

Personalised Stratified Follow Up (PSFU) Pathways in Cancer

Qualitative Evaluation Study

October 2020





“The roll out of PSFU should be viewed as an incredible achievement for cancer teams, IT teams, diagnostic services, primary care, Trusts and Cancer Alliances. It is not the same as speeding up an existing well-understood pathway (e.g. diagnostic pathway) or digitisation of existing processes, but a new way of working. It requires staff to change behaviour to deliver truly personalised care.

They [staff] ask “what matters to you?”, then listen and act upon the answers; understanding that patients can self-manage when supported appropriately. PSFU requires staff to deal with more complex outpatient clinics that rarely include seeing the stories of patients who are self-managing and living well, free from cancer. Everyone involved in these transformational changes should be hugely applauded.”

Dr Lesley Smith

Living With and Beyond Cancer Senior Programme Manager, NHS Cancer Programme

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- Dr Lesley Smith, Living With and Beyond Cancer Senior Programme Manager, NHS England and NHS Improvement for her contribution to the evaluation.



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1. Executive Summary

The NHS Cancer Programme is committed to achieving all the ambitions set out in the NHS Long Term Plan including:

“By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.”

“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.”

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

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.

The NHS Cancer Programme commissioned this co-created qualitative evaluation study. It aims to capture the learning of Personalised Stratified Follow Up (PSFU) implementation across England up until early 2020, and outline what is required for PSFU to become business as usual for people affected by cancer.

Evidence from this evaluation will inform policy development in 2020/21 and beyond. PSFU and personalised care in cancer are fully integrated with key NHS Phase 3 COVID19 response requirements on outpatient reform as well as delivery of personalised care for other conditions across the NHS, including:

- Patient Initiated Follow-Up (PIFU) pathways (essentially the ‘supported self-managed pathway’ within PSFU)
- Personalised care and support planning
- Support for self-management and wellbeing.

The evidence from PSFU in cancer is directly supporting roll out of PIFU into non-cancer specialties, which will contribute to achievement of the LTP target to reduce NHS outpatient attendances by 30 million by 2023. [The guidance](#) for implementing phase 3 of the NHS response to the COVID19 pandemic highlights the benefits of PIFU and provides practical information about how to implement in secondary care.

Interviews and questionnaires with the Cancer Alliances, the NHS Cancer Programme and Macmillan Cancer Support, in early 2020 contributed to the report. Due to the COVID19 pandemic, it was initially not possible to gain the NHS Regional Cancer Teams perspective. Given their pivotal role in supporting PSFU implementation, interviews occurred after the main evaluation study was completed, and findings are included in Appendix 1.

This evaluation found that the key factors influencing PSFU implementation include:

Whole Pathway approach: Where PSFU is viewed as integral to the whole cancer pathway, greater priority is given to implementing PSFU and benefits are seen within systems. An example of this is providing increased capacity to support the achievement of Cancer Waiting Time standards.

Digital: All Cancer Alliances reported digital challenges, which have delayed the delivery of digital Remote Monitoring (patient-tracking) Systems (RMS). Funding, interoperability and procurement for remote monitoring, present significant barriers to implementation. Cancer Alliances adopting an Alliance-wide approach, working with digital suppliers and digital leads in Trusts and STP/ICS (where available) have made the most progress. Patient portals appear to increase the benefit of PSFU pathways, with 24-hour access to information and support allowing patients to make real-time informed health and lifestyle decisions.



Workforce: Effective PSFU requires a properly resourced and appropriately skilled workforce. Implementation of PSFU has resulted in workforce development across cancer clinical and programme management teams. The cancer support worker (or similar) role has been a positive addition for patients and the wider workforce, delivering personalised care interventions and supporting PSFU. This has freed up specialist clinical staff to focus on delivering complex clinical interventions. However, many of these new roles are not substantively funded, posing a significant risk to achieving sustainable service changes.

Health Inequalities: In line with the recent Marmot report on health equity in England, it is essential that health inequalities are reduced through implementation of PSFU. The evaluation study highlighted the opportunities to consider in depth the health inequality challenges around health literacy, digital accessibility and service accessibility in relation to personalised care, PSFU and managing the impact of cancer.

Moving to Business as Usual (BAU): Cancer Alliances are transitioning from transformation projects to sustainably commissioned services for breast, colorectal and prostate PSFU. Most either have, or are close to having, agreed protocols in place for these cancer sites. Having a model approach to commissioning and contracting arrangements will support PSFU becoming BAU for all cancer sites in the long term.

Impact of COVID19: The current COVID19 pandemic has resulted in a different approach to the delivery of all cancer care. Virtual consultations are increasing, which is a potential enabler for implementation of PSFU. Accelerating remote monitoring systems will provide a safety net to safeguard patients. COVID19 also offers the opportunity to increase the number of patients using supported self-managed pathways, to release capacity and achieve effective self-management.

Recommendations

The report contains the following recommendations for NHS national, regional and local teams. The recommendations are listed in the order they appear in the report.

Recommendation 1 (Digital):

NHSX, who work to deliver the Department of Health's technology vision, and the NHS Cancer Programme to support the acceleration of sustainable implementation of digital RMS. They should use their collective influence to ensure that the digital requirements for PSFU are considered in national strategic approaches.

To support acceleration of digital RMS, NHSX and NHS Cancer Programme have started to develop a digital RMS technical guide. This guide will include:

- Outline of requirements for digital RMS and patient portals including interoperability with Trust PAS systems, rather than only focusing on cancer systems
- The production of common standards that can be used in procurement and contract reviews, to reduce variation and drive up quality
- An improved relationship with suppliers, and proactive action taken to develop the market for digital RMS systems. This will increase the choice of solutions offered and improve implementation timescales. Cancer Alliances should work with Trusts and IT suppliers to ensure those closest to achieving PSFU are prioritised for upgrades.

Recommendation 2 (Digital):

Cancer Alliances and Regions to take ownership, and accelerate implementation of digital RMS where possible. They should pro-actively identify local solutions to increase uptake and accelerate implementation. This should include being actively involved with and influencing wider regional and STP/ICS strategic digital decision-making processes.

Recommendation 3 (Digital):

Cancer Alliances to consider having digital patient portals where possible in all PSFU pathways. This would enhance effective patient care and communication, especially considering changes to patient pathways due to COVID19.

**Recommendation 4 (Workforce):**

To achieve the benefits of PSFU, Cancer Alliances and Trusts should implement an effective skill mix of Clinical Nurse Specialist (CNS) and Cancer Support Worker (CSW) roles within PSFU pathways. The NHS Cancer Programme should go further in identifying and promoting best practice in deploying CSWs at the national level.

Recommendation 5 (Governance):

Cancer Alliances, in their position as system leaders should raise the priority of PSFU and digital RMS by working on the PSFU initiatives closely with the STP/ICSs. They should ensure progress is tracked and monitored effectively across Cancer Alliance geographies.

Cancer Alliance SROs, who lead on LWBC initiatives, should be identified within all cancer governance structures to raise the priority of PSFU and personalised care interventions.

NHS Regional Cancer Teams to work towards increasing engagement with Regional Executive teams to reinforce and share the progress of PSFU.

Recommendation 6 (Leadership):

Cancer Alliances to identify Trust Lead Cancer Nurse (or equivalent roles) and Clinical Commissioning Group Clinical Leaders for all member organisations. They should develop and support an active peer network that champions PSFU within clinical teams, and influences decision-makers in STP/ICSs and Trusts to aid spread and implementation of PSFU pathways.

Recommendation 7 (Health Inequalities):

Cancer Alliances should review the current PSFU cancer pathway to ensure it helps tackle health inequalities. There needs to be understanding of where there may be unwarranted variation in access, experience and outcomes, and steps should be taken to improve this for all patients.

Recommendation 8 (PSFU Roll Out):

Cancer Alliances to scope and prioritise roll out of PSFU to other cancer types. This should be shared with the NHS Cancer Programme.

Recommendation 9 (Commissioning):

NHS Cancer Programme to work closely with the Payment Policy team to explore a payment policy approach that supports sustainable commissioning of PSFU. They should work together with Cancer Alliances, STP/ICSs, and Trusts.

Recommendation 10 (COVID19):

NHS Cancer Programme and Cancer Alliances to review the emerging learning and opportunities created by the impact of COVID19 on cancer pathways. They should proactively act upon this by adapting local PSFU pathways.

The NHS Cancer Programme will respond to the recommendations in this report.



2. Introduction

National Context

The NHS Cancer Programme is responsible for delivering the NHS Long Term Plan¹ (LTP) ambitions for cancer. Personalised Stratified Follow Up (PSFU) pathways are at the core of the Personalised Care ambitions.

“By 2023, stratified follow-up pathways for people who are worried that their cancer may have recurred will be in place for all clinically appropriate cancers. This will be achieved by having national adoption of PSFU pathways as follows:

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

The NHS Cancer Programme consists of the NHS England and NHS Improvement national team, Regional Cancer teams, Cancer Alliances and their constituent organisations. National and regional teams work closely together to support 21 Cancer Alliances in delivery of the NHS LTP goals for Personalised Care. Cancer Alliances work closely with their Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs).

The work on PSFU should be seen in the context of the LTP target to reduce overall NHS outpatient attendances by 30 million by 2023, through the introduction of Patient-Initiated Follow Up (PIFU) across a wide variety of specialties, including oncology. PIFU is what is known as supported self-managed follow up within PSFU. Following the COVID19 pandemic, ‘Implementing phase 3 of the NHS response’² (August 2020), highlights the benefits of PIFU, and provides practical information about how to implement in secondary care.

Personalised Care and Personalised Stratified Follow Up Pathways

The NHS LTP states that everyone in the NHS involved with cancer care is working to ensure that:

“People will get more control over their own health and more personalised care when they need it... the NHS also needs a more fundamental shift in how we work alongside patients and individuals to deliver more person-centred care.”

Delivery of improvements for people living with and beyond cancer consists of three inter-dependent priority areas³:

PRIORITY

1

Providing personalised care interventions by ensuring clinicians and patients actively use:

- Personalised Care and Support Planning
- End of Treatment Summaries
- Health and Wellbeing Information and Support
- Cancer Care Reviews.

PRIORITY

2

Providing Personalised Stratified Follow Up (PSFU) care via the two pathways:

- Clinician led follow-up – this is for complex patients and those at higher risk of recurrence. It can take the form of scheduled face-to-face or virtual appointments
- Supported self-managed pathway with digital remote monitoring – for less complex patients. This pathway ensures that patients will not have to travel back to hospital simply to be given scan/test results that show no cause for concern.

PRIORITY

3

Measuring people's quality of life by understanding the impact of cancer and how well people are living after their diagnosis.

In March 2020, the NHS Cancer Programme issued "Implementing Personalised Stratified Follow Up Pathways – A handbook for local health and care systems"⁴.

