Standard Operational Policy

Personalised Supported Self-Management Follow Up (PSSMFU) Patients with Cancer/Pre-Cancerous Conditions managed via the online portal

Version No: 3

Document Summary:

This SOP describes the Trust approach to the delivery of Personalised Supported Self-Management follow up (PSSMFU) for cancer/pre -cancerous conditions at St Helens and Knowsley NHS Trust (STHK)

Document status	Approved	
Document type	Standard Operating Procedure (SOP)Standard Operating Procedure (SOP)	**Trust wideTrust wide**
Document number	STHK0997	
Approving body	Clinical Effectiveness Council	
Date approved	07/02/2022	
Date implemented	21/02/2022	
Review date	***3 years from approval date 28/02/2025**	
Accountable Director	Director of Nursing, Midwifery & GovernanceDirector of Nursing, Midwifery & Governance	
Policy Author	Macmillan Lead Cancer Nurse	
Target audience	Specific staff group	

The intranet version of this document is the only version that is maintained. Any printed copies should therefore be viewed as "uncontrolled", as they may not contain the latest updates and amendments.

Document Control

[Author to complete all sections apart from Section 4 & 5]

Section 1 – Document Information	
Title	Standard Operational Policy Personalised Supported Self-management follow up (PSSMFU) for patients with Cancer / pre-cancerous conditions
Directorate	Cancer ServicesCancer Services
Brief Description of amendments	
addition of manual reporting being entered electronically onto Careflow ***Please state if a document has been superseded.***	
Does the document follow the Trust agreed format?	YesYes
Are all mandatory headings complete?	YesYes
Does the document outline clearly the monitoring compliance and performance management?	YesYes
Equality Analysis completed?	YesYes

Section 2 – Consultation Information*

*Please remember to consult with all services provided by the Trust, including Community & Primary Care where applicable

Consultation Completed	☐ Trust wide ☐ Local ☑ Specific staff group		
Consultation start date	21/10/2021	**Consultation end date**	04/11/2021

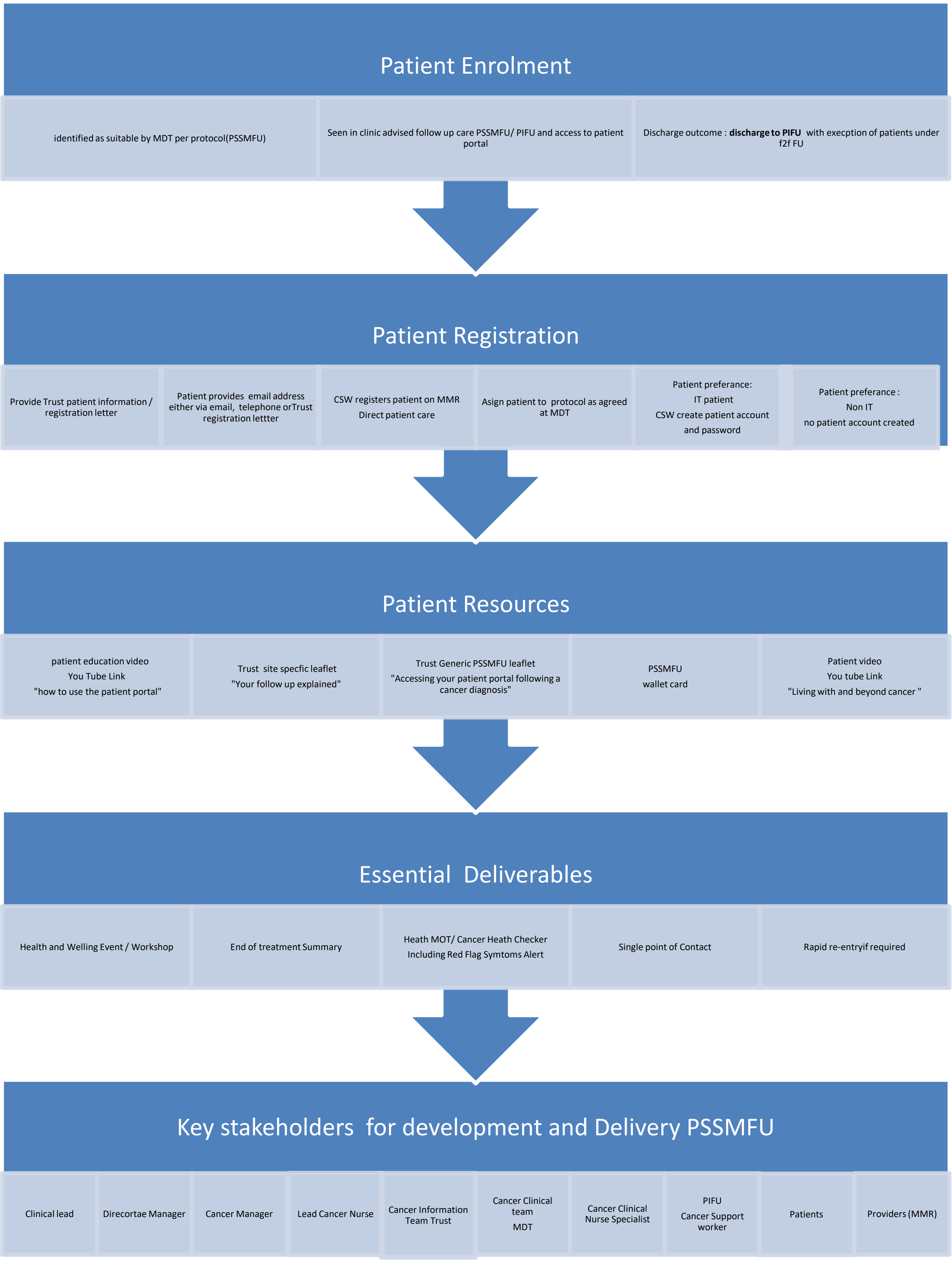
Section 3 – Version Control

Version	**Date Approved**	**Brief Summary of Changes**
3	07/02/2022	Addition of manual reporting being entered electronically onto Careflow
	Click here to enter a date.	
	Click here to enter a date.	
	Click here to enter a date.	
	Click here to enter a date.	

Section 4 – Approval – *To be completed by Document Control*			
Document Approved	☐ Approved ☑ Approved with minor amendments		
Assurance provided by Author & Chair	☑ Minutes of Meeting ☐ Email with Chairs approval		
Date approved	08/02/2022	**Review date**	07/02/2025

Section 5 – Withdrawal – *To be completed by Document Control*	
Reason for withdrawal	☐ No longer required ☐ Superseded
Assurance provided by Author & Chair	☐ Minutes of Meeting ☐ Email with Chairs approval
Date Withdrawn:	Click here to enter a date.

