7. Cancer Navigator/ Cancer Support Worker/ Cancer coordinator role:
8. The safety and quality of the service is dependent on a dedicated coordinator function to organise and manage aspects of the pathway, to facilitate the release and appropriate realignment of CNS clinical time in secondary care and ensure safe support to people from diagnosis.
9. This role 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.
10. Examples of clinical knowledge could include NVQ Level 3 / 4 in health-related subject / equivalent knowledge and experience.
11. 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.
12. 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.

13. 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.
14. This also applies to other Health Care Professionals involved in Personalised Care Planning at various points on the pathway.
15. 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.
16. Resources needed for Personalised Stratified Follow Up PSFU.
17. To ensure effective personalised follow up systems are in place each NHS Trust will have Remote monitoring systems to enable the following to happen:
18. There should be a designated member of the specialist cancer team such as a Cancer Navigator/Support Worker or Clinical Nurse Specialist who may guide/triage callers who is responsible for ensuring the following takes place:
19. The scheduling, monitoring and communication of surveillance tests and subsequent results
20. Scheduling systems to ensure appropriate individuals are contacted with the test results and no individual is 'lost to follow up'

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.

Appendix 6
List of available resources

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

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

Gateway C	https://www.gatewayc.org.uk/gwc-cancer-map/
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 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
Lymphoma Action	https://lymphoma-action.org.uk/

Figure 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.

Figure 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.
NHSE PSFU handbook 2020	NHS England » Implementing personalised stratified follow-up pathways

Appendix 7:
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.

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

Appendix 8
Health and Wellbeing Information and Support (HWBiS)

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 Living with and Beyond Cancer programmes in the Trust
Able to support a patient portal going forward

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 Programme6 https://www.macmillan.org.uk/healthcare-professionals/for-your-patients/hope-programme

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:

1. Information about local groups
2. Emotional support Finances
3. Healthy eating
4. Exercise
5. Signposting and access to local services for cancer as a long-term condition health and wellbeing management.
6. Online support groups
7. Online tools and support– examples include: https://www.cancercaremap.org/ https://www.macmillan.org.uk/Cancer Research UK

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

Appendix 9
Personalised Care

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 key points in the pathway including 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 HNAs are offered and completed in the person's pathway E.g.: 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.

HNAs 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. HNAs 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 (CNS), Navigator/Cancer Support Worker, Radiographer or Allied Healthcare Professional (AHP). 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.

<u>Information leaflet</u>

1. Each Leaflet will include WMCA & Trust Logo

Why have you given me this leaflet?

You have been given this leaflet to explain Personalised Follow-Up which **Trust Name** has put in place for patients who have been treated for xxx cancer.

What is Personalised Follow-Up?

Personalised Follow-Up is a type of follow-up that is being introduced at all hospitals. It is where routine, clinical examination appointments are replaced by a system

where patients can call us when they have a problem so that they don't have to come to hospital at times when they are feeling well and symptom-free.

Why has Personalised Follow-Up been introduced?

We have already introduced Personalised Follow-Up as it has been shown to be better for patients in lots of ways.
It means that you don't have to make unnecessary trips to the hospital at times when you are feeling perfectly well and just want to concentrate on living your life.
Patients often find traditional clinical appointments can lead to anxiety and delay reporting worrying signs and symptoms if a routine clinical appointment is 'not too far away.'
Also, it's been proven that new problems are unlikely to happen in line with your appointment time and are identified by patients themselves, in between routine appointments.
It will also mean that you can access support and advice quickly from the right people when you need it, allowing you peace of mind.
You will also get back into the system quickly should this be necessary.
Communication between all of the people involved in your care will be better, those in the hospital and outside, such as your GP. This will mean everyone can support you or signpost you on to others who can support you at the right time for you.

What information will I be given?

In addition to this leaflet, you will have an End of Treatment Review with a member of your specialist team and will discuss key information, including specific symptoms you should report without delay to your team.
You will also be given written information in a Treatment Summary on:

1. Your diagnosis and medication.
2. The treatment you have had and the possible side effects;
3. Signs and symptoms to report;
4. Being body aware;
5. Arrangements for any tests that you may need to have to help monitor you;
6. How to use the Helpline which gives you fast access to your specialist team if you need it
7. Advice on Exercise and Nutrition
8. Health and Wellbeing Information and Support
9. Any local support groups and useful contact numbers

Will I still be able to access the xxx service if I have concerns?

Yes. You can call the Team on the dedicated **Helpline telephone number (xxxx)** if you have any queries or problems, and you will be encouraged to do so. The helpline is monitored between **0900 and 1700 Monday to Friday** and if you leave a message, with your name, hospital number and telephone number, in the evening or over the weekend you will be called back by the team on the next working day. If they feel that it would be appropriate for you to come back to clinic to be seen, you will be offered a clinic appointment, or if necessary, an appropriate diagnostic test within 14 days of your telephone call.

Will I continue to have routine (Insert specific test)?

Yes. Unless it has been otherwise specified at the end of your treatment, you

will continue to be called for (State frequency and test) for at least five years after your treatment, or until…… If, as a result of your specific treatment, you do not need to have (State specific test), you and your GP will be informed about this.

Are there any other regular tests that I may need to have?

Following your treatment you and your GP will be told if you need any additional regular checks, such as (Give specific examples and reasons why) If you are invited to join the any of the national NHS Cancer Screening Programmes, you should participate when invited to do so.