This handbook describes PSFU as:

"An effective way of adapting care to the needs of patients after cancer treatment, to ensure that we are providing world class services."

Patients who complete their primary treatment and experience PSFU pathways will be offered:

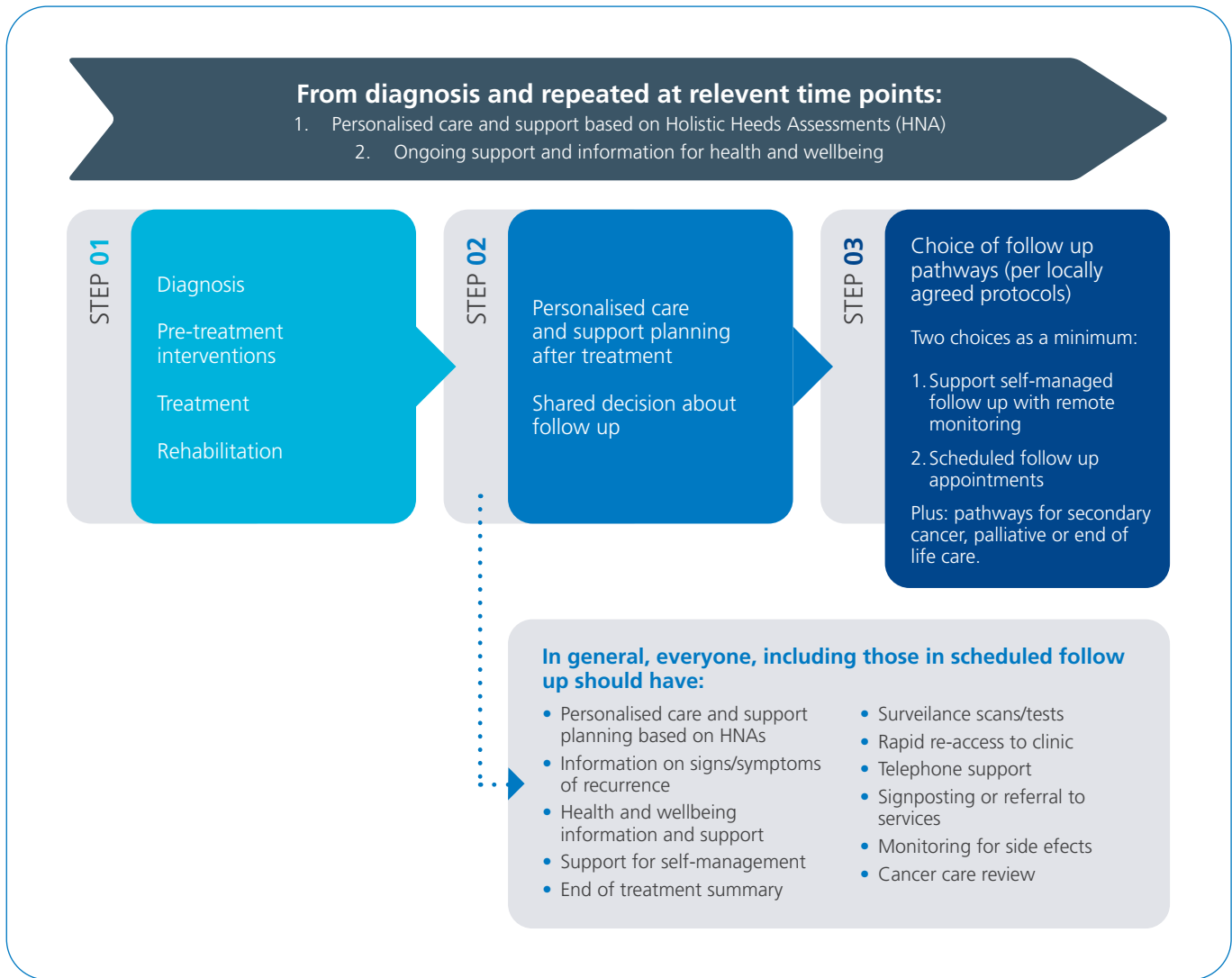
- Information about signs and symptoms, which could suggest their cancer has recurred or progressed, or which may be side effects of treatment
- Rapid access back to their cancer team, including telephone advice and support if they are worried about any symptoms
- Regular surveillance scans or tests (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.

The figure on the next page outlines a PSFU pathway. It illustrates how personalised care interventions (shown in blue sections) integrate into PSFU. Regardless of which follow-up pathway a patient is on, PSFU requires delivery of those interventions.



Figure 1: PSFU Pathway Outline.




Taken from [NHSE Implementing PSFU Pathways - A handbook for local health and care systems](#)



The implementation of PSFU pathways offers benefits for patients, professionals and the wider system. This is summarised in Table 1 below:

Table 1: Benefits of PSFU.

Summarised from [NHSE Implementing PSFU Pathways - A handbook for local health and care systems](#)

| | |
|---|---|
| <p>For Patients</p>  | <ul style="list-style-type: none"> • Access to higher quality care • Support for self-management • Improved patient experience |
| <p>For Professionals</p>  | <ul style="list-style-type: none"> • 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 |
| <p>For Systems</p>  | <ul style="list-style-type: none"> • Improved productivity through the redeployment of professionals' time, outpatient capacity, including room availability, and reduced duplication of surveillance tests • Increased transparency around costs of cancer follow-up, allowing resources to be targeted at patients with complex needs |

Changing landscape

The NHS LTP was released in January 2019. It was a catalyst for reconfigurations across the NHS. Many of these changes were formalised throughout 2019 and 2020. They included:

- Integration of NHS England and NHS Improvement, and changes to regional boundaries
- Merging of some Clinical Commissioning Groups to reflect STP footprints
- Merging and/or sharing of executive boards for some primary and secondary care Trusts to reflect emerging ICS designs
- Redesign of some Cancer Alliance boundaries, changing the total from 19 to 21 (during the period the evaluation was undertaken)
- The formation of 1264 Primary Care Networks (PCNs)⁵ (correct as of 10.07.2020), and the delivery of PCN service specifications and the Network Directed Enhanced Services (DES)
- Changing approaches to digital planning across systems.

These changes have created shifts in staff roles across systems. New teams are repeating completed processes and re-visiting previously agreed actions. This increases the risk of losing local corporate memory regarding delivery of the NHS Cancer Programme, including PSFU. The effects of this changing landscape have been explored as part of the theme chapters within this report.

Evaluation Aims

This qualitative co-created evaluation was commissioned in early 2020, for NHS South, Central and West Commissioning Support Unit (SCW), to capture lessons from PSFU pathway implementation across England. The aim of this evaluation was to understand what has been achieved, and what is still required to deliver the NHS LTP ambitions. The evaluation does not analyse the clinical elements required for transition onto supported self-managed pathways, as this varies considerably across different tumour sites and at individual patient level.

Evidence generated from this evaluation will inform ongoing implementation and policy development for 2020/21 and beyond, in the following ways:

- Understand the barriers and enablers in implementing PSFU and share this learning with others, to increase the pace of PSFU implementation across England
- Support the shift of PSFU from transformation into business as usual activity for all clinically appropriate cancers, in all Trusts in England
- Consider what learning from PSFU can be used to aid developing the national and local approach to recovery from the COVID19 pandemic
- Develop evidence for replication of supported self-managed follow-up to non-cancer specialties, such as PIFU.

How was the process evaluation undertaken?

The design of the process evaluation was based on the following principles:

- Co-creation
- Agile learning
- Reflective practice
- Refinement.

As part of fieldwork, the evaluation team connected Cancer Alliances who had specific challenges with others who had overcome them. This process provided an environment where participants influenced the lines of enquiry of the evaluation and benefited from learning in real time.

The evaluation focus was on PSFU implementation across all cancer sites, recognising the changing landscape of the NHS, as described above. A range of data collection activity collectively referred to as "fieldwork", was undertaken as summarised in the table on the next page.

Table 2: Evaluation Fieldwork Summary

| Data Collection Method | Who was involved | Purpose |
|--|--|---|
| An online survey | Surveys were distributed by the Cancer Alliance Living with and beyond Cancer (LWBC) Leads to their local stakeholders | Provide clearer understanding of local PSFU stakeholders within a Cancer Alliance |
| Pre-interview questionnaire | Cancer Alliance LWBC Lead prior to interview | Provide focus to help shape the semi-structured interview |
| Hour long semi-structured interviews | Cancer Alliance representatives who understood local PSFU pathway implementation | Understand the journey that the Cancer Alliance had experienced in implementing PSFU |
| | Macmillan Cancer Support national representative | Gain a national charity perspective on the delivery of PSFU to date |
| Questionnaire | NHS Cancer Programme's LWBC Senior Programme Manager | Gain a national NHS perspective on the delivery of PSFU to date |
| Sustainability Matrix self-assessment based on the NHSE Improvement Quality, Service Improvement and Redesign Framework ⁶ | Cancer Alliance LWBC Lead prior to interview | Understand how different elements of service improvement methodology were used to deliver sustainable change to PSFU pathways across Cancer Alliances |
| Examples of reports, protocols and other assets produced by Cancer Alliances in the support of implementation of PSFU pathways | Single point of contact within each Cancer Alliance prior to and after interview | Informed the semi-structured interviews. Provided additional evidence to inform the enablers required for PSFU. |

Based on this fieldwork, the analysis of all data collected was completed and assimilated into the following key themes:

- Enablers: Digital, Workforce, Leadership, Engagement and Governance
- Roll Out to other Cancer Sites and Primary Care
- Moving to Business as Usual
- COVID19: Impact and Opportunities

Each theme is discussed as a separate chapter within this report.

