Meeting	Peninsula Cancer Alliance Board 29 January 2020
Title	**Personalised Care For Cancer**
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Agenda Item	7

Summary

The Alliance has provided a template for business case for recurrent funding of local of the Personalised Care for Cancer Services. These services are currently funded from Cancer Transformation Funding, which will not be available in 2020/21. This is attached.

The Alliance has also supported provider to complete the national Outpatient Appointment Estimator Tool. This estimate the number of outpatient appointments avoided by moving patient from routine follow-up to supported self-management, facilitated by delivering the nationally mandated components of Personalised Care for Cancer. This uses provider inputs on the number of appointments for professional-led follow up vs supported self-management and the proportion of patients suitable for supported self-management. Using information provided this national tool estimates 21,243 appointments could be saved each year, at a tariff value of £2.8m. A summary of the tool, as completed locally, is attached.

The Long-Term plan mandates Personalised Care for Cancer. The national Cancer Alliances Five Year Planning Guidance confirms the milestones as follows:

- By 2021 everyone diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.
- By 2020 all breast cancer patients will move to a personalised (stratified) follow-up pathway once their treatment ends, and all prostate and colorectal cancer patients by 2021.
- By 2023 All Alliances to implement personalised (stratified) follow up for other cancers

The South West Central Commissioning Support Unit supported this work.

Recommendation

- **The Alliance Board are asked to recommend that providers use this support to secure the recurrent Personalised Care for Cancer services that were funded by the Cancer Transformation Fund, such that providers can comply with national requirements to deliver Personalised Care for Cancer for all patients**

Peninsula Cancer Alliance

Peninsula Cancer Alliance Personalised Care in Cancer

Business Case to support sustainable funding of Cancer Personalised Care and Support Service

1. Executive Summary:

The Long-Term Plan says the NHS service model will change so "People will get more control over their own health, and more personalised care when they need it."

This means that:

- 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.
- By 2023, stratified, follow-up pathways for people who are worried their cancer may have recurred. These will be in place for all clinically appropriate cancers.

The Peninsula Cancer Alliance received NHS England Cancer Transformation funding in April 2018 to accelerate the roll out of the Personalised Care and Support for Cancer programme[1]. The introduction of a new workforce in the form of Band 4 Cancer Support Workers, combined with investment into Allied Health Professional teams has delivered personalised care and support and enabled an increase in patient self-management.

In specific cancer sites stratified models of follow-up care, known as Personalised Stratified Follow-Up (PSFU) have been introduced. This enables significant numbers of patients to move away from professional-led follow-up to self-managed care. To achieve this stratification of patients, the recovery Package is required as indicated in the NHSE Personalised Stratified Follow-Up guidelines[1]. These include Holistic Needs Assessment and Care Planning; Treatment Summary; Health and Wellbeing interventions.

This shift to self-managed care significantly reduces the demand on outpatient capacity and frees up clinician and nurse specialist time, whilst delivering a more tailored service to patients that addresses their individual needs. It thus enables increased capacity for new and complex patients which has a positive impact on cancer performance.

Currently the services provided are not recurrently funded therefore the document below outlines the case for change, the requirements to deliver the services and the impact if the services were withdrawn.

[1] £1.6m each year for 2018/19 and 2019/20

2. Background:

Personalised Care and Support for Cancer (PCS), which was previously known as Living With and Beyond Cancer (LWBC) is a national requirement and a key feature of the NHS Long Term plan[2].

The requirements are as follows:

- 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.
- By 2023, stratified, follow-up pathways for people who are worried their cancer may have recurred. These will be in place for all clinically appropriate cancers.

The core PCS interventions, which were previously known as the Recovery Package are as follows:

- Holistic Needs Assessment (HNA) and Care Planning at diagnosis and after completion of treatment
- Treatment Summary at the end of treatment. This is communication between secondary and primary care which details the treatment patients have received, the likely side-effects, signs and symptoms of cancer recurrence, follow-up plans and details of how to contact and re-access the service
- Health and Wellbeing Information and Support, which is available at different points in the pathway. This can be offered via a face-to-face group event, or it can be virtual.

All of the above are delivered in secondary care, however health and wellbeing events are often undertaken in community settings nearer to patients' homes.