Appendix 10

PSFU Protocol development outline pathway

NHS England and Improvement Implementing Personalised Stratified Follow Up Pathway A hand book for local Health Care Systems March 2020 (https://www.england.nhs.uk/wp-content/uploads/2020/04/cancer-stratified-follow-up-handbook-v1-march-2020.pdf)

Figure 12

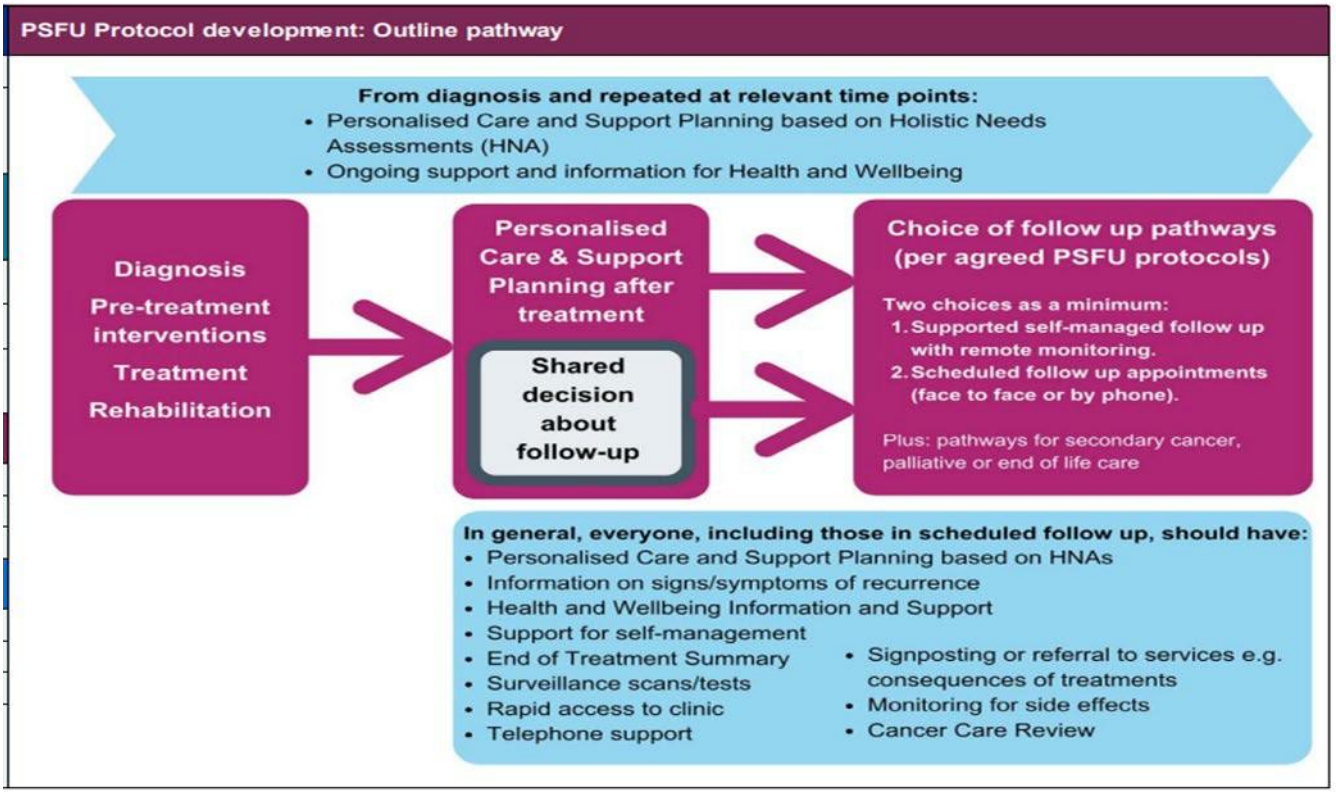

Figure 13: Types of Personalised Follow-Up Pathways – Method of delivery

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/Primary treatment. 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	
To optimise outcomes both to patients and the healthcare system, GP practices should consider the wider benefits of offering Cancer Care Reviews (CCRs) as best practice. WMCA recommend that Practices continue to provide patients with the opportunity to have a conversation within 12 months of a cancer diagnosis, with the aim to increase their awareness of the support available to them at the practice, as well as signposting/referring them to additional support within the wider local community.	
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 (E.g.: 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.	

Appendix 11
For Information to Primary Care

Stage A CLL patients
If the patient presents to Primary Care and the GP requests investigative bloods for a presenting condition these are the indicators below that would trigger further investigation.

GPs should receive information that should include information below and ask to refer back if any of the symptoms below / blood counts.

- Progressive fall in patients' blood counts (without other cause): Hb < 100 g/L or Platelets < 100 x 10^9/L.
- A lymphocyte counts of >100 x109/L
- A lymphocyte count those double over a 6-month period if the preceding lymphocytes are >30 x109/L
- New lymphadenopathy in > 3 regions
- Rapidly enlarging lymph nodes
- Persistent symptoms of fatigue/anorexia/unintentional weight loss (>10% in 6 months)
- Drenching night sweats (changing linen > 2 times a week for >2 weeks)
- Recurrent or severe infections

This is also a useful leaflet we send to GPs for extra advice. https://cllsupport.org.uk/wp-content/uploads/2024/01/GP-GUIDE-FINAL-AMEND-1.pdf