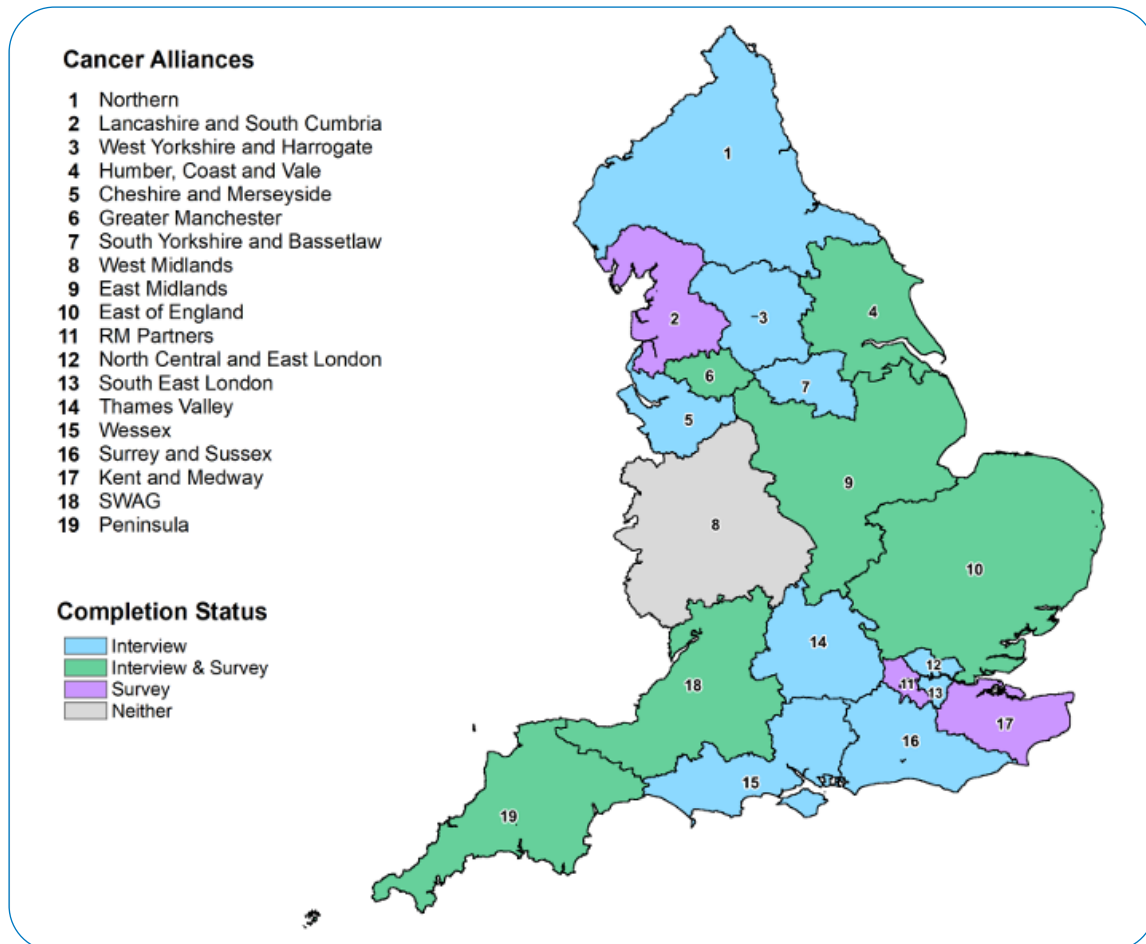
Who is represented in this evaluation?

Representative coverage across all Cancer Alliances in England was sought. This evaluation was initiated in February 2020. In early March 2020, the World Health Organisation declared COVID19 as a pandemic, and England formally moved into the containment phase of the national management plan. This had several impacts for the evaluation of PSFU including:

- Stakeholders (Cancer Alliances and NHS Regional Cancer Leads) having to limit or cancel participation in the fieldwork
- Delay in receiving examples of good practice documents from Cancer Alliances
- Delay to the original timeframes of delivery of the evaluation report.

Participation is shown in Figure 2

Figure 2: Map of Cancer Alliance participation with evaluation



Below is a summary of the uptake to the evaluation:

- 15 out of a possible 19 virtual interviews were carried out with Cancer Alliance LWBC Leads
- 2 Cancer Alliances were unable to participate in an interview due to the timing of the COVID19 pandemic
- 18 completed online surveys were returned.

The analysis and recommendations of this report are based on a representative sample of Cancer Alliances. It is recognised there is potential that some specific nuances of under-represented Cancer Alliances may have been missed. Input from the NHS Regional Cancer teams was captured through interviews carried out after the main evaluation report was completed, and the findings are shown in [Appendix 1](#).



3. Enablers: Digital, Workforce, Leadership, Engagement and Governance

The NHS Cancer Programme, in their report about digital Remote Monitoring Systems (RMS) for breast cancer⁷ define full implementation of PSFU pathways as Trusts having developed and implemented:

- Clinically agreed PSFU protocols
- A digital system that allows safe remote monitoring of patients.

In order to achieve this, a number of enablers were identified. Each will be discussed as a sub-theme within the chapter, and recommendations will be provided at the end of the chapter.

3.1 Digital

"We now have close to 6,000 patients on this pathway, across the three tumours groups, and none have been lost to follow-up. Previously they were just on spreadsheets or stored in a filing cabinet."

Cheshire and Merseyside Cancer Alliance

The digital remote monitoring system (RMS) can be stand-alone software designed for remote monitoring purposes, or an RMS module integrated into the Trust's main cancer system, or Patient Administration System (PAS). It is not acceptable to rely on non-digital methods such as spreadsheets for the monitoring of self-managed patients, because of patient safety and data management concerns.

Digital RMS gives a range of benefits:

- Increased safety-netting of patients
- Efficient administration for the cancer team who check and communicate results
- Greater clinical confidence to use the full range of PSFU pathways available
- Builds evidence to aid with roll out of PSFU and specifically supported self-managed pathways to other cancer and non-cancer sites.

Digital issues were raised at almost every interview, demonstrating that this is exceptionally challenging. The NHS Cancer Programme digital RMS for breast cancer report highlighted key reasons for delays in RMS implementation. These included:

- Complexity of transformation work due to multiple aspects to achieve successful PSFU
- Financial implications due to increased cost of digital RMS and project management relative to expectations
- Competing priorities of key stakeholders, e.g. Trust IT Leads, STP Digital Leads and Trust clinical teams
- Technical delivery, such as software and hardware issues
- Lack of digital workforce expertise to achieve implementation and business as usual
- Reduced performance management of personalised care deliverables, which include PSFU due to prioritisation of alternative cancer programme requirements.

Unsurprisingly the findings from this evaluation mirrored and corroborated the findings from the national report.

Learning/ Best Practice

Digital RMS Integration

Trusts with digital RMS integrated with their Patient Administration System (PAS) have experienced enhanced interoperability, improved holistic patient care and the opportunity to use RMS beyond cancer care. This



allows for greater opportunities for economies of scale, which strengthens the argument for inclusion of these criteria in business cases. My Medical Record offered good interoperability with PAS, and some RMS modules are part of common cancer systems, such as Somerset and Infoflex. Some trusts are developing internal digital systems to achieve greater interoperability.

Patient Portal

Digital RMS supports the clinical management of patients on supported self-managed pathways. Trusts who used an RMS interfaced with a patient portal found it enhanced the benefits of PSFU. Patients found having an interactive patient portal useful, as they could access their results and the outputs of personalised care interventions i.e. Personalised Care and Support plans and End of Treatment Summaries. They were able to communicate with the cancer team virtually and had more control of the process. This meant they were less likely to use formal appointments.

Portals have additional relevant easy to read patient information, providing trusted and local sources to help them self-manage their post-treatment care. A range of patient portals are being used by Cancer Alliances. Most common was My Medical Record. In line with the 2015 Cancer Taskforce⁸ digital communication recommendations, patient portals should be included where available, as part of PSFU implementation. Patient portals have positive benefits to patient care and support patients to self-manage their health and wellbeing.

Challenges

Digital Strategy

- All Cancer Alliances reported challenges in having differing digital strategies from the member STP/ICs and Trusts, and this directly affected the pace of progress of digital roll out
- The lack of co-ordination between the digital requirements for cancer programmes and wider initiatives has inhibited the development of digital solutions for PSFU
- Where a small number of Trusts were merging or undergoing major IT restructuring, they were not able to support and prioritise the implementation of RMS
- A lack of access to Information Management and Technology, digital transformation and business intelligence expertise has hindered PSFU programme delivery. Support from digital transformation teams helps to anticipate and overcome digital issues and enable strategic approaches. Business intelligence expertise is required to support data collection and analysis, to inform pathway design and monitor impacts of implementation.

Digital Procurement

- Procurement of systems has been undertaken locally, with varying arrangements put in place across different Trusts. This local delivery approach has reduced the opportunity to share knowledge of procurement and deployment strategies for RMS
- IT suppliers have set the timescales for new releases and prioritisation of developments, which affected the pace of roll out
- It has been difficult for new suppliers to break into the market, as they have to engage with so many purchasing organisations. There are mixed purchasing models in existence in different Cancer Alliances and STP/ICs so local context needs to be considered when addressing this challenge
- Balancing the opportunities of work to influence suppliers and undertake localised procurements by STP/ICs, continues to be a challenge for Cancer Alliances to navigate. This can affect quality and delay implementation.

Digital Suppliers

- Some Alliances reported that some of the digital suppliers have been unable to fulfil the Trust demand for RMS, resulting in a waiting list to receive the RMS modules. This was correct at the time of the evaluation interviews (Feb/ March 2020)
- Costs to implement digital RMS have been higher than expected following quotes from suppliers. These include additional costs related to IT integration, data migration and the requirement to purchase RMS across breast, colorectal and prostate
- There are limited suppliers of digital RMS. Infoflex and Somerset Cancer Register continue to be the main suppliers currently. RMS is only available in the latest versions of these systems. Trusts within a Cancer Alliance often have different versions of the same system, due to differing contractual arrangements



- It is understood that some of the IT suppliers had delayed the release of their RMS module, meaning that Trusts were unable to access the module and implement RMS prior to 2020, even if contractual arrangements were in place.

Patient Portal Issues

Although patient facing portals bring a range of benefits, there are challenges reported with their implementation:

- The maturity of the systems means that there are limitations in inter-operability between RMS components, patient portals, cancer systems and Trust PAS systems
- Staff need to change ways of working, processes, job plans and have training in place to be able to manage patients remotely using technology. This applies to cancer teams and the wider workforce across primary, secondary and community care
- Getting the Information Governance requirements in place to share data across organisations and with patients, is time-consuming and requires specific expertise that is in demand and not always readily available when required.

In summary, the key digital challenges relate to interoperability of cancer systems, procurement and RMS suppliers. Digital requirements for PSFU have not been included in wider digital strategies. The three recommendations below aim to address these challenges.

| Recommendation 1 | |
|---|---|
| Timescale: To begin immediately | <p>NHSX, who work to deliver the Department of Health’s technology vision, and the NHS Cancer Programme to support the acceleration of sustainable implementation of digital RMS. They should use their collective influence to ensure that the digital requirements for PSFU are considered in national strategic approaches.</p> <p>To support acceleration of digital RMS, NHSX and NHS Cancer Programme have started to develop a digital RMS technical guide. This guide will include:</p> <ul style="list-style-type: none"> • Outline of requirements for digital RMS and patient portals including interoperability with Trust PAS systems, rather than only focusing on cancer systems • The production of common standards that can be used in procurement and contract reviews, to reduce variation and drive up quality • An improved relationship with suppliers, and proactive action taken to develop the market for digital RMS systems. This will increase the choice of solutions offered and improve implementation timescales. Cancer Alliances should work with Trusts and IT suppliers to ensure those closest to achieving PSFU are prioritised for upgrades. |

| Recommendation 2 | |
|--------------------------------------|--|
| Timescale: Within 6 months | <p>Cancer Alliances and Regions to take ownership, and accelerate implementation of digital RMS where possible. They should pro-actively identify local solutions to increase uptake and accelerate implementation. This should include being actively involved with and influencing wider regional and STP/ICS strategic digital decision-making processes.</p> |

| Recommendation 3 | |
|---------------------------------------|---|
| Timescale: Within 12 months | <p>Cancer Alliances to consider having digital patient portals where possible in all PSFU pathways. This would enhance effective patient care and communication, especially considering changes to patient pathways due to COVID19.</p> |



Interdependency between Digital and Workforce

For PSFU and digital RMS to be effective there needs to be:

- Workforce who can deliver personalised care interventions to enable PSFU
- Administrative support to record and track patients on the digital RMS
- A sustainable funding model for the digital RMS product(s) and the workforce.