- Cancer Care Reviews, which is a GP or practice nurse appointment that takes place around six months following cancer diagnosis and is a requirement for the GP Quality Outcome Framework (QOF). N.B. Cancer Care Review does not form part of this business case.

These elements form part of an overall support package for people with cancer and enables greater levels of self-management. This includes:

- Encouraging and empowering people to manage their own care by giving the appropriate information and support from the point of diagnosis and throughout the pathway.

- A shift in focus from a standard "one size fits all" approach to one where follow up care is truly patient centred and where clinical, psychological and practical needs are assessed and managed effectively.

- The number of people with cancer is increasing. In 2018, there were xxxx new cancer cases diagnosed at XXXX and a XX% increase in the number of new primary cancers diagnosed at xxx in 2017 (source: Insert local cancer data)

- Cancer incidence for both Devon and Kernow CCG's (2018/19) is significantly higher than the average for England, at 671 per 100,000 standardised population (Devon) and 654 per 100,000 standardised population (Kernow) versus a national average of 507 (Public Health England Cancer Dashboard).

- Over 60% of new cancers are diagnosed in people aged 65 and over. Comorbidities often make care more complex and time consuming. The number of people living with cancer is growing, with half of people diagnosed surviving for 10 years or more. Both Devon and Kernow CCG have significantly more people aged over 65 years than the national average (Devon 24.4%; Kernow 24.3%; England 17.4%). Information taken from the Public Health England Cancer Dashboard.

- The number of people living with cancer is expected to double between 2010 and 2030[3]. However, many of these people are not living well. Around one in four people experience poor health or disability following treatment and many people are now living with multiple long-term conditions. Care is becoming more complex as people are living longer, meaning that a broader range of services are required, leading to rapid growth in demand. This poses a significant challenge for the cancer workforce both now and in the future.

- The increase in cancer prevalence, the evidence of unmet needs and workforce challenges require a transformation nationally in the way that the NHS cares for people affected by cancer. This means moving away from the emphasis on acute and episodic care towards a holistic and personalised approach that is well coordinated and integrated.

- Both patients and professionals have identified that many appointments are unnecessary, add no value and incur unnecessary costs for patients.

- The concept of supported self-management recognises that not all patients require the same intensity of support from their healthcare professional team and that many patients, given the right support, can self-manage aspects of their care.

- A key part of the PCS programme is to deliver a new model of outpatient care. This involves the introduction of PSFU pathways, which patients move onto at the end of treatment. To do this safely and effectively it is essential that the PCS interventions described above are delivered which enables the patient to self-manage. This significantly reduces the number of professional-led follow up appointments required.

- Multi-disciplinary Teams (MDTs) have either introduced a PSFU pathway or are in the process of doing so for the core cancer sites (breast, colorectal and prostate) as recommended by NHS England. This has involved reviewing current clinical pathways and introducing a self-management with open access pathway option. This is principally for lower risk patients following the completion of treatment and when the short terms effects of treatment have subsided. Key enablers to support this pathway are an effective assessment process to identify and manage individual needs and a remote monitoring system to ensure required surveillance tests are safely monitored.

Evaluation of the programme provides information on the following:

- Activity and performance data related to delivery of HNAs and Care Plans, Treatment Summaries, PSFU Pathways and Health & Wellbeing Events (a summary of currently available information is shown in appendix).

- Patient and staff feedback and case studies (see appendix).

INSERT IF YOU HAVE ANY DATA FOR PAMS AND PROMS

- Patient Activation Measures (PAMS) are used to establish the knowledge, skills and confidence a person has in managing their own health and care.

- Patient reported outcomes (PROMS)

3. Case for Change:

- PSFU will enable a reduction of unnecessary outpatient appointments. The traditional method of face-to-face follow-up is unnecessary for a large proportion of patients who attend outpatients simply to receive the result of surveillance tests.

- The PCS core interventions enable more patients to safely move onto a self-managed pathway. The new model improves patient experience and the quality of life for people following treatment for cancer, as well as making services more efficient and cost-effective.

- The national LWBC team has developed a comprehensive tool , which calculates the number of follow up appointments which are released through the use of new PSFU pathways. The graph below shows the number of follow up appointments which are released for breast, colorectal, prostate cancer pathways in xxxx.

- These figures are only based on PSFU in Breast / Prostate and Colorectal. CHANGE IF APPROPRIATE. There is potential for future additional outpatient appointment capacity to be released through stratification in all other pathways (for example: gynae-oncology, haematology, skin and lung). which would bring further cost savings.

