Living With and Beyond Cancer

Implementing Personalised Stratified Follow Up Pathways

A handbook for local health and care systems

March 2020

NHS England and NHS Improvement

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Foreword

Personalised Stratified Follow Up (PSFU) is an effective way of adapting care to the needs of patients after cancer treatment, to ensure that we are providing world class services.

The implementation of PSFU pathways tailored to individual needs offers huge benefits to patients and the NHS. Stratified follow up improves patient experience and quality of life for people following treatment for cancer, as well as making services more efficient and cost-effective.

As PSFU is implemented around the country, we are seeing that people are having their needs met in a more timely manner and are better informed about their disease, treatment, signs of recurrence and any longer-term effects. With an increased focus on health and wellbeing, they are being supported to make healthier lifestyle choices and manage their care better.

In addition, PSFU is already allowing a substantial volume of outpatient appointment slots to be redeployed for new referrals and people with complex needs. We predict at least one million slots will be repurposed over the five years of the Long Term Plan.

By 2020/21, as part of PSFU roll out, a significant proportion of breast, colorectal and prostate cancer patients will have moved to supported self-management pathways with remote surveillance and guaranteed access back to their cancer team when needed. In 2020 we will decide which other cancer types will follow suit by 2023.

Alongside the roll out of PSFU, Cancer Alliances are working with local systems to ensure that every patient has access to personalised care interventions from diagnosis by 2021. These include Personalised Care and Support Planning based on Holistic Needs Assessments, Health and Wellbeing Information and Support, and End of Treatment Summaries (collectively formerly known as a 'recovery package').

The NHS is at the cutting edge of introducing these improvements to patient care. There has already been international interest[1] in our model, and we hope that this handbook will be helpful to all staff who are working to implement PSFU pathways in their Cancer Alliance areas.

We sincerely thank all those involved in personalised care and PSFU implementation whilst also managing current workload pressures. Our thanks also go to the multi-disciplinary consensus group who helped to develop this handbook.

Feedback is welcomed - please email england.cancerpolicy@nhs.net.

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NHS England and NHS Improvement

What it means for patients (in a nutshell)

Having a Personalised Stratified Follow Up (PSFU) pathway means patients know that when they complete primary treatment they will be offered:

- **Information about signs and symptoms to look out for** which could suggest their cancer has recurred or progressed
- **Rapid access back 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 and support for self-management**, to help them to improve their health and wellbeing in the long term.

Patients having the remote monitoring option within PSFU (see page 14), will not have to travel back to hospital simply to be given scan/test results that show no causes for concern.



How to use this handbook

Cancer Alliances, trusts, commissioners and all partners in cancer care delivery should use this handbook to help embed the principles of PSFU and personalised care within cancer care pathways. This is a vital part of the large-scale transformation required to meet Long Term Plan (LTP) ambitions.

This handbook complements existing resources, such as NICE cancer guidelines on follow up and surveillance and the 2013 'How To' guide on stratified follow up[2] (endorsed by charities and Royal Colleges), and should be read alongside that guidance.

The handbook can be read as one document or dipped into. **It is not an instruction manual but includes advisory notes (page 10 onwards) which are designed to provide an overall steer to local work on PSFU**, and to point staff in trusts, primary care and Cancer Alliances to ideas and useful resources.

Whilst the current focus (2020/21) is on PSFU in breast, colorectal and prostate cancer, this handbook is also relevant for teams who are working on PSFU in other cancers.

This handbook will be updated in late 2020 when a decision will be made regarding the other cancer pathways we will be prioritising for adoption of PSFU.

The case for change

It is a great success story that more and more people are living longer after a diagnosis of cancer. The number of people living with and beyond cancer in England is forecast to grow from 2.3m in 2018 to 3.3m in 2028. However, it also presents the NHS with a question: what is the best way to meet the growing needs of this population, many of whom are coping with cancer or its long term effects alongside the demands of aging and/or comorbidities[3]?

The redesign of cancer follow up pathways, so that they are stratified and personalised to individual needs, offers the opportunity to answer that question.

A USA-UK summit on PSFU[1] concluded that **current follow up care models (focused on detecting cancer recurrence) are inadequate, and that people report numerous unmet physical, functional, psychosocial and financial needs, leading to reduced work productivity, quality of life and survival.**

For some patients, follow up can be expensive, inconvenient and cause anxiety, whilst others are very satisfied. **Research suggests that different models of follow up are acceptable to patients,** if informed of the risks and benefits, given a choice and with a clear way to access further support[4].

The National Cancer Survivorship Initiative[2] found that 'one-size-fits-all' routine follow up of cancer patients takes up a good deal of service capacity, time and resources. While individual professionals try to meet the ongoing needs of patients, care has often been organised around the convenience of services, conducted in overstretched clinics, with some people experiencing long waits.