Each of these elements interrelate, and without all of them, patients, clinicians and systems will not fully realise the benefits of having implemented PSFU pathways.

3.2 Workforce

Cancer care is changing rapidly, with new diagnostic approaches and ever improving treatment options and regimes. This combined with an older population has resulted in significant changes to the complexities of cancer patients. As such, the cancer workforce is having to adopt and adapt clinical and management practices to respond to the changing context. To respond to this, cancer workforce planning across multiple clinical settings is being led by the NHS Cancer Programme, Health Education England and other partners. Recognising this, the report focuses only on the workforce enablers required to deliver LWBC, PSFU and the components of personalised care.

Learning/ Best Practice

Cancer Support Workers

Delivery of PSFU pathways and the wider LWBC work programme has been significantly improved by the introduction of Cancer Support Workers (CSW) or similar roles, usually at Band 4.

CSWs are non-registered professionals, who increase workforce capacity by providing holistic patient-centred support. They enable Clinical Nurse Specialists (CNS) to focus on different parts of the pathway and undertake more clinically complex work. CSWs play a key role in empowering patients to self-manage all or parts of their health and wellbeing, which contributes significantly to their quality of life.

The success of LWBC and PSFU programmes relies on having sufficient numbers of appropriately skilled staff in the workforce. Patients cannot move onto supported self-managed pathways without the delivery of personalised care interventions. The successful implementation of digital RMS requires administrative support to be effective. CSWs play a pivotal role in delivering both functions.

Cancer Alliance-led co-ordination of the CSW role, including definition, training, championing and peer support, has resulted in greater integration and acceptance of the roles within clinical teams.

Clinical Nurse Specialists

Cancer Alliances, who have developed the CNS role alongside deployment of CSWs, have been most successful in implementing PSFU pathways and supported self-management. CNSs should see CSWs as a valuable addition to the team and not a replacement for their own roles. Where CSWs deliver most of the non-complex activities, the CNS workforce has increased their involvement in the diagnostic pathway, undertaking nurse-led triage and follow-up, and embracing digital developments.

Allied Health Professionals

Cancer Alliances who embraced the use of the Allied Health Professional (AHP) workforce found that they could support patients more effectively to self-manage. This includes a combination of registered and unregistered therapy professionals delivering prehabilitation, rehabilitation and consequences of treatment services. This is reported to greatly improve the outcomes for patients on all PSFU pathways.



Challenges

Cancer Support Worker

- Speed of acceptance of CSWs by clinicians and CNSs limited how quickly and effectively they integrated into clinical teams and pathways
- There are often not enough CSWs to deliver care to all patients, creating inequity of care
- Many of the CSW and other LWBC roles are currently short-term funded and are not substantive roles. The main sources of this short-term funding include NHS transformation funds, Macmillan Cancer Support, and other charities. Short-term funding means vacancies are often harder to fill, staff turnover is higher, training and recruitment costs are increased, and development of skills within the role is reduced. Since COVID19, these challenges have further increased, and charities are trying their best to manage services with limited funding
- Before COVID19, commissioning contracts were based on purchasing of services/ activity and did not consider individual staff roles or operating models. This made it more difficult to develop sustainable funding arrangements for the LWBC/ PSFU workforce.

Clinical Nurse Specialist

- Some CNSs do not always see the link between personalised care interventions and PSFU, and specifically their role in the delivery of PSFU
- There have been concerns that their roles will become replaced or redundant with the increase in CSWs. To date, however, there is no firm evidence to demonstrate this is taking place
- Increased CSW numbers could enable CNSs to provide appropriate support to patients who have negative consequences of treatment from their cancer. CNSs do not always have the skills and confidence required to do this effectively, and training may be required to address this
- Advances in genomics and personalised medicine have required the CNS role to change to provide different types of intervention in the early part of the cancer pathway. This represents a shift in CNS job plans, creating additional capacity challenges, which can negatively affect the amount of time available to support delivery of PSFU.

Psychological Impact of PSFU on staff

- The mix of cancer team caseloads has changed due to the introduction of supported self-managed pathways. Non-complex patients are now not attending outpatient follow-up clinics, resulting in a higher percentage of patient appointments addressing complex issues. This means that each appointment now takes longer than the previous average appointment time. An impact of this is the increased psychological burden for cancer teams
- To mitigate for the impact on staff and improve the level of care for these more complex patients, changes to clinician and nursing job plans and clinic restructuring is suggested. Increasing the length of appointment times, and having multi-disciplinary clinics are possible solutions to consider
- Provision of additional emotional support for staff may be required to mitigate for this loss of personal contact with patients with good outcomes. Sharing patient 'success stories', outcomes data, Quality of Life survey results and patient satisfaction surveys with the clinical team could be used to address this.

Programme Management Workforce

- Programme and project management structures varied across and within Cancer Alliances, resulting in variable outputs. Some Cancer Alliances supported this through their own core team structures, and/or embedding project managers within Trusts or STP/ICSS
- The scope of many roles was to support the roll out of LWBC programme. PSFU was a subset of the overall plan, which in some situations resulted in PSFU not being prioritised
- The majority of the posts were contracted on a short-term basis (circa 24 months). This negatively affected the attrition rates of those posts, which in turn affected the pace of PSFU implementation progress, when posts were vacant.

Impact of PSFU on Primary Care Workforce

Delivering personalised care interventions, which support PSFU, require increased involvement of primary care. This includes Cancer Care Reviews and community-based support. It is important that PSFU programmes consider the following impacts on primary care:



- Primary Care is currently going through a significant workforce redesign in response to the changing NHS landscape and needs of the population
- LWBC and PSFU will result in a need to increase the support offered by primary care practice nurses to people with cancer
- The CSW role will be working across primary and secondary care, linking in with the social prescribers.

There have been significant developments with the workforce who deliver LWBC and PSFU. To date, this has been done at a local level, resulting in variable delivery models and outcomes. To reduce variation and maximise impact on outcomes a more standardised approach supported by national bodies would be beneficial.

Recommendation 4

Timescale:

Within 12 months

To achieve the benefits of PSFU, Cancer Alliances and Trusts should implement an effective skill mix of Clinical Nurse Specialist (CNS) and Cancer Support Worker (CSW) roles within PSFU pathways. The NHS Cancer Programme should go further in identifying and promoting best practice in deploying CSWs at the national level.

3.3 Leadership, Engagement and Governance

“Having dedicated clinical leadership and a LWBC project manager has significantly increased buy-in for PSFU”

Somerset, Wiltshire, Avon and Gloucestershire Cancer Alliance

Leadership, engagement and governance are interrelated and influential in the implementation of PSFU pathways at all levels (national, regional and local). Implementing PSFU requires a significant change in culture and behaviour for clinical teams, system leaders and patients. Implementing change management models in Cancer Alliances, which include the use of strong authentic clinical and managerial leadership, can lead to sustainable embedding of changes in practice. This can be harder and more time consuming when stakeholders have competing priorities.

Learning/ Best Practice

Embedding within existing Leadership and Governance Structures

Successfully implemented PSFU pathways had the following common factors:

- Cancer Alliances whose Trusts had board level ownership and accountability, actively supported by their associated STP/ICSs boards
- Senior representation from Trusts and STP/ICSs on Cancer Alliance LWBC Project/Programme boards (or equivalent), as well as active involvement of all other key stakeholders, including patients and the public
- Cancer Alliance LWBC Project/Programme boards (or equivalent), being directly embedded in STP/ICS and NHS Regional governance structures.

Having these factors in place enables stronger engagement with all stakeholders, specifically commissioners, which in turn enhances:

- The achievement of sustainable funding
- Embedding of PSFU pathways within Trusts’ contracts and CCGs commissioning intentions
- Measurement of the impact of PSFU
- Visibility, system ownership, leadership support and influence on wider strategic decision-making programmes boards, such as planned care and digital
- A much wider understanding of how PSFU implementation might support the delivery of personalised care, and PIFU beyond cancer.



Use of Clinical Leadership

The Lead Cancer Nurse (or equivalent) was the most pivotal role in championing PSFU pathways within Trusts. This was especially true where strong leadership from the Cancer Alliance, STP/ICS and the Trust organisation supported this. An effective Lead Cancer Nurse can drive PSFU development and implementation. This was particularly apparent where they had presence and influence at Trust Executive level. The Lead Cancer Nurse provides a positive impact by:

- Credibly articulating the impact of PSFU on cancer waiting time performance
- Championing the benefits of LWBC and PSFU on patient experience
- Understanding the operational and clinical requirements of the whole cancer pathway
- Strategically representing the Trust at STP/ICS level
- Influencing clinical teams in order to increase engagement and affect change
- Working closely with Cancer Alliance LWBC Leads as a collective network
- Working together as a network of peers across one or more Cancer Alliances to influence decisions at STP/ICS, Cancer Alliance, Regional and National level.

Engagement with Cancer Alliance Clinical Advisory Groups or Tumour Pathway Boards provides increased clinical support for PSFU across Trusts within specific cancer sites. These groups provide a forum for Cancer Alliances to raise the profile of LWBC, PSFU and their benefits. With the endorsement of these groups and their clinical leaders, roll out to other tumour sites becomes more likely and significantly increases the clinical buy-in for PSFU implementation.

Effective planning and delivery of communication and engagement

To enable effective engagement, it is important to understand and stratify local stakeholders through formal stakeholder analysis. Appendix 2 provides a list of key stakeholders identified during the evaluation who should be included during the design and implementation of PSFU. The following were examples of increased stakeholder engagement in relation to the Cancer Alliance PSFU Programmes:

- Facilitated Cancer Alliance-wide workshops with stakeholders, started early in the programme and continued throughout the programme lifespan. The workshops actively involved patients and used the outputs to consider the impact of PSFU on the whole pathway
- Regular meetings with representatives of specific stakeholder groups, which empowered them to influence PSFU pathway implementation. This helped to gain and maintain momentum, whilst anticipating and overcoming barriers early
- Effective working relationships with local communication and engagement specialists, and increasing LWBC Leads skills in these areas, improved the active use of engagement within project development and delivery
- Creating an ongoing dialogue with each stakeholder group, using social media and technology beyond conference calls and websites, worked well in gaining greater representative input and raising the profile of PSFU
- Ensuring representation from national/ local charities and third sector on PSFU project boards. This brought a different perspective, access to learning from a wider range of engagement activities and use of additional resources.