Quick Reference Guide**



Patient Enrolment

- identified as suitable by MDT per protocol(PSSMFU)
- Seen in clinic advised follow up care PSSMFU/ PIFU and access to patient portal
- Discharge outcome : **discharge to PIFU** with execption of patients under f2f FU

Patient Registration

- Provide Trust patient information / registration letter
- Patient provides email address either via email, telephone orTrust registration lettter
- CSW registers patient on MMR Direct patient care
- Asign patient to protocol as agreed at MDT
- Patient preferance:
  IT patient
  CSW create patient account and password
- Patient preferance :
  Non IT
  no patient account created

Patient Resources

- patient education video
  You Tube Link
  "how to use the patient portal"
- Trust site specfic leaflet
  "Your follow up explained"
- Trust Generic PSSMFU leaflet
  "Accessing your patient portal following a cancer diagnosis"
- PSSMFU
  wallet card
- Patient video
  You tube Link
  "Living with and beyond cancer "

Essential Deliverables

- Health and Welling Event / Workshop
- End of treatment Summary
- Heath MOT/ Cancer Heath Checker
  Including Red Flag Symtoms Alert
- Single point of Contact
- Rapid re-entryif required

Key stakeholders for development and Delivery PSSMFU

- Clinical lead
- Direcortae Manager
- Cancer Manager
- Lead Cancer Nurse
- Cancer Information Team Trust
- Cancer Clinical team
  MDT
- Cancer Clinical Nurse Specialist
- PIFU
  Cancer Support worker
- Patients
- Providers (MMR)

Contents

1. Scope

This Standard Operational Policy (SOP) is to be used by Cancer Services, Cancer MDT's, Clinical Leads, Cancer Clinical Nurse Specialists and Directorate Managers who lead on the delivery of care for Patients Living with and Beyond cancer (PLWBC) across STHK.

The SOP provides a Trust wide approach to the delivery of Personalised Supported Self- Management Follow up (PSSMFU): Cancer Patient Initiated Follow up (PIFU), for cancer patients within STHK across all cancer sites for patients aged over 18.

PSSMFU is the model of care which enhances and supports the delivery of Patient Initiated Follow up (PIFU) within cancer, for purpose of policy PIFU will be referred to within the context of PSSMFU.

Patient cohorts identified as suitable for PSSMFU by the MDT must all be recorded and managed through the online portal. PSSMFU is not an opt out model of follow up care and is classified as direct patient care.

Patient's care is managed by the clinical team through an on-line patient portal. Patients on PSSMFU have the choice to access the cancer specific online patient portal (IT-user) or be non-IT.

IT access enables patients to view their plan of treatment and follow up, specific test results per protocol, outcome letters, education material including leaflets and videos, health checks and to contact their clinical team via email. Patients who opt not to use the patient portal (non-IT) will still have their care managed through the portal, resources will be sent in paper format so that they are not disadvantaged.

Within the Trust the current portal is My Medical Records (MMR) provided by Southampton University. The SOP should be read in conjunction with the Trusts Policy for Patient Initiated Follow up (PIFU). Details of the business continuity for MMR are extracted from the SLA and outlined in Appendix four

The SOP does not include the protocols for each cancer teams clinical follow up, these are owned by the MDT.

2. Introduction

The NHS Long Term Plan for Cancer states that by 2021:

'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 when they are worried that their cancer may have recurred.'

Delivering personalised supported self-management pathways means that when a person completes their primary treatment, they will be offered:

- Information about signs and symptoms to look out for, which could suggest their cancer has recurred
- 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
- Personalised care and support planning, education, and support to help them to self-manage their condition and improve their health and wellbeing in the long-term.

The elements of personalised care include:

- **Personalised Care and Support Planning** (based on holistic needs assessments) which ensures people's physical, practical, emotional, and social concerns are identified and addressed at the earliest opportunity.
- **End of Treatment Summaries**, which provide both the person and their GP with valuable information, including a detailed summary of treatment completed, potential side effects, signs and symptoms of recurrence and contact details to address any concerns.
- **Primary Care Cancer Care Review**: this is a discussion between the person and their GP/primary care nurse about their cancer journey. It is intended to help the person to discuss any concerns, and, if appropriate, to be referred to services or signposted to information and support that is available in their community and from charities. This is outside the scope of the Trust.
- **Health and wellbeing information and support** includes the provision of accessible information about emotional support, coping with side effects, financial advice, getting back to work and making healthy lifestyle choices. This support will be available before, during and after cancer treatment.

The basic principles that underpin PSSMFU are that patients have:

- Personalised care plan developed with a heath care professional
- End of treatment summary and protocol driven follow up care
- Programmed education session from a Clinical Nurse Specialist (CNS) and Patient Initiated Follow Up Cancer Support Worker (PIFU CSW)
- Personalised written information
- Signposting to local and national resources such as support groups and Health and Wellbeing programmes
- Clinical surveillance investigations continue unchanged as per site specific NICE Guidance
- Care that is managed robustly, ensuring management, and monitoring of investigation requests and results
- Fast track re-entry for clinical review if / when required
- Direct access to their clinical nurse specialists / clinical team
- Access to online electronic portal; personalised with their plan of care and support information
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3. Statement of Intent

The Trust aims to ensure, through this policy to ensure that the Cancer PSSMFU programmes are delivered by:

- Staff following the NHSE personalised care framework
- Staff who have had access to required training
- Staff who work within the clear lines of accountability
- Service that monitors performance against the Key Performance Indicators (KPIs)
- Cancer MDTs with an aspiration that all teams will offer PSSMFU by 2023
- Cancer MDT's who demonstrate they are listening to patients views and demonstrate service improvement through any patient feedback and learning

4. Definitions

Definition	Meaning
Self-Management	Awareness and active participation by the person in their recovery, recuperation, and rehabilitation to minimise the consequences of treatment and promote survival, health, & wellbeing (Co-Creating Health –The Health Foundation)
Supported Self-Management	What health services do to aid and encourage people living with a long-term condition to make daily decisions that improve health related behaviours and clinical and other outcomes (Co-Creating Health –The Health Foundation)

5. Duties, Accountabilities and Responsibilities

5.1 Chief Executive

The Chief Executive has overall responsibility for the strategic and operational management of the Trust including and ensuring that this document complies with all legal, statutory, and good practice guidance requirements and is implemented effectively and efficiently.

5.2 Director of Operations

The Director Nursing is accountable to the Trust Board for providing assurance of compliance with this document

5.3 Clinical Leads

Clinical leads across all tumour sites / MDTs will retain overall clinical responsibility for the patient's wellbeing, taking national guidance into account and reviewing the practice against recommendations/best practice annually. They will ensure that personalised support self- management (PSSMFU) is discussed at their business meetings to raise any issues and performance against KPI. They are accountable for ensuing patient experience is considered in service delivery.

5.4 Lead Cancer Nurse

The Lead Cancer Nurse is responsible for

- setting the vision for personalised care within cancer across the organisation in line with the NHS Long-term plan
- supporting Directorate Managers, clinical leads, and CNSs in the implementation and delivery of PSSMFU
- review performance against any national targets and work with the teams to develop improvement plans
- ensuring clear communication of the national, regional, and local priorities for PSSMFU in cancer care
- sharing any learning across the organisation, and
- identifying opportunities for investment, training, and development
- facilitating CNS to present patient experience annually at Cancer Patient Experience and Quality Assurance Group

5.5 Directorate Managers

Directorate Managers are accountable as service leads for

- implementing PSSMFU programmes within their services in line with the NHS long term plan
- supporting the clinical teams with the delivery of PSSMFU, ensuring protected time in job plans, adequate skill mix
- monitoring performance against national requirements for each cancer site.
- Identifying opportunities to utilise the additional capacity created by patients being moved onto a PSSMFU programme
- identifying opportunities to introduce PSSMFU across all cancer pathways, and
- ensuring PSSFU programmes adhere to the Patient Imitated Follow up (PIFU) models as described in the Trust policy
- Achieving ensuring 5* patient experience Specialist Care Group Meetings annually

5.6 Clinical Team

5.6.1 The Multidisciplinary team is accountable for

- ensuring cancer specific PSSMFU protocols are in line with Cheshire and Merseyside cancer Alliance Clinical Quality Groups (CQG) / NICE approved protocols
- ensuring process are in place for rapid re- entry into mainstream follow up as required