Macmillan Cancer Support estimated that **care and support for people with cancer beyond their initial treatment will cost the NHS at least £1.4 billion a year** by 2020, which is comparable to the cost of surgery, radiotherapy and other non-drug treatments (at least £1.5 billion a year). Hence a significant proportion of current NHS cancer costs relate to treating people in the phase after the main primary anti-cancer treatment has finished[5,6].

More tailored care in this phase, including care and support closer to home, has the potential to be at least cost neutral, through reducing recurrences, better managing the side effects of treatment and supporting people to live well[7] whilst also improving patient experience and other outcomes – see benefits on page 6.

By promoting a person-centred, personalised approach to cancer care and follow up, PSFU implementation will require cancer teams and their partners to review their practice and ensure that equality and health inequalities issues are identified and addressed.

The benefits of Personalised Stratified Follow Up (PSFU)

For patients:

Access to higher quality care that:

- is personalised and tailored to people's specific needs and conditions
- is based on what matters to people and their individual strengths, needs and preferences
- helps to detect and manage cancer-related psychosocial problems
- provides more support for those with complex needs
- helps people find services that meet their individual needs, and
- increases the proportion of people continuing to have surveillance tests (i.e. fewer 'lost to follow up').

Support for self management that:

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

Improves patient experience by:

- reducing travel to hospital (if on remote monitoring)
- reducing anxiety through more timely access to results.

For professionals:

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

For systems:

- improves productivity through the redeployment of professionals' time, outpatient capacity* and reduced duplication of surveillance tests
- supports greater integration of care
- supports better communication across different care settings
- reduces demand for unplanned care, and
- increases the transparency around costs of cancer follow up, allowing resources to be targeted at patients with complex needs.

*modelling suggests that for every 1,000 referrals per cancer type, PSFU could allow redeployment of outpatient slots over the subsequent five years in Breast: 2,850; Colorectal: 2,750, and Prostate: 1,900.
See endnote p.24

What are health systems required to do?

Cancer Alliances are working with their local providers across breast, colorectal and prostate cancer, to deliver the Long Term Plan[8,9] commitments to adopt PSFU:

- by 2019/20 for breast cancer
- by 2020/21 for prostate and colorectal cancers
- by 2023/24 for other cancers where clinically appropriate.

STPs/ICSs must ensure that commissioners and providers come together as part of their Cancer Alliance to plan for and deliver PSFU.

Systems should ensure that PSFU operational protocols are clinically agreed, safe and robust, and tackle equality and health inequalities. Protocols should take into account:

- the introduction of personalised care across the NHS, using the Comprehensive Model for Personalised Care[10]
- the particular personalised care interventions (formerly known as 'recovery package' interventions) which should be offered to all patients from cancer diagnosis onwards (see page 8).