Challenges

Embedding within existing Leadership and Governance Structures

- Cancer Alliances whose Regional Senior Responsible Officer (SRO) had limited capacity or lacked Senior/ Executive support from their STP/ICSs and Trusts found it more difficult to increase awareness of PSFU against a backdrop of competing priorities
- NHS organisational restructuring has had a direct impact on the core team staff within Cancer Alliances. New teams are repeating completed processes and re-visiting previously agreed actions for PSFU. In addition, there has been a review and governance structures are being re-established
- There was little evidence of close links between Cancer Alliance LWBC Leads and NHS Regional Cancer teams. LWBC Leads rely on Cancer Alliance Managing Directors to bring LWBC issues to Regions' attention



- Due to funding arrangements with Macmillan for some Trust LWBC Leads, there was focus on the implementation of the Macmillan ‘Recovery Package’ for patients (now known as personalised care interventions) and not PSFU
- Despite PSFU being in NHS Planning guidance since 2017, Cancer Alliances were not always clear about their role in coordinating delivery of PSFU alongside personalised care.

In summary, implementing PSFU cannot be done in isolation. Cancer pathways are part of wider specialties and elective care decision-making. In order to develop PSFU further, it is important that governance structures be integrated and work closely together. Recommendations to achieve this are detailed below.

Recommendation 5

Timescale:

Within the next 6 months

Cancer Alliances in their position as system leaders should raise the priority of PSFU and digital RMS by working on the PSFU initiatives closely with the STP/ICs. They should ensure progress is tracked and monitored effectively across Cancer Alliance geographies.

Cancer Alliance SROs, who lead on LWBC initiatives, should be identified within all cancer governance structures to raise the priority of PSFU and personalised care interventions.

NHS Regional Cancer Teams should work towards increasing engagement with Regional Executive teams to reinforce and share the progress of PSFU.

Recommendation 6

Timescale:

Within the next 12 months

Cancer Alliances to identify Trust Lead Cancer Nurses (or equivalent roles) and Clinical Commissioning Group Clinical Leaders for all member organisations. They should develop and support an active peer network that champions PSFU within clinical teams, and influences decision-makers in STP/ICs and Trusts to aid spread and implementation of PSFU pathways.

Health Inequalities

The recent Marmot Review 10 years on⁹, states that ‘Health inequalities are not inevitable and can be significantly reduced’. The evaluation identified that Cancer Alliances had considered the impact of health inequalities in pathway design to varying levels.

Considerations related to health inequalities are summarised below:

- Ensuring that health inequalities are positively addressed through implementation of PSFU is key to delivery. Increasing and having ongoing access to a two-way conversation with the patients and public, helps to identify unwarranted variation and refine PSFU pathways to achieve this aim
- Having an active process for testing emerging pathway approaches with an Equality Impact Assessment (EIA), and acting upon the outputs from these frameworks, should inform decision-making around tackling inequalities
- The EIA should review the effect on inequalities pre- and post COVID19, and identify areas for urgent action. Key factors for consideration include age, sex, ethnicity and deprivation.

The evaluation identified the following points related to health inequalities:

- Expertise in reducing health inequalities is often attributed to a small specialist team. There was little evidence that many Cancer Alliances made active use of this expertise
- Some Cancer Alliances had attempted to understand the localised issues around health inequality, but they struggled to articulate how this changed the way the PSFU pathways were designed or implemented
- The NHS Cancer Programme undertook a national EIA at the beginning of the national work to implement the 2015 Taskforce recommendations. It is not known how many Cancer Alliances have used this to inform their own work



- During the response to COVID19, the health and care system has seen unprecedented levels of uptake of digital tools and services, helping keep patients, carers, friends, relatives and clinicians' safe, and ensuring that essential care can continue. Digitally enabled services provide an opportunity to create a more inclusive health and care system. The shift needs to be carefully designed to ensure it does not affect health inequalities for others, due to barriers such as access, connectivity, confidence or skills.

Recommendation 7

Timescale:
Within
the next 6
months

Cancer Alliances should review the current PSFU cancer pathway to ensure it helps tackle health inequalities. There needs to be understanding of where there may be unwarranted variation in access, experience and outcomes, and steps should be taken to improve this for all patients.





4. Roll out to other Cancer Sites and Primary Care

"[Our clinical lead said] "Having the ambition and plans for [LWBC/PSFU] to be in all cancer sites. This should be something which every patient deserves."

Peninsula Cancer Alliance

This chapter focuses on progress in implementing PSFU pathways. It recognises that Cancer Alliances and their member organisations have all started at different points. This has impacted on progress to date and plans for roll out to other cancer sites. To support roll out, Cancer Alliances found some of the resources and support from the NHS Cancer Programme team helpful, and request that these continue. Of note, the 'share and learn' programme, networking opportunities and audit tools were of value to Cancer Alliances.

Each Cancer Alliance was asked at interview:

'Will your Cancer Alliance be able to deliver on the National targets for breast PSFU in March 2020 and colorectal and prostate PSFU by March 2021?'

Most Cancer Alliances either had or were close to having agreed colorectal and prostate protocols in place. The main barrier to implementing protocols was Trusts not having a digital RMS. Breast PSFU is now considered business as usual for many Cancer Alliances. All Cancer Alliances felt confident that by March 2021 they would have implemented colorectal and prostate PSFU. The interviews took place before the COVID19 pandemic, therefore delivering on these PSFU targets may have been adversely affected. There were Cancer Alliances with a mix of engaged and less well engaged Trusts. Those with more engaged Trusts used clinical and managerial champions to promote the positive outcomes with other Trusts. Cancer Alliances reported that additional support and leadership from STP/ICS and NHS Regional Teams would enhance and accelerate engagement.

Learning/ Best Practice

- Where PSFU protocols are agreed and standardised at Cancer Alliance level, this helps to improve patient flows, navigation and reduce inequalities in service provision. This takes into consideration the movement of patients across multiple Trusts for differing treatments
- It is important to have a LWBC Lead in each Cancer Alliance who can provide central oversight to the roll out of PSFU and LWBC. They should work alongside clinical leads, digital leads and all other stakeholders involved to have a consistent focus, to drive delivery of milestones across Cancer Alliance footprints
- In 2019, the NHS Cancer Programme developed a PSFU audit support tool¹⁰. This was for Cancer Alliances and Trusts to understand their current position and identify key areas to develop. It was initially completed for breast PSFU. Cancer Alliances found the audit tool useful to review Trust progress with breast PSFU, and some Cancer Alliances have re-designed the audit tool for other cancer types.

Roll out of PSFU to other Cancer Sites in Secondary Care

Cancer Alliances acknowledge that PSFU should be implemented in all cancer sites. Lessons from the implementation of PSFU can inform the NHS England and NHS Improvement Outpatient programme to increase supported self-managed pathways in non-cancer conditions. The approaches taken by Cancer Alliances to drive wider roll out are:

- Increasing engagement with clinical teams to develop PSFU in tumour sites other than breast, colorectal and prostate, with ambitions in some areas to be ahead of the NHS LTP commitments for this
- Actively develop and use clinical champions including Lead Cancer Nurses and Cancer Alliance Clinical Advisory Groups/ Tumour Pathway Boards, to create buy-in and start early design work
- Development of PSFU implementation plans for other cancer types, such as lymphoma, other haematological cancers, gynae-oncology and skin
- Some Cancer Alliances were reporting early stage roll out of PSFU to cancer sites with a traditionally high level of medical follow-up and poorer outcomes e.g. lung, head and neck, upper gastrointestinal cancers. This demonstrates that supported self-management and remote monitoring could be possible in all cancer sites to some degree.



Table 3: PSFU progress across Cancer Alliances.
Information collected from 2019/20 Q3 Cancer Alliance Assurance reporting and Interviews with Cancer Alliance LWBC Leads

| Region | Cancer Alliance | Cancer Site | | | | | | | | | | | |
|-----------------|---|-------------|------------|----------|--------------------------|-------------|---------------|------|----------|------|------------|---------|-------------------------|
| | | Breast | Colorectal | Prostate | Gynaecology | Haematology | Head and Neck | Lung | Lymphoma | Skin | Testicular | Thyroid | Upper Gastro-Intestinal |
| North East | Northern | ✓ | ✓ | ✓ | | | | | | | | | |
| | West Yorkshire and Harrogate | ✓ | ✓ | * | | | | | | | | | |
| | Humber, Coast and Vale | ✓ | ✓ | * | * | | * | * | | * | | | |
| | South Yorkshire and Bassetlaw | ✓ | ✓ | ✓ | * | | | * | | | | | |
| North West | Cheshire and Merseyside | ✓ | ✓ | ✓ | * | * | | | | | | | |
| | South Lancashire and Cumbria* | ✓ | ✓ | * | No information available | | | | | | | | |
| | Greater Manchester | ✓ | ✓ | ✓ | | | | * | | | | | * |
| Midlands | East Midlands | ✓ | ✓ | ✓ | | | | | | | | | |
| | West Midlands* | ✓ | ✓ | ✓ | No information available | | | | | | | | |
| East of England | East of England North and South | ✓ | ✓ | * | | | * | | | | | | |
| London | South East London | ✓ | ✓ | ✓ | | | * | * | | | | | |
| | North Central and East London | ✓ | ✓ | ✓ | | | | | | | | | |
| | RM Partners* | * | ✓ | * | No information available | | | | | | | | |
| South East | Thames Valley | ✓ | * | ✓ | | | * | | | | | | |
| | Wessex | ✓ | ✓ | ✓ | * | | * | * | * | | | | |
| | Surrey and Sussex | ✓ | ✓ | ✓ | | | | * | | | * | * | |
| | Kent and Medway* | * | ✓ | ✓ | No information available | | | | | | | | |
| South West | Somerset, Wiltshire, Avon and Gloucestershire | ✓ | ✓ | * | * | | | | ✓ | * | ✓ | | |
| | Peninsula | ✓ | ✓ | ✓ | * | * | * | * | * | * | * | * | * |

✓ - Protocol in place * - Protocol in development

N.B. The British Gynaecological Cancer Society have produced PSFU guidance¹¹. * Information taken from 2019/2020 Q3 Cancer Alliance assurance reporting and the evaluation interviews, which were carried out pre-COVID19. It is acknowledged that the position of Cancer Alliances may have changed since this time.