- It is anticipated that PCS services could reduce emergency department attendances , emergency admissions and GP attendances, but further evaluation is required locally and nationally.

- Delivery of PCS is a quality improvement for patients, utilising alternative pathways instead of traditional professional-led follow up services.

- Outpatient capacity has already been released through the introduction of PCS. This released capacity has been filled with new and follow up appointments to meet rising two-week wait demand.

- Release of these OPA slots releases time for clinicians – doctors and nurses as well administration time, clinic room space and other resource utilisation. These can be re-utilised for other purposes in cancer care, such as additional theatre time, more time to manage complex patients, more capacity for new-suspected cancer diagnoses or recurrence and improved delivery of personalised care interventions.

4. Outpatient Appointment Release:

Insert Trust OPA data

5. Work Force Requirements:

The delivery of an effective PCS programme which enables outpatient appointment release relies on having an appropriately skill mixed cancer workforce who can deliver the PCS interventions at times when patients require them in their pathway. Previously, cancer outpatient care was delivered by doctors (surgeons, oncologists) and cancer nurse specialists (CNS). To increase capacity to enable the delivery of PCS interventions and to provide effective holistic support the Cancer Support Worker role was introduced. This is an unregistered health professional working at AfC Band 4 who with the correct level of induction, training and supervision can undertake the following:

- Holistic needs assessments and care plans
- Administrate and co-ordinate health and wellbeing interventions
- Provide emotional and practical support for patients from the point of diagnosis and throughout their cancer pathway
- Be present in cancer clinics to support patients

Macmillan Cancer Support introduced the Support Worker role in 2012 as part of their national 1:1 pilot. Following the success of the new role in pilot sites, they have been introduced to most NHS acute cancer providers including across the Peninsula Cancer Alliance. The role has enabled clinician and CNS time to be released to provide more complex care, whilst enabling more PCS interventions to take place.

Impact Evidence of Support Worker role

The evaluation of the PCS programme in Peninsula has included the impact of the Support Worker role on both patient care and how it has released capacity for doctors and CNS's. The following is some of the evidence that supports this. For more details see Appendix 2: Change if required

- **Single point of access for patients**

  'The Support Worker is the main point of contact alongside their CNS for patients whom she has met and is supporting. They will often call for her if they have any new concerns or need help with a specific need. the Support Worker then passes this information on to the nursing team so we are aware and can follow up if necessary which saves us considerable time a previously we would have had to take the patient phone call. The patients have understood her role and use her as a point of contact for support.'
  Haematology CNS

  Prior to the introduction of the Support Worker role patients would have phoned their CNS team with any concerns, often resulting in lengthy phone calls as the CNS deals with their concerns, which are often clinical and non-clinical. The Support Worker can triage calls, deal with the non-complex clinical and non-clinical issues and then if needed the CNS will call the patient to address the complex issues. This saves the CNS considerable time which can be redirected to other patients.

- **Delivery of HNA and Care Plans**

  Case Study:
  Patient Concerns following HNA with Support Worker
  - Weight gain following surgery and treatment
  - Changes in bowel habit limiting daily activities
  - Frequent Panic attacks
  - Fatigue/ Loss of concentration/ Tired at work
  - Hot flushes

- Struggling with psychological and emotional issues

Intervention

- Patient attended the site-specific Health and wellbeing Clinic
- Self-referral to Cancer Information Centre for complimentary therapies and Anxiousness course
- Counselling sessions in place at Cancer Information Centre
- Appointment with finance advisor at Cancer Information Centre to discuss financial needs
- Approached workplace for long-term service benefits.
- Holistic needs & concerns discussed and a care plan formulated
- Advised to discuss ongoing management of HRT & medications with GP
- Referred to LWBC dietitian team for 12-week weight loss programme

- **Release of Doctor and CNS capacity**

  Gynae joint clinic: Feedback from Gynae-oncology Consultant on Support Worker role

  '*It is imperative that the nurse specialists are able to provide support and information to patients. Nurse specialists must primarily be in the clinic to provide patients with the benefit of their knowledge support and understanding, and not as a spare pair of hands in the clinic.*

  Hence the support worker role is key to the efficient running of this clinic in the following ways.