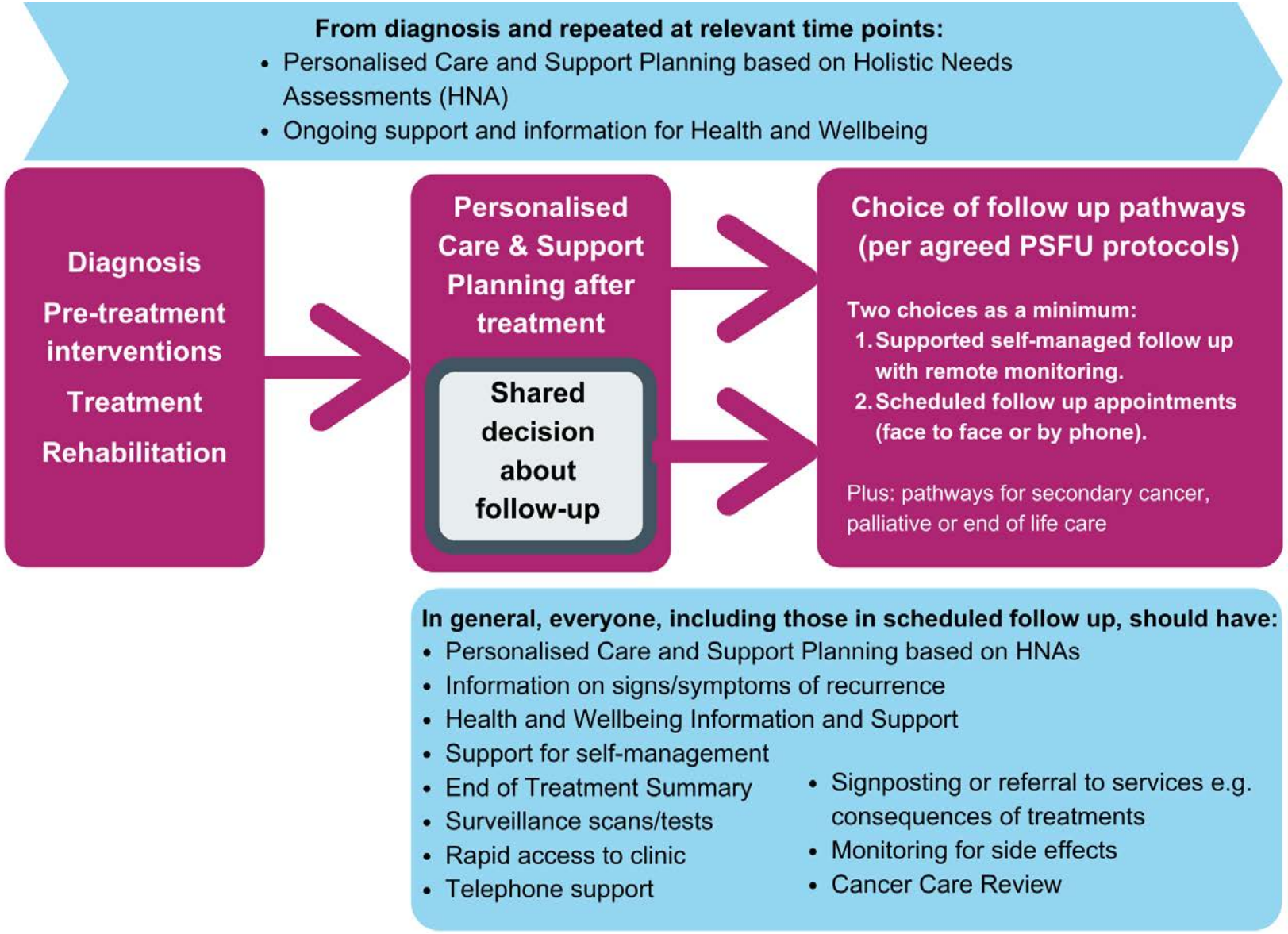
Several Cancer Alliances have agreed Alliance-wide PSFU protocols for each trust to adopt, while in other areas trusts have each created their own in agreement with their Cancer Alliance team. Responsibility remains with trusts' clinical governance arrangements to ensure that PSFU protocols are adopted safely, particularly with regards to remote monitoring. See Advisory notes on page 10 onwards.

Within the overall implementation approach for PSFU, it is recommended that teams:

- **Prioritise IT procurement/implementation** so that the patient management system (particularly remote monitoring) has the correct functionality to support PSFU.
- **Consider interdependencies across the pathway**, so that PSFU pathway implementation is integrated with other pathway changes such as rapid diagnosis pathways (to meet the Faster Diagnosis Standard) and cancer MDT working.
- **Use levers that help establish PSFU as 'business as usual'**, such as writing PSFU into local service specifications and contractual arrangements, agreeing how adherence to PSFU is monitored, and which organisation/parties/teams are responsible for the monitoring.

Case studies and examples of PSFU protocols can be found on the Cancer Alliances Workspace – for access please email england.cancerpolicy@nhs.net.

PSFU Protocol development: Outline pathway



Key Principles of a Personalised Stratified Follow Up Pathway

1. Ensure choice of follow up pathway is a shared decision between the person living with and beyond cancer and the clinician.

2. Offer Personalised Care and Support Planning (based on Holistic Needs Assessment (HNA)) at key points in the pathway.

3. Provide End of Treatment Summaries to people living with and beyond cancer and their GPs.

4. Guarantee timely access to appropriate professionals.

5. Ensure information, advice and support (from diagnosis) is tailored to individual needs, knowledge, skills and confidence, and supports wider health and wellbeing.

6. Enable surveillance tests and scans to be monitored remotely via digital systems.

7. Provide seamless, personalised, coordinated care through cross-organisational working.

8. Support people living with and beyond cancer, where able, to take responsibility for optimising future health and wellbeing.

9. Optimise workforce skillmix e.g. use support workers to help release Clinical Nurse Specialist (CNS) time for complex patients.

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU

Pages 10 to 22 contain advisory notes to support trusts and Cancer Alliances to continue their work to implement high quality, clinically agreed PSFU pathways for breast, prostate and colorectal cancers which follow the principles on page 9. Some of these advisory notes will be more relevant to local cancer teams and trusts than Cancer Alliances. All organisations should be aware that a decision regarding PSFU in other cancers will be made later in 2020.

Section A (page 10): **Advisory notes about how to explain PSFU to patients and carers**

Section B (pages 11 to 19): **Advisory notes about the content of PSFU protocols**

Section C (pages 20 to 22): **Advisory notes about enablers for PSFU.**

Advisory notes Section A

Box 1 **A1. How to explain PSFU to patients and carers:**

Trusts are using a variety of terms with patients (there is no standard terminology), such as:

- Open Access Follow Up
- Patient Triggered Follow Up
- Remote Follow Up
- (Supported) Self-Managed Follow Up.