Roll out of PSFU in Primary Care

Most Cancer Alliances have focused on delivering PSFU pathways in secondary care. Currently, there can be a reluctance for secondary care to 'release' these patients, and for primary care to have capacity or feel confident to be part of a whole-pathway approach to PSFU. The case study below shows how PSFU for many stable prostate patients can be delivered safely and effectively in primary care. This provides valuable evidence to support Cancer Alliances to plan for a shift of prostate follow-up care away from secondary care. It is important to acknowledge that stakeholders need to be mindful of the capacity constraints of primary care whilst developing and delivering the plan.

Case Study

Primary Care Involvement in Prostate PSFU



North Central London Primary Care Pathway for Stable Prostate Cancer

In January 2016, the North Central London (NCL) Cancer Board agreed to implement primary care PSFU for stable prostate cancer patients as per NICE Prostate Cancer Guidance CG175 2014, now revised to NG131 2019¹². Barnet CCG, on behalf of the five NCL CCGs led the project from January 2016 - April 2017. An external GP provided clinical leadership, and the steering group included clinical and commissioning leads from the five CCGs, Transforming Cancer Services Team (TCST) in London, UCLH Cancer Collaborative and the Chair of the Urology Pathway Board.

Key drivers for change included:

- Patients were being 'lost to follow up' by not being appropriately followed up, as no safety netting was in place
- There was variation in the quality and frequency of the urology service
- There was a large demand on urology outpatient appointments
- GPs were not receiving adequate onward information about patients
- Patients were not being supported to self-manage.

The model developed included the following:

- Patients identified as suitable for primary care-led follow-up receive an End Of Treatment Summary from their cancer team and a welcome letter from their GP practice
- The GP or practice nurse delivered an initial prostate review and personalised care and support plan
- This review was integrated with care for other long-term conditions and identified rehabilitation requirements.

Stakeholder engagement was one of the critical success factors, and this involved representation from patients, primary care, secondary care, and commissioners. This led to the development of a single pathway co-designed for London. The report, published by Prostate Cancer UK¹³ showed that for a population of 500 patients, whose care has been transferred to primary care, a saving of £16,500 is made in year one, then £42,000 per year. Data from the project demonstrated that 40-45% of patients with prostate cancer are suitable for primary care follow-up based on NICE criteria. It was estimated that over 13,000 hospital appointments would be released annually if all London STPs were involved. The pathway was considered one of two 'must do' cancer commissioning intentions for London.

Patient feedback:

"I have known my GP for over 25 years and their surgery is very local. I still work full time and when I attended [hospital] appointments I sometimes waited for over 2 hours. I am always seen promptly at the GP surgery."

Commissioner feedback:

"The TCST have reshaped prostate care in the community and is so far forward compared to other areas in the South East. This work really supports prostate cancer but also supports other tumour sites such as colorectal and breast in long term follow-up."

Case Study

Primary Care Involvement in Prostate PSFU *(continued...)*



Challenges

Some clinical teams are reluctant to change their pathways and 'let go' of their patients to self-managed follow up, believing clinically led follow-up is safer and provides a better patient experience. This is particularly challenging to manage where local clinical champions do not exist to help to understand and work through the concerns of clinical teams.

Recommendation 8

Timescale:
Within the
next 12
months

Cancer Alliances to scope and prioritise roll out of PSFU to other cancer types. This should be shared with the NHS Cancer Programme.



5. Moving to Business as Usual

The NHS Cancer Programme are committed to achieving all the ambitions set out in the NHS Long Term Plan including:

“Now we’ve got all the evidence. We’ve got the patients on the [RMS] system, it’s beneficial for the patient, it’s beneficial for the NHS economy as it’s showing outpatient appointments have been saved”

Cheshire and Merseyside Cancer Alliance

Most Cancer Alliances are beginning to move to sustainable business as usual (BAU) models for breast, colorectal and prostate PSFU. However, Cancer Alliances have made variable progress through this stage of development.

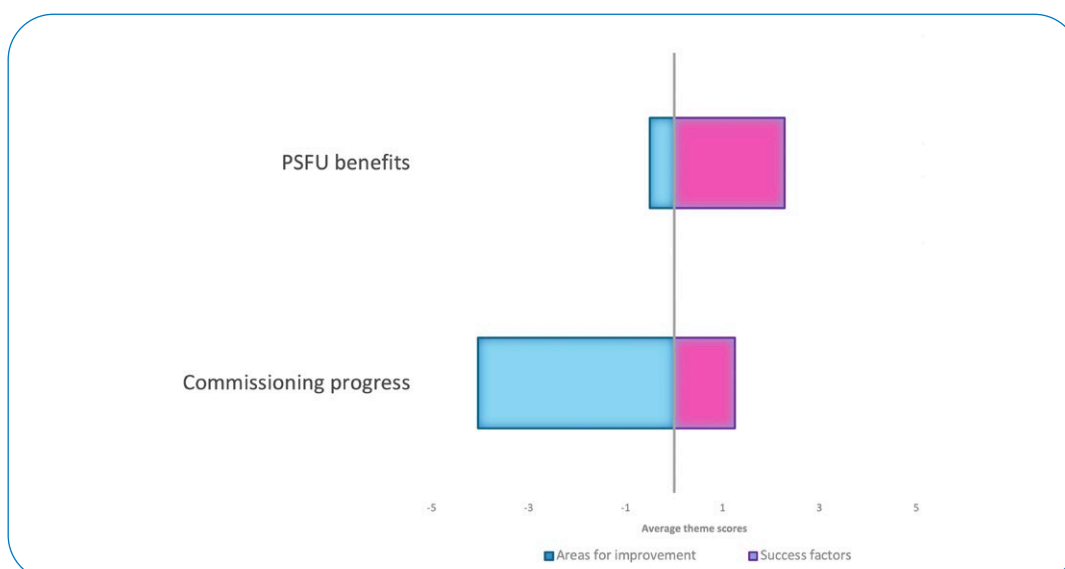
Moving to BAU is often a difficult and vulnerable point in a project, as new practices are being embedded just as the project is closing. If the timing is not right, the progress gained in PSFU may be destabilised by the loss of raised profile that comes from project resourcing and governance structures. A successful transition to BAU for PSFU will include:

- Being supported by fully agreed commissioning arrangements to create properly resourced and funded workforce and digital solutions
- Sustainable embedding of the changes made within the project and having processes in place to avoid clinical teams reverting back to previous behaviours
- Focus on continuous service improvements to ensure benefits are realised by patients, professionals and the wider system
- Increasing patient numbers on PSFU pathways, especially those on supported self-managed pathways, until such point that demand is fully met.

The time to transition to BAU is often under-estimated. This can result in project support being removed too early. Cancer Alliances should use the above list to check when the Trust has fully embedded PSFU and can efficiently deliver PSFU without additional support. This will make transition as fast and seamless as possible.

Interview analysis, shown in Figure 3 below, highlighted that Cancer Alliances could identify the benefits of PSFU but had significant issues with commissioning progress.

Figure 3: *Thematic Interview Analysis related to Business as Usual*





Learning/ Best Practice

Benefit articulation and realisation

Articulating, and starting to experience at scale, the benefits to patients, professionals and organisations is key to shifting to BAU. Cancer Alliances and/or cancer teams, who have mapped the whole cancer pathway (not just follow up) as part of PSFU implementation, found it much easier to demonstrate the benefits and raise the profile more widely within STP/ICs and Trusts. This in turn has made it easier to gain sustainable commissioning agreements and move to BAU. Pathway mapping provides the following benefits:

- Clearer understanding of the impact of PSFU on the diagnosis and initial treatment phases of the cancer pathway
- Supports clinical teams to better understand how PSFU can be implemented within the pathway
- Identifies key points of focus and benefits to achieve for delivery of personalised care interventions from diagnosis onwards.

Where patient outcomes were evaluated, there were a range of positive benefits to being on a supported self-managed pathway and not having to attend hospital appointments. These included not having to take time off work, find childcare and incur travel and parking costs.

Use of the OPA Tool

To quantify the capacity benefit of PSFU and measure the shift towards supported self-managed pathways, the NHS Cancer Programme developed an Outpatient Appointment (OPA) estimator tool in 2019. The tool currently applies to breast, colorectal and prostate follow-up pathways. It calculates the number of appointments that could be re-purposed in the system, if patients move from traditional follow-up to supported self-managed pathways.

Cancer Alliances reported a mixed response to the value of the OPA tool. Having a single tool to assess progress is welcomed. For some, it was helpful when building business cases for sustainable commissioning and resourcing arrangements. Having a digital RMS is not a prerequisite to using the OPA tool, but it does appear to enhance its value. Where digital RMS was in place, accurate figures on patient numbers were available to input to the OPA tool, making the outputs more meaningful.

Case Study

Use of the OPA Tool to support Business Planning



Somerset, Wiltshire, Avon and Gloucestershire (SWAG) and Peninsula Cancer Alliance

Both SWAG and Peninsula Cancer Alliances extended the use of the OPA tool. By applying financial tariff information to the OPA tool findings, they were able to demonstrate the financial effect of having PSFU in existence.

They showed the difference in activity costs against current demand if PSFU did not exist and compared that with the effect on managing demand with current partial, and future full implementation of PSFU. In SWAG, this equated to circa £420,000 annually (based on breast, colorectal and prostate only). This was a combination of financial benefit to both Trusts and Commissioners and built a compelling case as it showed that having fully implemented PSFU pathways could demonstrate a positive financial impact to STP/ICs.



Sustainable Commissioning Arrangements

Some Cancer Alliances have managed to work through the challenges of finding sustainable commissioning arrangements using local approaches. This has been through a mixture of local tariffs, risk-sharing arrangements, and/or using other contractual levers. There is no single approach adopted by a significant majority, and support with the commissioning process is something that many Cancer Alliances would welcome.

Cancer Alliances who had access to commissioning and finance expertise to help build the solutions achieved sustainable commissioning arrangements.

Challenges

Benefit articulation and realisation

- Articulating, and then demonstrating benefits realisation in practice, continues to be challenging for many. It is something Cancer Alliances would welcome additional ongoing support with
- STP/ICS and Trust senior leadership need to be convinced of the benefits of implementing PSFU, and increasing use of supported self-managed pathways increases capacity for the diagnosis and initial treatment phases of the cancer pathway
- LWBC and PSFU do not feature on most organisation performance dashboards or board reporting systems. This continues to influence the ability of PSFU and LWBC to be seen with parity of priority with cancer waiting time standards.