1. *The support worker has specific insight into the gynae-oncology cancer service and so can pick up on the issues patients may raise and pass this on to doctors or nurse specialists*
2. *The support worker will run the clinic, act as chaperone and collect outcome data*
3. *For medico legal reasons male doctors require a chaperone for all female pelvic examinations and I believe female doctors would feel far more comfortable with a chaperone as well. The support worker is an excellent chaperone, because of the understanding and familiarity with the patient group resulting from a defined role in gynaecology.*
4. *The support worker will allow the nurse specialists time to perform the important duties for which they are employed*
5. *By freeing up the nurse specialists there will be less cause for dissatisfaction on the part of the patients who may have come to the joint gynae clinic expecting to see their nurse specialist as well as a doctor*
6. *The support worker by being attached to gynaecology will get to know the patients and the way the doctors work so increasing efficiency in the clinic.'*

- **Patient Feedback on Urology Support Worker**

  "I appreciate your call"

  "Thank you for your help with my appointments"

  "You've been helpful and supportive"

  "It is nice to know I haven't been forgotten"

"Thanks for taking the time to listen and help me understand my own concerns and how to help myself"

"Thank you for assisting with my transport difficulties"

"You've been so kind and helpful"

"I appreciate being kept updated. It eases anxiety when I know what to expect. This makes managing my expectations easier"

"It's been really lovely to speak to you and I appreciate knowing there is someone I can make direct contact with if I have questions or need support"

Allied Health Professionals (AHP)

In addition to the Support Worker work force, additional AHP roles were funded to provide support for unmet needs following treatment and to introduce prehabilitation programmes. These included physiotherapists, dietitians, counsellors and exercise specialists. It is widely acknowledged that the effects of cancer and its treatment can lead to significant negative physical and psychological effects for patients.[4] Cancer prehabilitation and rehabilitation services provide appropriate assessment and treatment to prevent, minimise and address many of these negative effects.[5,6]

Depending on existing services already provided the Trusts had varying AHP requirements, therefore different roles were introduced at different organisations.

AHP Case Study examples:

Dietetics:

Patient X: 45-year-old lady diagnosed with hormone responsive breast cancer 1 ½ years ago and treated with chemotherapy, bilateral mastectomy with lymph node dissection, radiotherapy and subsequently started on hormonal therapy for 5 years.
Previously very active and attended regular gym classes twice per week (aerobics) and ran <5km on a weekly basis. Activity limited acutely by PICC line needed for chemotherapy, and frequent hospital appointments. Since completion of treatment she had suffered with reduced energy levels, fatigue and reduced range of movement in arm relating to surgery and radiotherapy.

Concerns:

- 10kg (1.5st) weight gain since diagnosis 1 year ago, presently BMI 33kg/m^2. Significant concerns with comfort eating and fatigue following treatment
- Skipping meals at times and trying to avoid carbohydrates to promote weight loss. Not eating same meals as family
- High state of anxiety due to association between hormone responsive cancers and being overweight. Had seen media campaigns relating cancer and obesity and wanted to do everything possible to reduce risk for the future
- Had cut out dairy products due to fear of hormones driving cancer growth/recurrence. Using organic oat milk as an alternative

Impact on patient:

- Thorough review of her approach to eating which enabled a regular and balanced meal pattern, which resulted in improvements to her energy levels and satiety
- Well-paced weight loss of 1-2lb/week, with improved levels of satiety and noted associated improvements to confidence
- Able to involve her family in meal planning and preparation, which resulted in improvements to their diet e.g. her husband had also lost weight
- Increase in calcium intake to help support long term bone health to offset the effects of hormonal therapy
- Accessed physiotherapy support to help reintroduce physical activity, to support her physical and psychological health

Physiotherapy:

Patient Y: 65-year-old man referred by cancer support worker following Holistic Needs Assessment. Seen by physiotherapist within 7 days of referral. Patient had undergone abdominal anterior resection 3 months previously and had sustained biceps rupture during inpatient stay. Patient had received no specific physiotherapy input post-op

Reason for referral: Patient unable to wash and dress without pain in posterior thighs. Ongoing weakness from ruptured biceps with weakness and pain in left upper limb. Patient unsure what exercise he can return to with a colostomy and previously enjoyed walking and swimming. Previously did daily exercises for persistent low back pain.