It can be useful to reflect on the information patients and carers receive from diagnosis onwards about follow up. Feedback suggests that patient experience improves if they know (as appropriate) what to expect. For example:

- they understand early in their pathway (a) about personalised care and support planning and (b) whether they might be suitable for supported self-management follow up and what this means
- they are aware of what Health and Wellbeing Information and Support (HWBIS) they can access before, during and after treatment
- they understand that, regardless of what pathway, they can call the team at any time
- they can discuss how they feel about their follow up e.g. if not comfortable on self-managed pathway.

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

Advisory notes Section B - Development of PSFU protocols

B1. Content of PSFU protocols should be developed and agreed locally, taking account of:

- local procedures, contact details, referral forms etc.
- NICE guidance (see section B2 below)
- the Comprehensive Model of Personalised Care[10] and personalised care interventions (see section B5)
- the 2013 Stratified Follow Up How To guide[2] which provides further detail
- whether the Cancer Alliance wishes to agree a PSFU protocol for Alliance-wide adoption (but each trust remains responsible for clinical governance)
- equality and health inequalities issues (see menu of evidence-based interventions)
- example PSFU protocols and/or case studies, which are available in the LWBC section of the Cancer Alliances' Workspace.

B2. NICE guidance (see also section C5):

- **Breast Cancer** (*Early and locally advanced breast cancer: diagnosis and management NG101 July 2018*[11])
  - Guidance on follow up and surveillance ; providing information and psychological support ; complications of treatment and menopausal symptoms ; and lifestyle
  - Quality Statement on Key Worker.
- **Prostate Cancer** (*Prostate cancer: diagnosis and management NG131 May 2019*[12])
  - Guidance on localised and locally advanced prostate cancer on managing adverse effects of radical treatment (section 1.3.33 to 1.3.41) and follow up for people with localised or locally advanced prostate cancer having radical treatment or on watchful waiting (section 1.3.42 to 1.3.47).
    - Note section 1.3.46 states 'after at least 6 months' initial follow up, consider a remote follow up strategy for people with a stable PSA who have had no significant treatment complications, unless they are taking part in a clinical trial that needs formal clinic-based follow up'.
  - Quality Statement on managing adverse effects of treatment.
- **Colorectal Cancer** (*Colorectal cancer: NICE guideline NG151 January 2020*[13])
  - Guidance on information for people with colorectal cancer
  - Guidance on ongoing care and support.

B3. What is meant by the 'supported self-managed' pathway within PSFU?

PSFU pathways are evolving and adapting so it is not appropriate to provide a precise definition of the supported self-managed pathway option within PSFU, but some key elements are provided in Box 2 on page 13.

There are opportunities to **increase the knowledge, skills and confidence that ALL cancer patients have in managing their own health and care - also known as patient activation** (which is part of the NHS Comprehensive Model of Personalised Care[10]). This is regardless of whether they are on a supported self-managed pathway or are in scheduled clinic follow up.

Figure 1. Patient Leaflet (reproduced courtesy of University Hospital Southampton NHS Foundation Trust)

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

Box 2. Key elements of the supported self-managed pathways option within PSFU:

Relationship with the hospital team is clear and is maintained, so that:

- a person is not 'discharged' and can still access care from their hospital team
- Personalised Care and Support Planning, plus supportive conversations about follow up is always offered
- a person can call their cancer team with any concerns, and immediately be recalled to clinic depending on the situation
- the GP is informed of the self-managed pathway and the cancer team's contact details.

Support for monitoring of recurrence and ongoing self-management is provided, including:

- provision of information on potential markers of recurrence/secondary cancers and what to do if these are found
- checks to ensure that the information on these markers is understood by the patient
- provision of health literacy support, including self-management education programmes and health coaching
- provision of an End of Treatment Summary(ies) which is also copied to primary care and incorporated into hospital notes.

Surveillance scan/tests and communication of results (remote monitoring) is done so that:

- a person does not have scheduled appointments (whether face to face, by phone or digitally) which are for the purpose of reviewing the results of surveillance scans or tests
- 'all clear' results are communicated by letter, phone or digitally
- all results are communicated - do **not** inform people that if they do not hear from the hospital after a scan/test, then this means their result it clear
- a person is immediately recalled to clinic if there are any surveillance or other results of concern
- a person is kept under surveillance for the time period in line with NICE guidance (after/during which they may enter national cancer screening programmes as appropriate).

Access to other services is provided, so that (see section B8):

- a person has access, as needed, to the same range of rehabilitation and other services for managing the impact of cancer and its treatment as is available for people in clinic-based follow up.

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

B4. Remote monitoring and patient portals:

PSFU requires a digital solution for remote monitoring. The main cancer IT systems (Somerset Cancer Register and Infoflex) now offer this functionality. Be aware that digital remote monitoring functionality may require a wider software upgrade and/or other modules, which could delay remote monitoring being adopted.