Capturing and using Data

- There are currently no national reporting requirements for collecting patient level data for patients on a supported self-managed PSFU pathway. This is because the data currently available does not directly measure PSFU progress
- Cancer Alliances felt having a national reporting requirement on PSFU would be of value for informing commissioning decisions and performance management. However, while this has been considered, such a request will result in additional significant demand on Trusts to supply this information, therefore it has not been pursued to date
- In the absence of national PSFU data, local patient activity around PSFU could be used as a proxy measure. Cancer Alliances can then monitor the number of people on supported self-management follow up via the Trust digital RMS systems, or calculate the estimation of outpatient slots released by the OPA tool
- Holistic data, which shows the impact of LWBC and PSFU on patient and clinical outcomes, is reported to be difficult to capture. It is possible to capture the personalised care intervention activity e.g. holistic needs assessments, however quantifying the actual benefits to patients is much harder
- Some cancer system suppliers are trying to support automated data capture. This will prevent the requirement for manual data collection, which is time-consuming, open to human error, and variation in interpretation. There have been issues with release dates for these upgrades, and issues with how the data captured can inform organisations
- The variation in interpretation makes it hard to benchmark and compare different Trusts and systems, or pathways within the same Trust or system.

Use of the OPA Tool

Some Cancer Alliances and Trusts had different perspectives about the usefulness of the OPA tool. Reasons for this include:

- They desire a greater level of accuracy to make significant decisions
- It was perceived to be difficult for clinical teams to understand and use, despite national guidance
- Trusts felt this was a significant additional information request, without directly seeing the benefit in using it.

As a result, the NHS Cancer Programme team produced an FAQ document and hosted several 'share and learn' webinars, to clarify how to use the tool and the benefits to Cancer Alliances.



Sustainable Commissioning Arrangements

It has been difficult for some Cancer Alliances to navigate STP/ICS decision-making structures, or influence Commissioner and Trust contracting arrangements. Particular issues include:

- STP/ICSs and Trusts recognise that the workforce required to deliver LWBC and PSFU needs to be funded, and it is understood that PSFU should release outpatient capacity to manage additional demand in the system. Trusts, working on behalf of the STP/ICS should take a lead on developing this with support from commissioners. The acceleration of PIFU as part of phase 3 guidance will support STP/ICSs and Trusts to understand the benefits of PSFU and realise the cost efficiencies
- Until April 2020, Trusts were usually paid for outpatient attendance activity through the tariffs within Payment by Results (PbR), and some had block funding arrangements. Some Trusts have not fully understood the financial efficiencies of PSFU to the system. This is due to concern that they may receive a reduction in income from the incentive tariff-based outpatient attendance. It is understood that outpatient contracts for Trusts have moved to block contracts due to COVID19, so this disincentive has been removed
- These shifts in the cost base were not reflected in PbR tariff arrangements. If there is a shift away from tariff-based contracts and contractual arrangements, it may be that the wider changes in the system reduce the impact of this in the future.

Community Phlebotomy

Colorectal and prostate PSFU requires patients to have routine surveillance blood tests. To improve patient experience, this activity is expected to take place within the community, close to the patients' home. The results are then sent to the cancer team for interpretation and reporting. There are challenges related to this:

- There is no consensus on a funding mechanism for primary care for carrying out surveillance phlebotomy. Some GP practices are refusing to undertake the phlebotomy procedures, meaning patients have to attend secondary care settings
- As more patients require remote surveillance blood tests with PSFU roll out, this becomes an increasing challenge. Whereas goodwill previously existed, increased patient numbers means there are more GP practices refusing to carry out this work without formal contracting arrangements being in place
- There are financial incentives being considered for primary care to carry out bowel surveillance phlebotomy, and this should be extended to include primary care remote surveillance¹⁴.

Evaluation of Projects

There is a requirement to build business cases in order to successfully transition into BAU. Strong evaluation provides support for business cases. Cancer Alliances could have done more evaluation of the holistic patient outcomes of implementing PSFU. Although most Trusts and Cancer Alliances were planning to do this in the future, this takes time to develop and requires high levels of patient engagement. Equally, evaluation activity generally seemed to be viewed as something to undertake at the end of projects. The most successful and sustainable solutions used formative evaluation from project initiation onwards to inform each key decision. The exact areas of focus and way of evaluating can change over the lifespan of the project.

In summary, commissioning of PSFU is essential to the transition to BAU. The evaluation found significant challenges for Cancer Alliances with achieving sustainable LWBC and PSFU services.

| Recommendation 9 | |
|---|--|
| Timescale: To begin within 3 months and complete within 6-12 months | NHS Cancer Programme to work closely with the Payment Policy team to explore a payment policy approach that supports sustainable commissioning of PSFU. They should work together with Cancer Alliances, STP/ICSs, and Trusts. |



6. COVID19: Impact and Opportunities

The COVID19 pandemic continues to change the health and social care landscape. The opportunities from COVID19 are still emerging, and there is a great deal of research and evaluation activity occurring, which will help inform future decisions.

In late April 2020, the NHS moved from considering immediate actions to mitigate the first surge, to phase two of the COVID19 response¹⁵. Nationally, cancer was seen as an immediate priority, and remains a key priority for recovery. The response has been to support new opportunities created due to COVID19 and adapting focus on recovery planning. Since 31st July, the NHS has moved into the [third phase](#) of the NHS response to COVID19. The guidance provided addresses urgent actions to protect the vulnerable by reducing health inequalities, prioritising restoring of NHS services, and development of digital enabled care pathways for patients. The aim is to increase inclusion, and strengthen leadership and accountability. The guidance emphasises the importance of delivering Patient Initiated Follow Up (PIFU) across a range of conditions. In the case of cancer, this can be understood as the existing PSFU pathway, as both enable shared decision-making and supporting patients with self-management.

Cancer Alliances have had some of their Living With and Beyond Cancer work disrupted by COVID19. They are now seeking to recover full implementation of PSFU and personalised care interventions, whilst capitalising on innovations introduced during the pandemic, and the increased motivation of cancer teams to release capacity and support self-management. The most pertinent elements and learning obtained from the impact of COVID19 are captured within this section.

Successful innovations that have been prioritised and are being accelerated due to the pandemic include:

- Implementation of PSFU protocols in additional cancer types
- Improvement of IT and clinical teams' engagement at a local level to prioritise delivery of digital systems for PSFU and personalised care
- Introduction of meaningful data on personalised care interventions and PSFU on local Cancer Alliance dashboards to monitor progress
- Virtual / remote digital consultations by clinicians for patients
- Working in partnership with charities to support patients in the community by providing virtual support for self-management, for example:
 - Virtual Health and Wellbeing Information and Support patient education sessions
 - Launch of local cancer Apps to support appointment administration, signposting to health and wellbeing resources, and easy access to information on when and how to contact the cancer team with concerns
 - Virtual peer support sessions
 - Videos to support health and wellbeing and to reduce patient anxiety.

Currently, as part of the third phase of the response, Regional Cancer Leads and Cancer Alliance LWBC leads are working together to plan for accelerating delivery and embedding the successful innovations that have been implemented during the pandemic. Ensuring that PSFU and personalised care interventions rapidly become business as usual is a vital element of the NHS response to the COVID19 pandemic. Restoration of PSFU and personalised care interventions will bring multiple benefits that support wider cancer service and NHS recovery, including:

- Increased clinical capacity, by repurposing appointment slots
- Reduced service demand, by improving patients' ability to self-manage
- Reduced travel to hospital sites, by offering virtual support as appropriate.

Digital enablement of workforce and patients

Across clinical pathways in primary, community and secondary care settings there has been an increased use of virtual interactions between clinicians, patients and teams via telephone, video conferencing, secure messaging and emails. This approach has started to demonstrate the benefits of virtual consultations and to question the need for face-to-face follow up. Using learning already gained through the implementation of patient portals and digital RMS this will raise the profile of PSFU and PIFU, which naturally lends itself well to a non-face-to-face approach.



Workforce and Pathway Adaptions

There have been workforce changes and staff redeployed away from PSFU during phase 1 and phase 2 of the pandemic. The impact of this was that PSFU implementation was paused for some of the Cancer Alliances. Currently as part of phase 3 staff are returning to previous cancer roles with adaptations. Some of the implications of this include:

- Reduced charitable income, due to a reduction in fundraising activities caused by COVID19, has resulted in funding being withdrawn from Macmillan and other charities for new roles and project initiatives. This highlights a need to move away from reliance on workforce funding from voluntary sector providers
- More interaction is occurring with patients virtually, therefore teams are having to adapt their approaches. This includes re-evaluating how to carry out multi-professional interactions with patients
- New models for delivery are starting to be considered. These will require upskilling of staff, and understanding the implications on clinical practice, informed consent and patient experience.

Leadership and Governance

Strong and effective leadership is required to respond to the rapidly evolving context of the COVID19 pandemic. Leaders should ensure PSFU is prioritised, and that it remains part of service recovery planning solutions as outlined in the [Phase 3 guidance](#). Particular points to note are:

- NHS Regional Cancer Leads to take ownership and advocate for the acceleration of delivery of PSFU and personalised care interventions as part of the recovery planning
- The NHS Cancer Programme has set up monthly networking meetings for Cancer Alliance LWBC Leads. This has included uploading of resources onto the national Cancer Alliances workspace (on the Future NHS Collaboration Platform), encouraging the use of the workspace for discussions, and the national LWBC team continues to be available for advice and support as required.

Health Inequalities

In the initial COVID19 response phase (March to June 2020), Cancer Alliances and Trusts were guided to make their own decisions about the pace (or cessation) of ongoing PSFU roll out. There is a need to consider how the PSFU pathway can reduce health inequalities, given the evolving research into the disproportionate impact of COVID19 on BAME populations, older people and those with comorbidities. In addition, any model developed needs to ensure patients who cannot access digital systems continue to receive the same level of care as others. As the pandemic has been managed as a major incident, patient and public engagement around decision-making could have been reduced. As command and control models transition to business as usual as part of recovery planning, it will be important to review and prioritise engagement with patients and the public.

Roll out to other cancer sites

Cancer Alliances are realising the benefits of PSFU, and how it can support COVID19 recovery. Therefore, now may be the right time to accelerate roll out of PSFU to a wider number of cancer and non-cancer pathways. Cancer teams are currently reviewing diagnostic and treatment pathways following the onset of COVID19, therefore it would seem logical to include review of follow-up pathways. Where this is occurring, it will be important to consider the following:

- There is concern from Cancer Alliances that implementing PSFU is being interpreted by clinicians as simply doing virtual appointments, rather than active recruitment of patients onto supported self-managed pathways with remote monitoring
- Safety netting of patients for delayed diagnosis, treatment and follow-up are key concerns. As part of recovery phases, processes will need to be implemented to move patients back into normal asymptomatic surveillance, and manage backlogs of patients who report symptoms of recurrence
- The challenges around remote surveillance phlebotomy, scanning and colonoscopy will need further consideration in light of infection control issues and social distancing requirements.