- ensuring process in place at the end of follow up to discharge patients
- identifying patients suitable for the PSSMFU
- ensuring process in place for discharging patients to Patient Initiated Follow up pathways once the decision to move to PSSMFU has been discussed with the patient.
- improving performance against national requirements, and
- the safe delivery of patient care during traditional follow up and PIFU models of follow up

5.6.2 The Clinical Nurse Specialists are responsible for

- the safe delivery of care for patients on PSSMFU
- managing the patient pathway when they are on PSSMFU
- delivering education programmes to patients enabling patients to recognise sign and symptoms of recurrence, consequences of treatment, who to contact if concerned and how to self-manage their heath living with and beyond a cancer diagnosis.
- escalating any concerns / challenges in relation to patient care
- developing patient materials to support education programmes
- authorising surveillance results and escalating appropriately
- requesting surveillance investigations
- validating all results letters sent to patients
- responding to red flag alerts in a timely manner
- undertaking HNA with the patient and developing a plan of care
- completing EOTs
- obtaining patient consent to add details to the portal if IT or Non- It
- ensuring patients have written information on PSSMFU to enable informed consent, and
- reporting via Datix and investigating patient pathways that fall outside of protocol
- undertaking annual patient experience as a minimum

5.6.3 The PIFU Cancer support worker will

- maintaining the data base (patient portal)
- management patient interventions ensuring investigations / OPD are done in line with the protocol
- escalate if OPD, investigations are cancelled / delayed to the CNS
- Triaging all calls and emails from patients on the PSSMFU
- escalating any delays in surveillance investigations to the CNS
- delivering education session on how to use the portal, and
- escalating clinical queries to the CNS

6. Process

6.1 Patient enrolment

Patients identified as suitable for a PSSMFU programme should be engaged by a core member of the MDT or delegated HCP, in line with agreed site-specific protocol. Recruitment will normally take place when patients have completed their cancer treatment and have been informed that they will be on surveillance follow up, with exception of skin cancer patients who are recruited following their treatment planning MDT for a defined cohort of patients. PSSMFU is furthermore offered to patients with pre-cancerous conditions (example haematology).

6.2 Identifying Patients

Prior to commencing a PSSMFU programme the MDT should have Cheshire and Merseyside Clinical Quality Governance Group agreed follow up protocols, which are in line with national / NICE guidance for the site-specific MDT agreed cohort of patients.

There must be an auditable trail to evidence.

- Why was the patient selected?
- Who selected the patient?
- Which protocol the patient will follow?
- What the patient has been told?

6.3 Consent (Appendix 1 – Registration Letter)

Consent from the patient will not be required for the processing of patient’s data within the portal. The portal will be used by the team for all patients to manage their care by uploading information such as their plan of care, results, education material, health checks and to contact the clinical team and for this consent is not needed.

There are 2 cohorts of patients:

- **Non-IT**. These patients have opted out of having access themselves to the patient portal, they will still have their follow up care managed by the site-specific cancer team via the portal and will receive all the patient resources / information in an alternative format to meet the patient’s needs.

- **IT**: these patients have opted to have access to the patient portal, they will have an account set up by the PIFU CSW which will be linked to their email address and password.

Patients that opt for access to the patient portal (IT) will need to provide them email address which will be used to register them to have access to the portal by doing this they are agreeing and consenting to using the portal (no other form of consent is required i.e., written consent). The Registration letter in Appendix 1 provides the patient with further information. Patients only need to complete and sign the registration letter if they wish to do so.

This process has been outlined in the Data Protection Impact Assessment (DPIA).

6.4 Information (Appendix 2)

Patients recruited to the PSSMFU programme, will be provided with the Trust approved Trust written information leaflet and contact card, ensuring that they have opportunity to make an informed consent regarding sharing of information, access to the portal and they have the contact details for the PIFU Cancer Support Worker (PIFU CSW).
This written information should be given in addition to verbal discussion and should **not replace** a conversation explaining the patient’s diagnosis and follow up plan of care.

6.5 Managing patient activity

Patient activity will be recorded on CareFlow

6.5.1 Workshops

Patients should be offered the option of face to face, virtual or telephone education sessions. If a patient declines to engage in education session (workshops) or they do not attend (DNA) a booked appointment, written information should be posted with links to site specific you tube videos. This will count as engagement with in a HWB Event (workshop) on Somerset Cancer Registry but not appointment attendance on the PAS system.

6.5.2 Suspension

Patient should be suspended from the portal for the following reasons
- Red flag symptoms suggest reoccurrence patients should have previously been advised that they are all clear of their cancer, this is any one in follow up protocol)
- Red flag symptoms suggest disease progression, this is progression whilst on treatment.
- Patient is for Best Supportive Care
- Patient referred for Oncology treatment and follow up will continue until the patient is referred to PIFU by the clinical team (MDT)

6.5.3 Discharge

Patients will be discharged from the portal in the following scenarios.

- Follow up completed per protocol
- End of treatment for follow up at another Trust
- Follow up transfer to another Trust at another time than end of treatment
- Discharge to another Trust

6.6 Re-entry to mainstream follow up

Patients on PSSMFU should have all their protocolised clinical appointments and/or test results /outcomes managed through the online portal. Skin cancer patient required face to face assessment in line with NICE guidance and should not be discharged from clinical follow up.

If patients protocolised investigations highlight an abnormality which needs to be discussed with the patient face to face or the patient alerts the team to red flag symptoms, which suggest reoccurrence or disease progression and requires a clinical assessment, a clinic appointment should be arranged with the relevant consultant within a timely manner. This should not exceed two weeks. Each MDT should have an agreed local process.

7. Essential Deliverables of PSSMFU

7.1 Health and Wellbeing Clinics (HWBC)

Health and Wellbeing Information and Support for patients includes the provision of accessible information about emotional support, coping with side effects, financial advice, getting back to work and making healthy lifestyle choices. This support should be available before, during and after cancer treatment and prior to commencing on a PSSMFU programme.

Within STHK patients can access HWBC via a range of models to suit the patient's need:

- Health and Wellbeing Event, which is held quarterly and runs parallel to a marketplace with the local community and voluntary services providing stalls for patients to access. The events are open to all cancer patients on completing treatment irrelevant of the treatment intent. The CNS teams each hold a group session. The CNS teams have evolved the sessions to include counselling and mindfulness tasters, health training, and psychological needs sessions on how to cope after a cancer diagnosis. The event is managed by the cancer support workers and Macmillan Information Team.

- Workshops: Patient group meetings are held at least monthly for all, there is a demonstration on how to use the portal by the PIFU CSW and information on signings and symptoms recurrence, consequences of treatment, how to complete a Health /holistic Need's assessment and who to contact if concerned by the cancer specific CNS. (See Section 7.3)
- Telehealth: patient group education session facilitated by a CNS and PIFU CSW. The presentations are also available on the patient portal or via email for patients to access and share with their families and carers.
- PIFU CSW telephone clinics: these are 1:1 (none face to face) with patients and should only be offered if the patient specifically requests not to attend a group session.

7.2 End of Treatment Summary (EOTS) (Appendix 3)

EOTS is a letter / proforma shared with the patient and their GP on completion of any cancer treatment. The information includes signs of recurrence: what to look out for, consequences of cancer treatments, services that the patient has been linked into and if the patient has a palliative diagnosis and has received a DS1500.

EOTSs can be generated from the patient portal and are available for patients to access or via templates in ESR or Somerset, these should be shared with the patient as an education opportunity to help them self-manage their heath. EOTS will be emailed to the GP via EDMS or MMR.

For Pre-cancerous / watch and wait surveillance patients on PSSMFU EOTS will not apply, patients are provided with information on how to manage their disease.