Within PSFU protocols, clearly describe and communicate to staff:

- the processes for digital remote monitoring being used, and
- the responsibilities of all relevant staff and departments, in order to ensure the system for arranging and conducting scans/tests, checking results and communicating results is safe and robust.

A patient portal (shared online digital platform) which can be accessed by both professionals and patients is an effective way for people to access their test results and care record, and to seek online advice and guidance from their hospital team. This potentially saves time and resource in handling issues that may arise. In turn, this may improve patient experience.

Trusts should ensure that follow up pathways that incorporate digital systems that rely on patients having access to the internet, do not disadvantage those without access (see Digital Inclusion in Healthcare).




PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

B5. Personalised Care Interventions (formerly known as the recovery package):

The term 'Recovery Package' was devised in 2013 to support implementation of four core interventions that support people to live well after a cancer diagnosis.

The terminology is changing to 'personalised care' but the core interventions remain the same (see Table 1 overleaf). The change reflects the importance of offering the core interventions:

- to everyone from diagnosis (i.e. not only as part of recovery from treatment) and
- throughout the pathway (i.e. not just in a one-off package).

Personalised Care and Support Planning (PCSP) is crucial for identifying wider unmet needs, based on a person's individual strengths and needs and what matters most to them. The involvement of all cancer care team members should be considered in the PCSP process where appropriate. For example treatment radiographers or counsellors may input to a PCSP or be copied into the PCSP.

The core personalised care interventions for cancer (Table 1), together with information on the consequences of treatment, healthy lifestyle, physical activity, work and financial support, all aim to help identify and address changing needs throughout a person's cancer experience, from diagnosis onwards.

Regular local analysis of the frequency and severity of concerns identified in HNAs will help to identify common unmet needs.

Education and training on personalised care is offered by NHS England and NHS Improvement. Macmillan have produced a guide for professionals[14] on holistic needs assessments and care and support planning and are due to launch training in 2020.






PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

Table 1. Language change from 'recovery package' to 'Personalised Care'

From		To	Reason for change of language
Recovery Package Interventions	›	Personalised Care Interventions	'Recovery' implies person has completed treatment, whereas the interventions should be from diagnosis, regardless of prognosis. 'Package' implies a one-off delivery, whereas the interventions should be at several time points and on request. 'Personalised Care' is a key objective of the LTP.
Holistic Needs Assessment (HNA) Care and Support Plan	›	Personalised Care and Support Plan (PCSP) based on Holistic Needs Assessment (HNA)	HNA is not a separate activity, it is part of care planning. Personalised Care and Support Planning is an essential component of the Comprehensive Model of Personalised Care.
Treatment Summary	›	End of Treatment Summary	The document should focus on informing and advising the patient and GP going forward once (a phase of) treatment has ended, or at another appropriate time. It is necessary to use 'End of' to avoid confusion with other data items in the COSD v9 dataset.
Health and Wellbeing Event (HWBE)	›	Health and Wellbeing Information and Support	Move towards provision of a comprehensive 'offer' that gives people access to a wide range of choices for information and support. A HWBE is potentially one component of this wider offer of HWBIS.
Cancer Care Review	›	Cancer Care Review	No change at present

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

B6. Provision of patient and carer education and support for self-management:

This is for local decision on timing and content. A post-treatment appointment could be extended to enable a discussion about moving onto supported self-managed follow up. Patient Activation Measures could be used.

A self-assessment checklist for teams on provision of Health and Wellbeing Information and Support will be available from March 2020 via the Cancer Alliances Workspace (see page 24).

Information should be provided on topics such as managing consequences of cancer and its treatment, diet and physical activity, finance, return to work and recognising the signs and symptoms of recurrence/metastasis. Information should be in accessible formats (for example, graphics from abcdiagnosis.co.uk[15] on the signs of recurrence/metastasis of ductal or lobular breast cancer, or this guide on secondary cancer symptoms from Breast Cancer Care[16]). Always check that the information is understood.

Some trusts offer a group 'Health and Wellbeing' event or a short course, and many also signpost people to cancer charity courses and workshops such as Moving Forward (breast cancer), Live Your Life (lymphoma) and Living Well (by Penny Brohn), HOPE and Where Now (by Maggie's) for any cancer.

The Cancer Care Map and Macmillan's In Your Area are examples of online directories that aim to link people to sources of support for self-management and peer support. Social Prescribing Link Workers in primary care networks will be increasingly available. Macmillan have a guide for primary care on social prescribing.

B7. Criteria that indicate suitability for entering self-managed follow up may include:

- Person is able to self-manage and is prepared for a self-managed approach
- It is what is best for the person
- Non-complex case
- Does not have metastatic disease
- Low risk for disease recurrence
- Not in a clinical trial
- Has no impediment to reporting new problems.