Considering these points related to the impact of COVID19, the following recommendation has been made:

Recommendation 10

Timescale:
Within 6 months

NHS Cancer Programme and Cancer Alliances to review the emerging learning and opportunities created by impact of COVID19 on cancer pathways. They should proactively act upon this by adapting local PSFU pathways.

7. Summary and Conclusion

The evaluation findings were representative of the majority of Cancer Alliances. Input from NHS Regional Cancer Leads has been captured through interviews carried out after the main evaluation report was completed and are included in Appendix 1. The evaluation aimed to provide evidence and recommendations to inform policy development. The specific aims, and how each has been addressed are as follows:

1. Provide recommendations to inform national policy development for 2020/2021 and beyond

Recommendations from this evaluation have been included in the report.

2. Understand the barriers and enablers in implementing PSFU and share this learning with others to increase the pace of PSFU implementation across England

Digital challenges, including procurement, integration and funding for remote monitoring systems have caused delays in the speed of implementation. Cancer Alliances who have taken a system wide approach, engaging digital suppliers and digital leads in STP/ICSSs and Trusts have made most progress.

Workforce development to support PSFU delivery has occurred across cancer clinical and programme management teams. The cancer support worker role (or similar) has been a positive addition to the workforce, to aid delivery of personalised care interventions required for effective PSFU. However, many of the new roles are not permanently funded, posing a significant challenge to achieving sustainable services and moving from transformation projects to business as usual.

Effective stakeholder engagement in PSFU requires strong leadership within Cancer Alliances, STP/ICSSs and Trusts. The role of the Lead Cancer Nurse (or equivalent) is key to driving leadership and engagement. Increasing the patient and public voice, to enable them to be effective stakeholders throughout the lifetime of PSFU implementation and delivery is beneficial.

3. Support the shift of PSFU from projects into business as usual activity for all clinically appropriate cancers, in all Trusts in England

This is yet to be fully achieved, but some Cancer Alliances have achieved some of the different elements required for a successful shift to BAU. Combining all these different elements and following the recommendations within this report should help to increase the amount of PSFU pathways that are sustainably commissioned and delivered as part of BAU.

The key stakeholders identified in Appendix 2 need to work together to champion PSFU and increase the priority of delivery of PSFU amongst other cancer and non-cancer specific programmes. This needs to happen at national, regional and local level with inclusion of PSFU on performance reporting dashboards and with senior leadership ownership.

Systems need to consider the impact of PSFU on the whole pathway as currently they often focus only on early diagnosis, follow-up or discharge. Understanding the benefits and articulating how PSFU contributes to achieving national cancer waiting time standards is important.

A whole system approach is required for both the digital and workforce elements of LWBC/ PSFU to be sustainably funded.



4. Consider what learning from PSFU can be used to aid developing the national and local approach to recovery from the COVID19 pandemic

COVID19 has been a catalyst for Cancer Alliances, STP/ICs and Trusts to adopt different approaches to delivery of personalised care in cancer and other cancer work programmes.

An increase in virtual consultations and provision of virtual and digital patient education to support self-management is a positive enabler for PSFU implementation and would be useful to capitalise within recovery planning.

Digital remote monitoring systems support safety netting of patients in follow-up and should be accelerated to move more patients onto supported self-managed pathways.

5. Develop underpinning evidence for replication of supported self-managed follow up to non-cancer specialties, such as PIFU

This report highlights the benefits of PSFU. Many Cancer Alliances have realised the benefits in breast, colorectal and prostate, and have started to roll out PSFU to other cancer types. The evidence from PSFU in cancer is directly supporting roll out of PIFU into non-cancer specialties, which will contribute to achievement of the LTP target to reduce NHS outpatient attendances by 30 million by 2023.

In line with the personalised care initiatives, PIFU /PSFU plays a key role in enabling shared decision-making and supporting patients with self-management, by helping them know when and how to access the right clinical input after treatment. Used alongside clinical waiting list reviews, remote consultations and a 'digital first' approach, PIFU/ PSFU is an essential tool for provider recovery.

Conclusion

Personalised care interventions and PSFU form the essential foundation upon which the NHS and its partners are building to achieve a positive impact on people living with and beyond cancer. The foundation will provide ongoing improvements in the experience of personalised care in morbidity, mortality and quality of life for people who use NHS services, their families and carers.

This evaluation has provided a comprehensive analysis of the PSFU implementation programme. The NHS Cancer Programme will use the report findings to develop their work programme. It is hoped the NHS Regional Cancer Teams, Cancer Alliances, and their partner organisations use the report findings and recommendations to accelerate PSFU progress. This will enable achievement of the key NHS Long Term Plan commitment for personalised care in cancer, ensuring that benefits are achieved for patients and the NHS.



Appendix 1:

Findings from the NHS Regional Lead interviews (July 2020)

Introduction and Context

Due to the timing of the COVID19 pandemic, it was not possible to undertake interviews with the NHS Regional Cancer Leads as part of the main fieldwork activities in February/March 2020. Therefore, in June/July 2020, all seven of the NHS Regional Cancer Leads participated in interviews with the evaluation team. These semi-structured interviews discussed the key findings from the main evaluation report and the role of the NHS Regional Cancer Leads in implementing PSFU. NHS Regional Cancer Leads discussed actions to date, and the future roll out of PSFU in light of COVID19.

In general, there was consensus from the NHS Regional Cancer Leads on the findings and recommendations stated in the main report. The key findings included in this section are new areas not previously covered in the report, and/or extended points made in the report.

Regional Support for PSFU

Many of the NHS Regional Cancer Leads acknowledged that they had not prioritised LWBC and PSFU compared with other work streams within Regional Cancer Programmes. This was due to having many competing priorities and limited capacity. To maximise impact, they have prioritised the elements of the NHS Long Term Plan that will give the greatest immediate return on investment of effort and/or budget.

After participating in this interview process, NHS Regional Cancer Leads have recognised the need for greater support for the acceleration of PSFU as part of the current COVID19 recovery planning. One suggestion made by NHS Regional Leads was to improve their contact with Cancer Alliance LWBC Leads. To further support this, NHS Regional Cancer Leads could consider participating in the NHS Cancer Programme 'share and learn' webinars to increase understanding and apply areas of good practice.

Delivering an Integrated Pathway

Many of the NHS Regional Cancer Leads commented on the concept of a whole pathway approach, as described in the main report. There is a misconception from some NHS Regional Cancer Leads that LWBC, including PSFU is a separate work stream within the wider NHS Cancer Programme. It is recommended that the NHS Cancer Programme clarify how LWBC/ PSFU works across the whole cancer pathway, in order to address this misconception, and to demonstrate how PSFU assists with capacity for new patients.

Consideration for integrating primary, community and secondary care into a single pathway approach, and aligning PSFU with wider outpatient transformation in non-cancer sites was felt to be a requirement. This would ensure that all areas of the health system were working together to achieve improved patient pathways. This would add weight to prioritising the implementation of PSFU within STP/ICSs COVID19 recovery plans.

Digital

NHS Regional Cancer Leads supported Recommendation 1 (Digital), specifically due to the involvement of NHSX. They felt that Cancer Alliances generally do not have the expertise on how digital systems should work together and have limited experience of working with digital suppliers.

Leadership, Engagement and Governance

NHS Regional Cancer Leads reported a lack of senior regional executive support for LWBC and PSFU. The NHS Cancer Programme and Regional Cancer Leads should work together to establish stronger executive sponsoring of PSFU implementation across all stakeholders. This will ensure PSFU is prioritised within cancer work programmes and wider COVID19 recovery work.



COVID19: Impact and Opportunities

Following COVID19, most LWBC/ PSFU activity was paused. NHS Regional Cancer Leads requested the prioritisation of PSFU, however, due to Cancer Alliance and Trust cancer team staff redeployments the ability to capitalise on this was limited. There remains concern that not everyone redeployed will return to previous cancer roles. Without staff in their previous roles, restarting PSFU implementation will continue to be a challenge due to a lack of capacity.

Additionally, confusion around funding is impacting on PSFU implementation post-COVID19. NHS Regional Cancer Leads reported that funding previously allocated to LWBC/ PSFU transformation work pre-COVID19 may be reduced. There appears to be some interruption of standard governance structures as well as changes to the financial regime for Cancer Alliances because of COVID19.

For more information on the financial regime in light of the COVID19 pandemic and how this impacts Cancer Alliances, guidance is now available on the [Cancer Alliance Workspace](#).

NHS Regional Cancer Leads felt that the data modelling to support management of backlogs should include the management of follow-up. This would help to build the case for including PSFU in COVID19 recovery planning and demonstrate how it would help to manage the limited capacity within secondary care more effectively.

Many NHS Regional Cancer Leads expressed concern following the onset of COVID19 about the significant reduction in Macmillan funding for new roles, and ongoing funding for current roles. The scale and long-term impact of this is currently uncertain. It is recommended that NHS Regional Cancer teams and Cancer Alliances carry out further work to understand the impact, as without these roles, the speed of PSFU implementation could be slowed significantly. In response to the NHS Regional Cancer Team concerns, the NHS Cancer Programme team have highlighted the [COVID19 Q&A](#) document, which states that Cancer Alliances should enable continuity of essential roles and services, by building this into their plans for recovery and the resumption of LTP programmes of work.

Equally, self-managed pathways rely on patients accessing a range of voluntary sector services. COVID19 has impacted the ability of charities to continue certain services, for example in-person counselling and education, although many have responded by creating more virtual services



Appendix 2: PSFU Stakeholders

This Appendix details the range of stakeholders who should be involved in PSFU Governance and Implementation.

| Stakeholder | Governance | Implementation |
|---|------------|----------------|
| NHS England and NHS Improvement: | | |
| Regional Lead representative | R | |
| Cancer Alliance: | | |
| Programme Lead | R | |
| Project Team | | R |
| Provider: | | |
| Executive (CEO/COO) | R | |
| Medical Director | R | |
| Clinical Lead for Cancer Services | R | R |
| Cancer Speciality Lead(s) | | R |
| Lead Cancer Nurse / Cancer General Manager | R | R |
| LWBC Project Lead | | R |
| Clinical Nurse Specialist (lead / representative) | | R |
| Digital (lead / representative) | O | R |
| Business Intelligence (lead / representative) | | R |
| Patient Engagement | | R |
| Finance/ Contracts (lead / representative) | | R |
| Clinical Commissioning Group: | | |
| Cancer Commissioning (Lead / representative) | R | |
| Primary Care (Lead / representative) | R | |
| LWBC Project Lead | | R |
| Primary Care: | | |
| GP representative | O | R |
| Others: | | |
| Voluntary Sector representative | O | R |
| Patient / Use representative | O | R |

R = Recommended
O = Optional

Appendix 3: References

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