7.3 Health MOT's/Cancer Health Checklist (Appendix 4)

The Health MOT's / Cancer health check list is a tool which promotes patients to highlight if they have any concerns. The tool is designed to highlight any symptoms which may suggest recurrence of cancer, These Red Flag symptoms are alerted via email to the PIFU CSW (See section 7.4)

The Heath MOT/ Cancer Heath checklist is available through the online patient portal for IT patients, for non- IT patients this will be completed in paper format if the patient rings / emails with any concerns.

The Heath MOT/ Cancer heath checklist includes physical, psychological, social, and spiritual concerns, this enables the person to highlight that they have concerns that they wish to discuss and to have holistic care.

7.4 Red flag Symptoms and Rapid Re-entry

In the event the patient highlights a red flag symptom on their Health MOT/ Cancer Heath Checklist which may indicate reoccurrence, a live alert email is sent to the clinical team from the patient portal.

The patient is then contacted by the PIFU CSW to gather further information, this patient is then contacted by a CNS via a booked telephone / Telehealth appointment the same working day.

The CNS will undertake a clinical triage, arrange any appropriate investigations, and arrange for the patient to be seen face to face in a clinic to be assessed and plan of care discussed as appropriate.

The patient is suspended from the PSSMFU pathway. The patient will still be able to access their historical records on the portal but will not be tracked / managed by the PIFU CSW as they will now be under the care of the clinical team.

The patient will be re-entered onto the PSSMFU pathway once agreed by the clinical team and will recommence follow up per protocol.

8. Non-IT Patients

Non- IT patients will not experience any inequity in care, leaflets and patient education presentations will be shared in paper format and the patient will have direct contact with the PIFU CSW if they have any concerns. A Heath MOT/ Cancer Health Checklist will be sent via post as per tumour site protocol or via telephone consultation.

9. Tumour Specific Pathways

Clinical surveillance protocols should continue unchanged for patients identified as suitable for supported self-management pathways. PSSMFU protocols must follow NICE guidance for the cancer site and be approved at the Clinical Quality Group for Cheshire and Merseyside Cancer Alliance.

Patients who complete their follow up care will be discharged from PSSMFU however they will still have access to the education and patient information page of the portal and can be reactivated if required.

10. Patient Experience (Appendix 5)

Patient experience will be presented bi- annually by the cancer teams at Cancer Patient Experience and Quality Assurance and at the care group speciality meeting.

- Patient experience should be sought using online / paper surveys
- Patient stories facilitated by the Macmillan Information and support team
- Shared learning from any incidents
- Patient compliments

11. Key Performance Indicators (KPI's) including Metrics for Submission to NHSE

KPI /	ID	Description	Why are we collecting it?	Source Data
KPI	1.0	% Of Patients registered on portal compared against the total number patients recorded as eligible per protocol for remote follow up (Cancers Only)	Demonstrate that patients are being monitored and supported through surveillance personalised supported self-management programme. Ensure that registration process is robust.	MMR, SCR
KPI	2.0	% Patients suspended from the PIFU programme	Demonstrate that patients no longer eligible to be managed through the portal are linked back into appropriate services for support.	MMR
KPI	3.0	% Patients with a CNS present at diagnosis	Demonstrates if every person living with cancer accessing the service is having the opportunity to have a CNS present at diagnosis and a named key worker	MMR, Somerset
KPI	4.0	% Patients who are recruited to MMR as IT user	Demonstrate if every person living with cancer can assess online resource including education tools and videos, demonstrate equity for non-IT Patients. Patients with IT or non-IT have access to core information. Promote IT access to the online portal	MMR
KPI	5.0	% Patients who complete a " Health Check/ MOT " by IT users.	Demonstrate patients have opportunity to raise any concerns about their heath	MMR
KPI	6.0	% Patients having their OPD and investigations within protocol	Demonstrate adherence to protocols	MMR

KPI /	ID	Description	Why are we collecting it?	Source Data
KPI	7.0	% Patients who report a positive experience of using PSSMFU	Demonstrates if every person living with cancer accessing the service is having the opportunity to have their needs and concerns assessed	MMR
KPI	8.0	% Patients attending the health & wellbeing education sessions.	Demonstrating that patients have access to training and education on the MMR portal, recognising signs and symptoms of recurrence, consequences of treatment and who and how to contact the team if concerned.	SCR

12. Governance for Monitoring Compliance and Performance

- NHSE PIFU: Activity reported monthly to NHSE responsibility BI team.
- Patient experience: Cancer Patient Experience and Quality Assurance Group and Specialist Care Group Meetings bi- annually, this the responsibility of the site specific PSSMFU CNS Lead and DM.
- Performance: Site specific annual business meeting and Cancer Operational Performance and Oversight Group, this is responsibility of lead clinician annually.

13. Roles and Responsibilities

Role	Team member
Identifying patients and informing patient of PSSMFU	Core member MDT
Referring patient to the PIFU CSW and assigning protocol	Core member MDT
Registration on patient on the portal, creating patient login	PIFU CSW
Consent	CNS
Delivery of Health and Welling Education Clinics	CNS
Delivery of Training on *how to use the portal*	PIFU CSW
Tracking investigations per protocol	PIFU CSW
Informing CNS team if patient DNA investigations	PIFU CSW
Planning ongoing care following a DNA for investigations	CNS
Reviewing investigation results and taking appropriate action	CNS
Updating portal with results letter following investigations	PIFU CSW
Reviewing incoming messages and health MOTs	PIFU CSW
Triaging and responding to red flag symptoms alerts	CNS
Suspending patients recalled back into face to face follow up	PIFU CSW
Informing the GP of results of investigations within two weeks	CNS
Monitoring compliance with protocols and reviewing deviations	Lead Clinician

from the pathway	

14. Training

PIFU CSW should have completed:

- Intermediate Communication skills training
- Understanding Personalised Care' and 'Personalised Care for People Living with Cancer' (Macmillan)
- Macmillan What matters to me

CNS

- Advanced Comms Skills training
- L2 psychological Assessment

15. Monitoring Compliance

Compliance with the policy will be audited annually by the site-specific teams

15.1 Key Performance Indicators (KPIs) of the Policy

No	Key Performance Indicators (KPIs) Expected Outcomes
1.	Patient supported self-management programmes within the trust subject to the scope of this policy deliver against the KPI's

15.2 Performance Management of the Policy

Minimum Requirement to be Monitored	Lead(s)	Tool	Frequency	Reporting Arrangements	Lead(s) for acting on Recommendations
Audit	Cancer Services Lead Cancer Nurse	Documentation Review	Annual	Cancer Patient Experience and Quality Assurance Group and Cancer Operational Performance Group	Lead Cancer Nurse; Cancer Operational Manager;

16. References/Bibliography

No	Reference
1.	Cheshire and Merseyside Strategic Clinical Networks Guidelines for Holistic Needs Assessment These guidelines available at: http://www.cmscnsenate.nhs.uk/strategic-clinical-network/our-networks/cancer/
2.	Cheshire and Merseyside Strategic Clinical Networks Key Worker Guidelines These guidelines available at: http://www.cmscnsenate.nhs.uk/strategic-clinical-network/our-networks/cancer/
3.	Cheshire and Merseyside Strategic Clinical Networks Clinical Guidelines for the Management of Breast, Colorectal, and Prostate Cancer These guidelines available at: http://www.cmscnsenate.nhs.uk/strategic-clinical-network/our-networks/cancer/
4.	My medical record IT setup and operational support Service Level Agreements (SLAs) and GDPR contract agreement 2021/22

17. Related Trust Documents

No	Related Document
1.	Trust Standard operational policy for Patient Initiated Follow up

18. Equality Analysis Form

The screening assessment must be carried out on all policies, procedures, organisational changes, service changes, cost improvement programmes and transformation projects at the earliest stage in the planning process to ascertain whether a full equality analysis is required. This assessment must be attached to all procedural documents prior to their submission to the appropriate approving body. A separate copy of the assessment must be forwarded to the Patient Inclusion and Experience Lead for monitoring purposes. Cheryl.farmer@sthk.nhs.uk. If this screening assessment indicates that discrimination could potentially be introduced, then seek advice from the Patient Inclusion and Experience Lead. A full equality analysis must be considered on any cost improvement schemes, organisational changes or service changes which could have an impact on patients or staff.