Criteria vary by cancer type and overall it is a shared decision. Some people may make an informed choice not to enter supported self-managed follow up when it is being offered, although in practice this is rare. Changes in a person's health status may lead to a review of the PCSP. A review may be triggered by the person or any healthcare team member. People can also enter a self-managed pathway after a period of clinic follow up.

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

B8. Consequences of cancer and its treatment (CoTs) including late effects:

Pathways/referral routes for the monitoring, diagnosis, care, treatment and rehabilitation of consequences of cancer and its treatment (CoTs) should be clearly identified and made integral to all PSFU protocols (see Table 2).

All cancer patients should have access to Level 2 psychological care from diagnosis, often from a CNS.

Clinical guidance on CoTs is increasingly available (a selection can be found via Macmillan or via the RCGP.

Access to a range of services and support for self-management is necessary to ensure care is individualised to a person's needs. For people who have completed routine cancer surveillance a clear referral route back to these services is also needed, should CoTs emerge many years after treatment.

Identification of people who have unmet needs in relation to consequences of treatment can be improved by:

- Ensuring the End of Treatment Summary includes full information on potential long term/late effects and what to do if symptoms are experienced
- Using tools and techniques that encourage a conversation about any problems, e.g.
  - Ongoing Holistic Needs Assessments
  - 'Trigger' questions (key questions about symptoms that most impact on quality of life, such as bowel or bladder urgency after pelvic cancer treatment)
  - 'What Matters To You?' conversations as part of Personalised Care and Support Planning
  - Taking account of possible embarrassment to raise certain problems.
- Monitoring via Patient Reported Outcome tools, online Holistic Needs Assessments and/or patient symptom diaries. Patient portals can also support people's questions addressed to the cancer care team about symptoms or other concerns.

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

Table 2 Consequences of treatment (CoT) services that should be identified within PSFU pathways and protocols (see Notes below table)

Specialist services and clinical support services		Other signposted services
• Dietetics and nutrition • Physiotherapy • Occupational therapy • Stoma care • Lymphoedema • Pain Clinic • Cardio-oncology • Endocrinology • Dermatology • Gastroenterology • Urology	• Psychological care (Level 3 counselling and Level 4 psychological) • Care for sexual problems (male and female) • Menopause care • Fertility care • Fatigue care • Metastatic Spinal Cord Compression care • Supportive Care and Palliative Care	• Support groups and peer support programmes • Social care • Finance and benefits • Vocational rehabilitation • Physical activity • Stop smoking • Achieving healthy weight • Alcohol support

Note: This list relates mainly to breast, prostate and colorectal cancers and is not exhaustive. Additional services will be required for other CoTs for other cancers e.g. for swallowing/speech problems.

Note: Multi-disciplinary clinics/pathways for complex CoTs can be considered, e.g. developing links to

- the nationally-commissioned breast radiation injury and complex cancer late effects rehabilitation service at Royal United Hospitals Bath NHS Foundation Trust
- locally developed multi-disciplinary late effects services
- experts in managing CoTs such as gastrointestinal, urinary, sexual, endocrine, heart, bone and nerve symptoms due to Pelvic Radiation Disease, Lower Anterior Resection Syndrome or other CoT syndromes.

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

Advisory notes Section C - Enablers for PSFU

C1. Workforce and system roles and responsibilities:

- The MDT, administrative and IT staff, primary care and patient representatives should be involved in developing and agreeing the PSFU protocols and pathways.
- Patient involvement will also help to ensure that the language, tone and format of patient information about their follow up reflect the needs of all parts of the population.
- Secondary care teams will carry out all or most aspects of PSFU. Some local protocols may specifically agree roles within Primary Care (e.g. PSA testing) and/or in community settings (e.g. Health and Wellbeing Information and Support).
- Support workers are increasingly employed to help support PSFU pathways, often freeing up qualified professionals' capacity.
- The Primary care team's role is to ensure they are aware of (and involved in, as appropriate) their patients' follow up pathways. Joint working between primary and secondary care is important, so that there is good communication around each patient's treatment and care, for example with managing comorbidities. Primary care teams should note the content of the End of Treatment Summary in relation to their role in ongoing care, red flags etc. Primary care should continue to offer the Cancer Care Review (CCR) in line with Quality and Outcomes Framework (QoF) guidance. Macmillan provide an access guide on CCR, and a wide range of other resources to support primary care teams and their patients .

C2. Integration of PSFU with redesign of other parts of the patient pathway:

It makes sense to address all cancer pathway changes in an integrated way across secondary, primary and community care, so that changes to follow up and adoption of personalised care interventions are not implemented in isolation from other changes, such as:

- Faster diagnostic pathways
- Streamlining MDT meetings – consideration of personalised follow up care remains the same whether or not a patient is discussed at the full MDT meeting, in line with the NHS England and NHS Improvement guidance for Cancer Alliances.