Outcomes:

- Reduced pain and increased function in upper limb. Able to carry out activities of daily living independently
- Attending local gym 3x per week
- Returned to previous job

Evidence for Prehabilitation services:

- **Respiratory Consultant feedback:**

'Physical activity and optimisation of nutrition are some of the best evidenced treatments in respiratory conditions. Unfortunately, investment in these treatments lags behind the evidence. There is significant evidence that optimisation of medical conditions, nutrition and physical activities in addition to smoking cessation is associated with improved outcomes.

Having support from allied health care professionals which expertise in nutrition, and safe exercise regimes will be critical in trying to offer patients the best treatment modality for their lung cancer. Spending less time recovering in hospital due to this optimisation is better for patients, hospital and the NHS. The team have been positive and focussed in their support of this initiative working alongside us as a team.'

7. Personalised Care Intervention Activity:

The workforce described above working alongside the traditional CNS/ medical roles has enabled the delivery of the PCS interventions across all cancer tumour sites

Insert Trust Recovery Package Data activity. You may want to include more detail in an appendix

8. **Summary of Staff and Costs for delivery of PCS:**

Insert individual tables – to include

Role	Band	WTE	WTE Cost £	Total Cost £	Funding needed from (date)

9. **Robust IT remote monitoring system:**

A key enabler to support robust self-supported management pathways is a remote monitoring system to ensure surveillance tests are scheduled, attended and safely monitored. It is a national requirement that all breast, colorectal and prostate patients have in place the following:

- A remote monitoring system integrated with their cancer system (e.g. Trust's bespoke cancer system, Infoflex etc) or a remote monitoring system which uses standalone software designed for the purpose (but not including spreadsheets).

Insert current remote monitoring/ tracking methods and preferred RMS option i.e. Infoflex; Trust own system, SCR. Include costs for system. (You may or may not want to include this section)

10. Options Appraisal:

	Advantages	Disadvantages
Option 1: **Do Nothing** **Patients would not receive Personalised Care and Support interventions and therefore Personalised Stratified Follow-Up would have to be stopped**		This option will not meet the requirements of the NHS Long Term Plan for the delivery of Personalised Care for all cancer patients from April 2021. This option would represent a backwards step in the care of cancer patients, reversing the transformation work undertaken in cancer services over many years. This option would present a performance and financial risk to the Trust, with large numbers of patients requiring Consultant and

		CNS-led follow up appointments. Post-operative length of stay would increase without the physiotherapy and dietetic services. This option is likely to result in a greater number of GP, other OP services and ED attendances as there are no services available via the cancer teams to address consequences of treatment. This option would increase the CNS workload and would require significant investment in Band 6 and 7 CNS to meet patient needs.
Option 2: **Incorporate Personalised Care and Support and Personalised Stratified Follow-Up as business as usual**	***Meets requirements of the NHS Long Term Plan.*** **PCS interventions enable to delivery of PSFU to maintain and increase outpatient capacity** **Appropriate support to patients offered from the point of diagnosis and throughout the pathway using a cost-effective workforce** Greatly improved patient experience.	**Cost to deliver the PCS service**

	Optimises skill mix, reduces demand on CNS and medical workforce.	

Appendix 1:

Outpatient appointment release supporting information

Appendix 2:
Evidence to support Support Worker role

Appendix 3:

Treatment Summary patient feedback

References:

[1]NHSE England (2019) Draft Personalised Stratified Follow-Up Handbook – available on request. Final version due end 2019
[2]NHS England (2019) NHS Long Term Plan. Available online: https://www.longtermplan.nhs.uk/
[3]Maddams, J; Utley, M., Moller, H. (2012) Projections of Cancer prevalence in the United Kingdom 2010 – 2040. British Journal of Cancer 107, 1195-1202
[4]Macmillan Cancer Support (2013) Throwing light on the consequences of cancer and its treatment. Available online: https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf
[5]Macmillan Cancer Support (2017) Cancer Rehabilitation Pathways. Available online: https://www.macmillan.org.uk/assets/macmillan-cancer-rehabilitation-pathways.pdf
[6]Macmillan Cancer Support (2019) Prehabilitation for people with cancer: Principles and guidance for prehabilitation within the management and support of people with cancer. Available online: https://www.macmillan.org.uk/assets/prehabilitation-guidance-for-people-with-cancer.pdf