Equality Analysis			
Title of Document/proposal /service/cost improvement plan etc:	Protocol for supported self-management in follow up for Cancer patients		
Date of Assessment	06/10/202106/10/2021	**Name of Person completing assessment /job title:**	Diane Dearden
Lead Executive Director	Choose an item.		Lead Cancer Nurse

Does the proposal, service or document affect one group more or less favourably than other group(s) based on their:		**Yes / No**	**Justification/evidence and data source**
1	Age	No	Click here to enter text.
2	Disability (including learning disability, physical, sensory, or mental impairment)	No	Patients who have communication difficulties should not be excluded from discussion regarding SSMFU
3	Gender reassignment	No	Click here to enter text.
4	Marriage or civil partnership	No	Click here to enter text.
5	Pregnancy or maternity	No	Click here to enter text.
6	Race	No	Click here to enter text.
7	Religion or belief	No	Click here to enter text.
8	Sex	No	Click here to enter text.
9	Sexual Orientation	No	Click here to enter text.
Human Rights – are there any issues which might affect a person's human rights?		**Yes / No**	**Justification/evidence and data source**
1	Right to life	No	Click here to enter text.
2	Right to freedom from degrading or humiliating treatment	No	Click here to enter text.
3	Right to privacy or family life	No	Click here to enter text.
4	Any other of the human rights?	No	Click here to enter text.
Lead of Service Review & Approval			
Service Manager completing review & approval		Diane Dearden	
Job Title:		Macmillan Lead Cancer Nurse	

19. Appendices

19.1 Appendix One: Registration Letter

Dear Patient

As part of your treatment and follow up care, you will have regular contact with the xxxx cancer team looking after you. Your treatment and follow up care will include a mixture of appointments such as investigations, treatments, telephone appointments and access to an online patient portal called **My Medical Record (MMR).**

MMR is a secure online portal which allows your XXX cancer team to manage and support you through your treatment and follow up. It does not replace contact with your clinical team but supports the care you will receive by enabling you to log onto a patient portal to

- Contact your XXXX team via e-mail
- Complete a XXXX health checklist if you have any concerns
- Access education session run by the xxxx team
- Access information and resources to help you understand your treatment and how to look after yourself
- Receive reminders that you are due an appointment

Access to education and information improves physical health and well-being and allows you to take an active role in your recovery with the help from your specialist team.

We understand that not everyone feels comfortable with technology or has regular access to a computer. You may have a relative, carer or close friend who can assist you in accessing **MMR**.
If you have any questions or require and further information, please feel free to contact us with any further questions.

Yes, please register me onto the My Medical Record (MMR).
Please tick the box if you would like this and fill in your contact details below. ☐

(By consenting to use MMR you also consent to us contacting you via e-mail)

Name: ___________________________

DOB: _____________ Hospital Number: __________________

Email: ____

Mobile/Contact Number: ____

Signature: ______________________________Date: __________________________________

No thank you I do not wish to register, and I would like the information to be paper and telephone format. Please tick the box if you would like this. ☐

(Please feel free to comment on the reason why you do not wish to register as this feedback will aid the trust for future practice)

19.2 Appendix Two: Patient Information

NHS
St Helens and Knowsley
Teaching Hospitals
NHS Trust

Accessing Your Patient Portal Following a Skin Cancer Diagnosis

This leaflet can be made available
in alternative languages / formats on request.

如有需要，本传单可提供其他语言/版式

此單張的其他語言/格式版本可按要求提供

Na żądanie ta ulotka może zostać udostępniona
w innych językach/formatach.

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Department: Cancer Services
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Version: 1
Review Date: 01 / 04 / 2024

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Your follow up will include regular face to face contact with your specialist skin cancer team and access to an online patient portal called My Medical Record (MMR).

This will:

- Help you to understand your condition and the treatments
- Ensure you have a named nurse specialist
- Enable you to contact your specialist team via e-mail/ telephone
- Ensure you can discuss worries and fears with the specialist team (Holistic Needs Assessment)
- Ensure you have access to your team through a single point of contact
- Ensure you have access to written information and local resources
- Ensure you understand your plan of care
- Provide access to education videos
- Ensure you have training and support on how to self examine
- Ensure you can initiate your own follow up if you are worried about and signs or symptoms related to your cancer
- Help you to self manage your heath and wellbeing with the support of the team

National Resources

Macmillan Cancer Support

https://www.macmillan.org.uk/

Telephone: 0808 808 0000 (Freephone) Registered charity. Provides emotional and practical support following a cancer diagnosis.

Cancer Research UK (CRUK)

https://www.cancerresearchuk.org/

Telephone: 0808 800 4040 (Freephone) Registered charity. Information service and signposting to local services. Nurses provide a listening ear to discuss worries.

Counselling Service Lilac Centre

Telephone: 01744 646173 / 01744 646174 to self refer for Counselling or holistic therapies

National Melanoma Focus Support Group

https://melanomafocus.com/support/helpline/

Telephone: 0808 801 0777 (Freephone) speak to a nurse about concerns

Cancer Care Map

https://www.cancercaremap.org/

Cancer Care Map is an online resource to help people living with cancer find care and support services in their local area, anywhere in the UK.

Please be reassured only you and the health care professionals involved in your care will be able to access and view your details on MMR.

MMR Login:

Name of Skin Nurse Specialist:

Name of Cancer Support Worker:

Name of Consultant:

If you change your address, GP or any other personal details, please let us know by contacting the team on:

01744 646807

The online portal (MMR) will allow you to access all this information in one place.

The aforementioned information and support will enable you to self manage your health and communicate any physical, practical and emotional or relationship concerns .

- MMR will empower you to self manage and communicate any physical, practical, and emotional or relationship concerns to your Skin Cancer Nurse Specialist or Support Worker.
- This type of follow up additionally allows the team to co-ordinate your care remotely i.e. ensuring appointments and results happen in a timely manner, and will hopefully offer reassurance and reduce any anxiety you may be experiencing.
- Patients can access clinical letters and appointments via an online system called My Medical Record (MMR). It avoids unnecessary hospital appointments at times when you are feeling perfectly well.
- Should you have any issues or concerns, then a face to face hospital appointment will be arranged.
- Your GP will also be made aware that you have entered onto remote monitoring.

Furthermore, the MMR patient portal allows the team to manage your care ensuring appointments happen in a timely manner and keeping you informed of next steps in your care.

How will I access My Medical Record (MMR)?

Every patient will be on the MMR portal.

To access it you will be provided with log in details when you meet the Nurse Specialists.

A Cancer Support Worker (CSW) will be available to help you, over the telephone, to log on (telephone number):

01744 646807

You will need to have an email address that we can use.

If you need help with working on a computer, the team will offer you information on how to obtain free training or you can nominate a family member to help you.

We understand, however, that not everyone feels comfortable with technology or has access to a computer / smart phone.

If you choose not to register to access MMR you can continue to take assessments and receive information in paper format or via telephone.

What support will I have?