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

C3. Data collection:

Cancer Alliances provide assurance reports about progress towards achieving NHS planning requirements on PSFU (see page 27). Part of this assurance includes local audit of adherence to PSFU protocols, starting with breast cancer in 2019/20 (see page 23).

Cancer Alliances are also required to estimate how many outpatient slots are being redeployed through the implementation of PSFU. A tool is provided on the Cancer Alliances Workspace (see page 24) to enable this estimate to be made.

At the time of writing, there is no national requirement to gather or submit patient-level data to the centre about what form of follow up pathway a patient is on. However, this may change.

C4. Funding, levers and incentives:

The NCSI 2013 'How To' Guide[2] provided advice on addressing financial issues. **The key is to engage with commissioners at the earliest opportunity to enable agreement on sustainable funding for patient-facing and surveillance activity within PSFU pathways**. For example, some Alliances are using Local Enhanced Service (LES) arrangements to support prostate cancer follow up in primary care. However, it is important to be aware that the NHS Long Term Plan is committed to reforming the NHS' payment systems and incentives.

One such reform is the introduction of a blended payment model. This is a framework that can be adapted to reflect local requirements. It can be particularly useful as a means of supporting new care initiatives where activity levels and costs can be difficult to forecast, and adjustments may need to be made accordingly. A 'blended payment' mechanism can be agreed to support services for different patient groups or services at the same time as other, perhaps more traditional, payment mechanisms remain in place.

The common element to all blended payment systems is an 'intelligent' fixed element. This part of the payment is based on forecasts of activity and the best available cost data. The fixed element is then combined with any one or more of three other elements: a variable rate, a risk-sharing element, and an outcomes-based or quality-based element. Each of these elements has a different role to play in ensuring that the quality of services are delivered in line with expectations, and that neither providers nor commissioners are adversely affected if activity levels are different from expectations.

PSFU protocol development: Advisory notes for breast, prostate and colorectal cancer PSFU (Continued)

C4. Funding, levers and incentives (continued):

Evidence from various studies shows that PSFU is cost-effective [2, 17, 18, 19, 20].

The NCSI report[2] concluded that for PSFU implementation, short term funding may be required to support pathway set up, but, in the long term, implementing PSFU should offer both quality and productivity benefits to the local health economy. A 'Quality, Innovation, Productivity and Prevention (QIPP) proven quality and productivity case study' report[21] in 2013 also concluded that financial benefits are achievable by allowing some outpatient capacity to become available for redeployment elsewhere in the cancer pathway.

Incentives may be agreed in the form of CQUIN payments etc.

Funding from Cancer Alliances (listed here) may be available to support project work, IT costs etc.

The Care Quality Commission (CQC) has been strengthening the cancer content in its end-to-end regulatory process and assessment frameworks. It will be rolling out its strengthened approach, including personalised care and PSFU, from January 2020.

C5. PSFU in other cancers:

The Long Term Plan sets the ambition for PSFU to be rolled out to other cancers as appropriate – a decision will be made later in 2020.

A number of trusts are already using PSFU in gynaecology, skin, haematology, head and neck, testicular and thyroid cancers. In addition, some other cancers have well-established practices in line with the principles for PSFU. For example, NICE guidance on oesophago-gastric cancers[22] (NG83) recommends a similar follow up approach for people who have no symptoms or evidence of residual disease after treatment for oesophago-gastric cancer with curative intent.

Cancer Alliances and trusts are encouraged to consider roll out in these and/or other cancers, and to share experiences and protocols via the Cancer Alliances Workspace (see page 24).

Additional information – Breast Cancer PSFU audit support tool

The Breast Cancer PSFU audit support tool (available on the Cancer Alliances Workspace, see page 24) forms part of the requirements for Cancer Alliances to report to NHS England and NHS Improvement regional teams on progress on cancer priorities, including the full implementation of PSFU in breast cancer in 2019/20. The tool is designed for team self-assessment in an MDT setting, to assess compliance with locally-agreed PSFU protocols as well as with national expectations described in this handbook.

The NHS Cancer Programme team have worked closely with Cancer Alliance colleagues in its development. The tool will support Alliances and trusts to understand their current position, celebrate good practice, identify key areas to further develop and establish good quality across the cancer pathway from delivery of personalised care interventions to implementation of PSFU pathways.

The NHS Cancer Programme team will not require results of audits to be provided to the national team, although discussion about key issues will be helpful at a Cancer Alliance level.

The tool has been designed so that there can be local determination of how the tool is used in a flexible manner incorporating any existing audit work.

The audit tool has four themes –

1. Personalisation of care and support
2. Implementation of PSFU protocols
3. Monitoring and evaluation
4. Patient experience and Quality of Life.

Each theme has several statements relating to a service. The MDT is asked to rate each statement to indicate their current position. They will be able to review their current position and identify areas where the MDT are performing well and areas to consider service improvement opportunities or changes to the protocol/systems/pathway.

It is recommended that the MDT:

- Allocates time away from clinical practice to complete the tool, or complete within a team meeting;
- Obtains feedback from service users, and
- Allocate time to discuss the audit results in detail, in order to create an action plan with all stakeholders.

Prostate, colorectal and other cancers

In addition, it is recommended that any cancer team that is using PSFU protocols should have a regular audit process in place, although only breast cancer forms part of Cancer Alliance monitoring in 2019/20. This audit tool will be revised in future to support implementation of PSFU in prostate, colorectal and other cancer PSFU pathways.

Resources

Cancer Alliance Workspace
Cancer Alliances and their NHS partners should access the Cancer Alliance Workspace on the FutureNHS online platform for national guidance, resources, and to share learning, such as:

- Example PSFU protocols
- Case studies of PSFU implementation
- PSFU patient leaflets.

To register for access, or to submit documents to share, contact england.cancerpolicy@nhs.net.

Further resources

NICE **Cancer guidance** covers certain cancers (see page 11), as well as generic cancer guidance such as: Supportive and Palliative Care; Neutropenic Sepsis and Metastatic spinal cord compression

NHS England and NHS Improvement **Personalised Care Guidelines** can support teams to ensure people have choice and control over the way their care is planned and delivered.

NHS England and NHS Improvement **Change Model** is a framework for achieving transformational, sustainable change.

The NHS **Improvement Hub** provides resources that can support service improvement including guidance, modelling tools, and webinars.

NHS England and NHS Improvement provide a menu of evidence-based interventions and **approaches for addressing and reducing health inequalities**

Endnote re Outpatient appointment slot modelling (see page 6)

For every 1,000 referrals for any of the different cancers (Breast, Colorectal and Prostate) and for a trust following typical PSFU protocols for these same cancers, modelling suggests that PSFU may enable redeployment of outpatient slots* over the subsequent five follow-up years of up to: Breast 2,850; Colorectal 2,750, and Prostate 1,900.

The modelling used estimates on the portion of patients being placed in self-management and on the redeployment of Outpatient Appointments from PSFU that were based on published pilot site and local implementation studies and were judged realistic. The modelling used the most recently published one-and five-year survival estimates at the time of the model's publication. Actual survival for each of the cancer cohorts may differ from the figures used in the model since these were computed for a historical cohort of patients and independent of PSFU pathway. Modelling tool available here.

**version 1.0 used, July 2019 release*

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Appendix. NHS Policy documents – excerpts on personalised care in cancer and in general

Personalised Care in Cancer:

NHS England Long Term Plan (January 2019)[8]:
"*3.65. After treatment, patients 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. This stratified follow-up approach will be established in all trusts for breast cancer in 2019, for prostate and colorectal cancers in 2020 and for other cancers where clinically appropriate by 2023.*" (see also para 3.64)

The Long Term Plan Implementation Framework (June 2019)[9]:
"2.27 *Local systems should engage with their Cancer Alliances to set out practically how they will deliver the Long Term Plan commitments for cancer over the next five years including on early diagnosis and survival, while improving operational performance through interventions by […] roll-out of personalised care interventions, including stratified follow-up pathways, to improve quality of life.*"

Additional guidance from the NHS Cancer Programme for LTP planning (September 2019): "*By 2020 all breast cancer patients will move to a personalised (stratified) follow up pathway once their treatment ends, and all prostate and colorectal cancer patients by 2021. […] All Alliances to implement personalised (stratified) follow up for other cancers as identified [by the national programme] by 2023/24.*"

The NHS Operational Planning and Contracting Guidance 2020/21[23] states the requirement for:
"*implementation of personalised stratified follow up pathways for colorectal and prostate cancer by April 2021 and ensure that at least two thirds of breast cancer patients benefit from stratified follow up.*"

Personalised Care in general:

The NHS Comprehensive Model for Personalised Care[10] gives people the same choice and control over their mental and physical health that they have come to expect in every other aspect of their life. A one-size-fits-all health and care system simply cannot meet the increasing complexity of people's needs and expectations. Personalised care is based on 'what matters' to people and their individual strengths and needs.

The Long Term Plan Implementation Framework[9]:
"2.22 Systems will be expected to set out how they will use the funding available to them to implement the six components of the NHS Comprehensive Model for Personalised Care as set out in Universal Personalised Care[24]."

Personalised Stratified Follow Up (PSFU) in cancer is completely in line with the Comprehensive Model for Personalised Care. Key components of the model that are incorporated into PSFU are:

- Patient choice, including legal rights to choice
- Shared decision making
  [note that 2020/21 CQUIN guidance covers a CQUIN for shared decision making that includes some cancers]
- Social prescribing and community-based support
- Supported self-management, including patient activation
- Personalised care and support planning.