You will have a dedicated Skin Cancer Support Worker who will be your first point of contact and to help you.

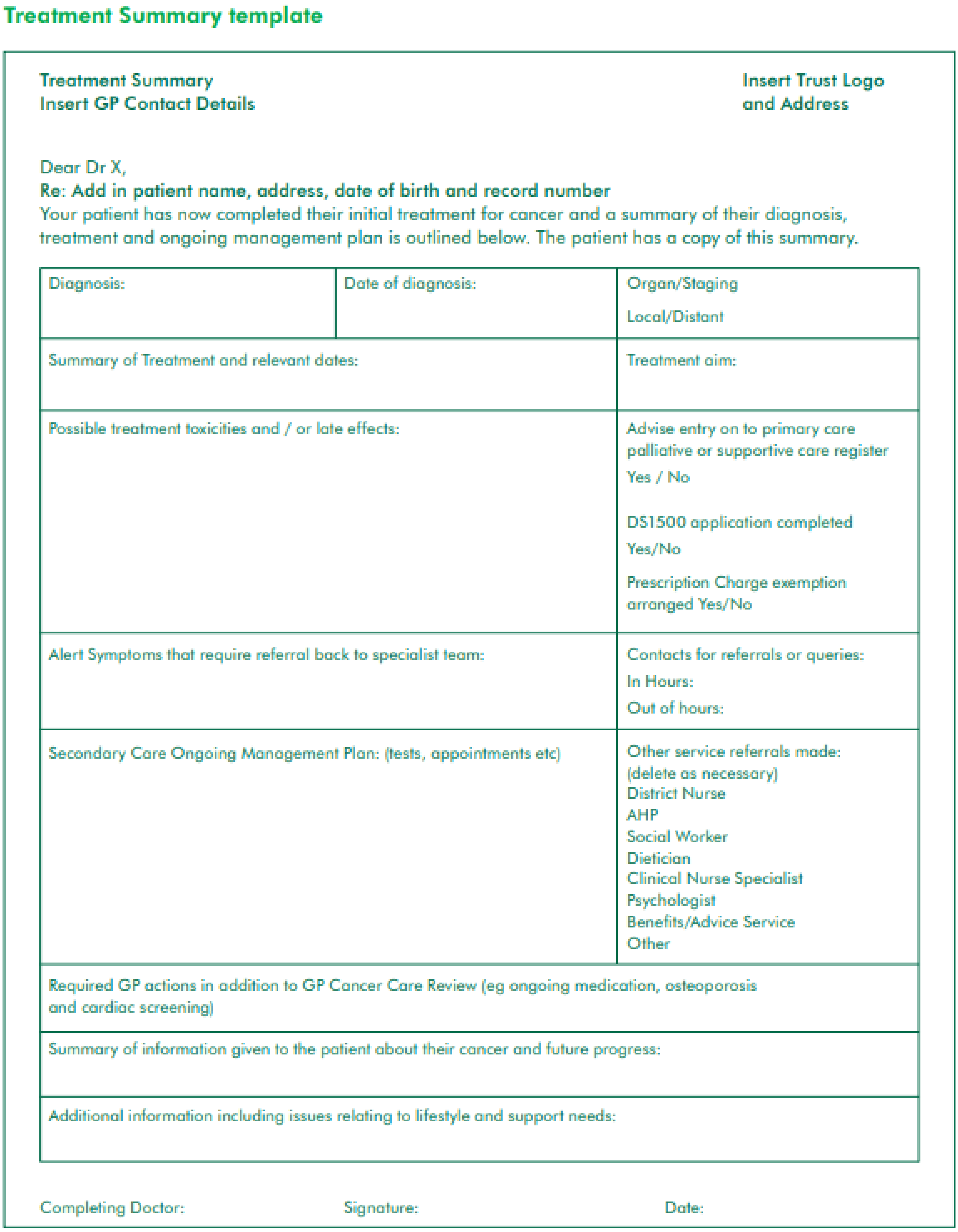
You will be invited to attend a Living with and Beyond cancer event when your treatment is completed and you go onto follow up care.

This can be done on a one to one basis, virtually or in a group session.

You can complete a health checklist on the MMR at any time if you have concerns.

These might include practical issues such as work, or dealing with the physical and emotional effects of your skin disorder, as well as highlighting any questions relating to your relationships or family life.

19.3 Appendix Three: Example Treatment Summary



Treatment Summary template

Treatment Summary
Insert GP Contact Details

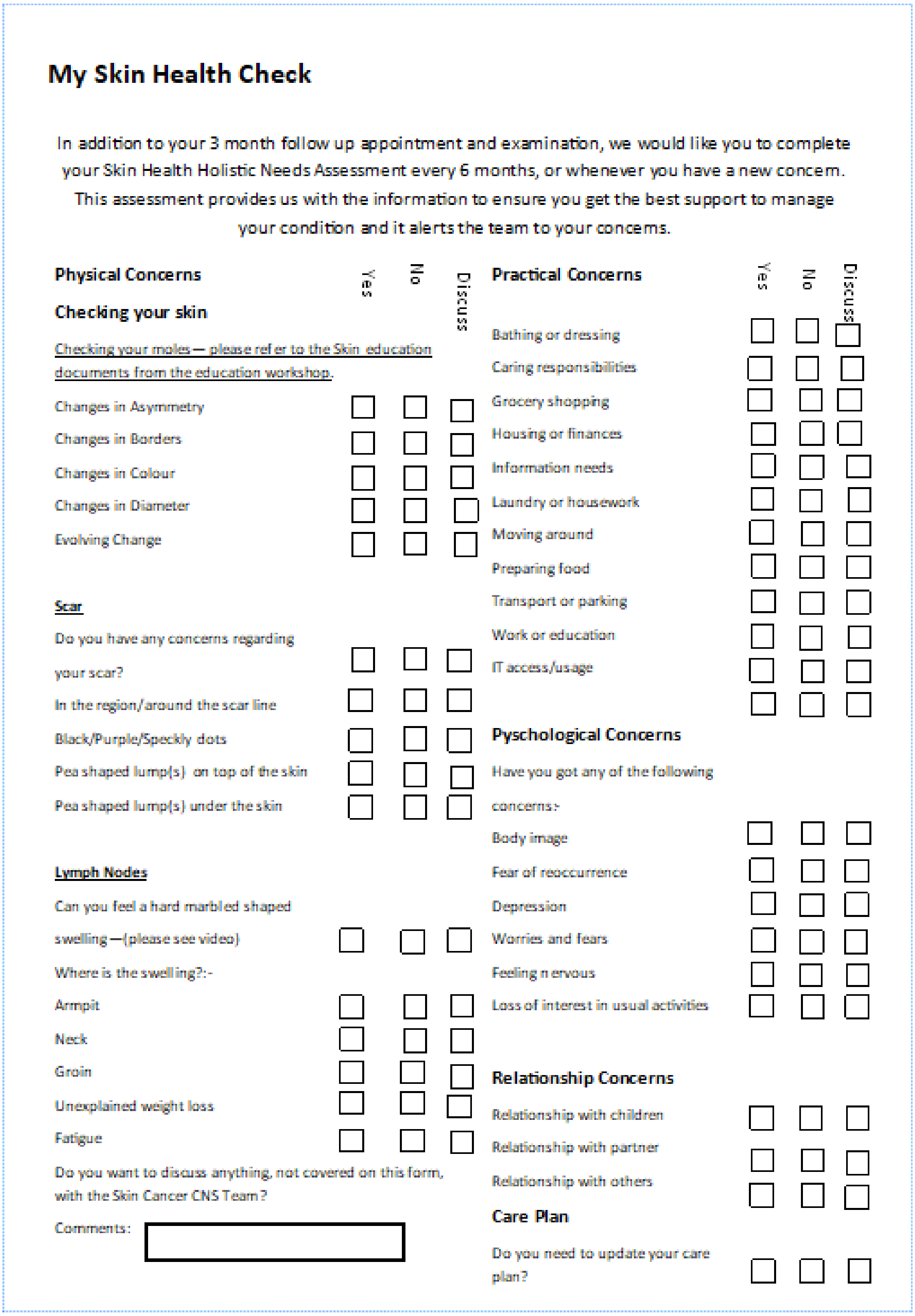
Insert Trust Logo
and Address

Dear Dr X,
Re: Add in patient name, address, date of birth and record number
Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and ongoing management plan is outlined below. The patient has a copy of this summary.

Diagnosis:	Date of diagnosis:	Organ/Staging Local/Distant
Summary of Treatment and relevant dates:		Treatment aim:
Possible treatment toxicities and / or late effects:		Advise entry on to primary care palliative or supportive care register Yes / No DS1500 application completed Yes/No Prescription Charge exemption arranged Yes/No
Alert Symptoms that require referral back to specialist team:		Contacts for referrals or queries: In Hours: Out of hours:
Secondary Care Ongoing Management Plan: (tests, appointments etc)		Other service referrals made: (delete as necessary) District Nurse AHP Social Worker Dietician Clinical Nurse Specialist Psychologist Benefits/Advice Service Other
Required GP actions in addition to GP Cancer Care Review (eg ongoing medication, osteoporosis and cardiac screening)		
Summary of information given to the patient about their cancer and future progress:		
Additional information including issues relating to lifestyle and support needs:		

Completing Doctor: Signature: Date:

19.4 Appendix Four: Example Health MOT/Cancer Health Checklist



My Skin Health Check

In addition to your 3 month follow up appointment and examination, we would like you to complete your Skin Health Holistic Needs Assessment every 6 months, or whenever you have a new concern. This assessment provides us with the information to ensure you get the best support to manage your condition and it alerts the team to your concerns.

Physical Concerns

Checking your skin

Checking your moles – please refer to the Skin education documents from the education workshop.

	Yes	No	Discuss
Changes in Asymmetry	☐	☐	☐
Changes in Borders	☐	☐	☐
Changes in Colour	☐	☐	☐
Changes in Diameter	☐	☐	☐
Evolving Change	☐	☐	☐

Scar

	Yes	No	Discuss
Do you have any concerns regarding your scar?	☐	☐	☐
In the region/around the scar line	☐	☐	☐
Black/Purple/Speckly dots	☐	☐	☐
Pea shaped lump(s) on top of the skin	☐	☐	☐
Pea shaped lump(s) under the skin	☐	☐	☐

Lymph Nodes

	Yes	No	Discuss
Can you feel a hard marbled shaped swelling – (please see video)	☐	☐	☐
Where is the swelling?:-			
Armpit	☐	☐	☐
Neck	☐	☐	☐
Groin	☐	☐	☐
Unexplained weight loss	☐	☐	☐
Fatigue	☐	☐	☐

Do you want to discuss anything, not covered on this form, with the Skin Cancer CNS Team?

Comments: ☐

Practical Concerns

	Yes	No	Discuss
Bathing or dressing	☐	☐	☐
Caring responsibilities	☐	☐	☐
Grocery shopping	☐	☐	☐
Housing or finances	☐	☐	☐
Information needs	☐	☐	☐
Laundry or housework	☐	☐	☐
Moving around	☐	☐	☐
Preparing food	☐	☐	☐
Transport or parking	☐	☐	☐
Work or education	☐	☐	☐
IT access/usage	☐	☐	☐
	☐	☐	☐

Pyschological Concerns

Have you got any of the following concerns:-

	Yes	No	Discuss
Body image	☐	☐	☐
Fear of reoccurrence	☐	☐	☐
Depression	☐	☐	☐
Worries and fears	☐	☐	☐
Feeling nervous	☐	☐	☐
Loss of interest in usual activities	☐	☐	☐

Relationship Concerns

	Yes	No	Discuss
Relationship with children	☐	☐	☐
Relationship with partner	☐	☐	☐
Relationship with others	☐	☐	☐

Care Plan

	Yes	No	Discuss
Do you need to update your care plan?	☐	☐	☐

19.5 Appendix Five: Example Patient Survey

Introduction

Your views are important and help us to improve our service; therefore, we would appreciate it if you could take some time to complete our questionnaire on your experience with the Skin Cancer Team.

Thank you

1. When you were told you had cancer, were you given written information about the type of cancer you had?

☐ ☐

☐ Yes, and it was easy to understand did not need written ☐ information

☐ Yes, but it was difficult to understand Don't know/Can't remember

No, I was not given written information about the type of cancer I had

2. Were you involved as much as you wanted to be in decisions about your care and treatment?

☐ Yes definitely

☐ Yes, to some extent

☐ No

3. Were you given the name of a Clinical Nurse Specialist/Cancer Support Worker who would support you through your treatment?

☐ Yes

☐ No

☐ Don't know/Can't remember

4. How easy or difficult has it been to contact your Clinical Nurse Specialist/Cancer Support Worker?

☐

☐ Very easy

☐ Neither easy nor difficult

☐ Very difficult

☐ Quite easy

☐ Quite difficult

I have not tried to contact my Clinical Nurse Specialist/Cancer Support Worker

5. While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?

☐ Yes definitely

☐

☐

☐

Yes, to some extent

No

I did not have any worries or fears

6. Are you aware that St Helens and Knowsley Teaching Hospitals NHS Trust is a research active trust?

☐ Yes

☐ No

Comments please

7. After your education session with the Cancer Support Worker, did you feel confident to access the online My Medical Record Portal?

☐ Yes

☐ No (Please explain why in the comments field below)

Comments please

8. How quickly have the team responded to any queries or concerns you may have raised via the online My Medical Record portal?

☐ Within 24 hours

☐ Within 48 hours

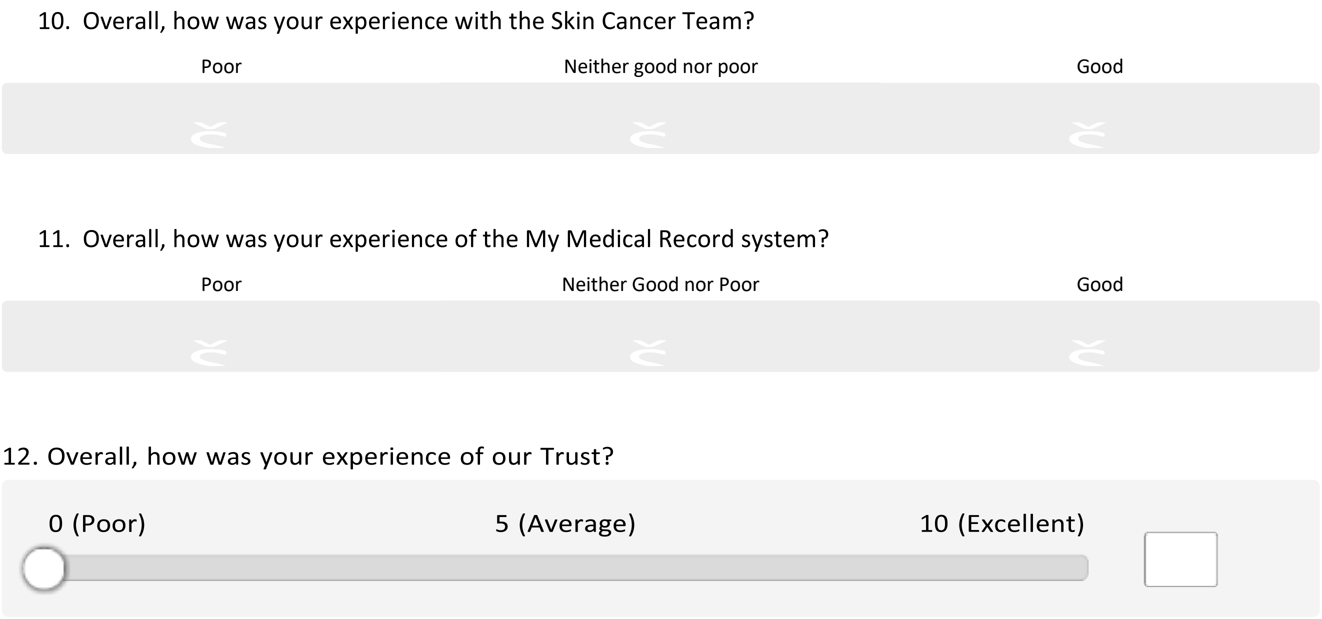
☐ Over 72 hours

9. Would you recommend the online My Medical Record portal to other patients?

☐ Yes

☐ No (Please explain why in the comments field below)

Comments please



10. Overall, how was your experience with the Skin Cancer Team?

Poor	Neither good nor poor	Good
○	○	○

11. Overall, how was your experience of the My Medical Record system?

Poor	Neither Good nor Poor	Good
○	○	○

12. Overall, how was your experience of our Trust?

0 (Poor) 5 (Average) 10 (Excellent)

19.6 My Medical Records Support

19.6.1 Support arrangements

STHK is expected to manage all local enquiries from any of their users, both patients and clinicians. Where appropriate these can be passed to the UHSFT My medical record support team, but a single one-to-one relationship should be maintained between UHSFT and the customer; patients and clinicians should not be directed to the UHSFT support team. Support issues deemed appropriate for passing to UHSFT can be categorised as any error, bug, data quality, loss of service or technical issue. Typical issues such as forgotten passwords can be resolved by the user via the patient facing website and it is the responsibility of the customer to direct the patient to these resources.

UHSFT will manage all UI issues with Get Real Health product team directly. However, it should be noted that.

- UHSFT cannot guarantee resolution times on UI bugs as some require code changes and, dependant on severity, may be resolved during planned upgrades

It is the responsibility of both UHSFT and the customer to work together in resolving any support issues. It is typical that most support issues will sit with UHSFT for resolution but matters relating to interfacing have a number of points of failure. As these issues could sit with UHSFT, the customer or respective network providers (HSCN etc), all parties are expected to work together to determine where the fault lies.

It is the responsibility of the customer to;

- Register patients as required
- Review patients as required using clinical patient tracker
- Monitor patient messages that come in
- Feedback any issues to UHSFT team
- Feedback any change requests to project lead for the module

The software that supports the My Medical Record service is hosted in Microsoft Azure.

Details on the support arrangements and the uptime guarantees and downtime credit policies that UHSFT have in place with Microsoft Azure can be found in appendix B.

19.6.2 Incident management

The UHSFT My medical record team will provide support throughout core working hours, 9am to 5pm, Monday to Friday, excluding UK public holidays. They can be contacted through a central email address that is continuously monitored during these times. Initial response to incidents will be managed by a rotating team of up to 4 technical specialists with second line support available in each area (e.g. interfacing issues).

The UHSFT My Medical Record team email is mymedicalrecord@uhs.nhs.uk

The customer will contact UHSFT via the email address when incidents occur. UHSFT will manage the incident from initial logging on service desk software through to resolution though it remains the responsibility of both UHSFT and the customer to work together in resolving support issues. Once the incident has been raised, UHSFT will acknowledge receipt within two hours and respond with a support ticket number and further contact/call management details as required. UHSFT will keep the customer informed whilst the incident is still live.

UHSFT will endeavour to resolve all incidents (outside of loss of service) within one working day of receipt though it is accepted that some supporting infrastructure, e.g. Get Real Health software, make some timescales beyond their control. In these instances incidents will be resolved as quickly as possible.

The customer will handle local enquiries from patients and will not share the My medical record support email with its user base.

19.6.3 Out of hours support

My medical record is a live 24/7 service and should be available at all times but UHSFT do not provide any out of hours support for the service. The customer can email at any time and this will be picked up at 9am on the next working da

19.6.4 Unplanned loss of service

Where unplanned loss of service occurs, UHSFT will manage this through to resolution. Where the issue relates to software, networking or hosting configuration, UHSFT will endeavour to restore service within one hour.

However, where the loss of service is a result of Microsoft Azure, UHSFT have no control over resolution or timescale. UHSFT will liaise with Microsoft through our support arrangements and pass relevant information back to the customer. Microsoft SLA arrangements are detailed in Appendix B.

Any extended period of service unavailability will be communicated to all users by UHSFT where timescales become known and when service is restored.
1.5 Upgrades and planned downtime
From time-to-time upgrades to My medical record need to be implemented. Where the upgrade relates to the core software, there may be instances where downtime is required. Upgrades to content changes and bespoke functionality do not typically require downtime.

All periods of planned downtime will be fully agreed and co-ordinated with the customer. UHSFT will ensure a minimum of 5 days' notice for planned downtime. UHSFT will work with the customer site to agree a shorter timescale in the event of an emergency change being needed. Once agreed, UHSFT will communicate the downtime to all users, explaining the reason for the downtime (and associated benefits).

All changes will be carried out in accordance with UHSFT change control procedures and industry best practice.

19.6.5 Requests for change

On occasion, the customer may require new functionality to be built into My medical record (e.g., resulting from a change in local practice or national guidelines/governance). In any instance of this kind, the request should be passed to the Project lead who will co-ordinate and manage all requests.

Where a request is validated by the Project lead as necessary to support the project, it will be passed to UHSFT for analysis and provision of a level of effort quote to the customer. This does not include changes mandated by national guidelines/legislation as UHSFT as responsible for these changes.

1.7 Reporting

UHSFT will provide a regular automated reporting on patient registration figures but no other reporting is provided by default.

UHSFT are prepared to provide ad-hoc reporting on any data item (e.g., how many patients have been reviewed in virtual clinic might be a typical request) providing the number of requests is not excessive.

If an ad-hoc reporting query is less than 2 hours effort, then UHSFT will provide this free of charge (with a limit of 10 such queries in any given financial year). If the effort to delivery to report requested is more than two hours, then UHSFT may provide a quote to complete the work.

The customer should make any reporting requests via the Change Control procedure (see comment LM17 above) 30 working days in advance of when they require the information. The request should make clear what data items are required and any relevant clauses (e.g., date ranges).

UHSFT will then produce the required data within 30 days and will supply this in XLS or PDF format as requested by the customer. All patient data should be anonymised wherever possible in line with NHS guidelines. Where patient identifiable data is required it will be sent to the customer over secure NHS net email only. Any requests for patient data must be in accordance with NHS Information Governance policy.

1.8 Web browser version

Whilst My medical record will typically work on any web browser, specific clinician and patient user experiences will be dependent on the version of web browser being used.

It is recommended that Google Chrome is used in order to provide the best user experience, though My medical record will also work acceptably on Internet Explorer, Mozilla Firefox and Opera. Where Internet Explorer is preferred, version 8 should be the minimum/oldest version used. It is not possible for UHSFT to support every browser version and bugs/queries relating to browser versions not listed above cannot be investigated extensively. Internet Explorer 7 is not supported.

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End of Policy