

Living With and Beyond Cancer Progress Report to March 2019

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1.0 Background

The independent cancer taskforce report - [Achieving World Class Cancer Outcomes, a strategy for England 2015-20](#), identifies key actions required to improve the long term quality of life for people affected by cancer in England. Chapter 7 includes a series of recommendations specifically aimed at meeting the needs of people living with and beyond a cancer diagnosis, particularly at the end of treatment. The report recognises that although more people are surviving their cancer, not all of them are living well, and that further work is required to ensure that care is tailored to their specific needs.

In 2017, the Cheshire and Merseyside Cancer Alliance (CMCA) was successful in a bid to secure cancer transformation funding to take forward key elements of the living with and beyond cancer (LWBC) agenda. Priorities set out in planning guidance included the roll out of risk stratified pathways for breast cancer follow up, and access to the "[recovery package](#)" for all cancer patients.

Each provider Trust in CMCA was approached, and an Alliance-wide improvement plan was developed. The plan included the priority areas mentioned above, but also extended to other tumour groups including colorectal, prostate, lung and gynaecological cancers, and an "after-cure" project at Alder Hey Children's Hospital. Clinical protocols for follow up, based on best available evidence were developed in collaboration with the Alliance Clinical Quality Groups, and these are integral to the remote surveillance patient management system (appendix 10.1).

With the support of a core Project Management team, improvement trajectories were agreed for these pathways, and funding was released for the recruitment of key personnel and infrastructure to deliver the programme.

The aim was to improve the number of patients in receipt of recovery package interventions at all cancer units, and to introduce a risk stratified follow up pathway at 6 Breast units, 7 Prostate units, and 4 Colorectal units as detailed below:

Trust	Breast	Prostate	Colorectal	Recovery package
Southport and Ormskirk	N/A	√	√	√
Aintree	√	√	√	√
Royal Liverpool and Broadgreen	√	√	√	√
St Helens and Knowsley	√	√	X	√
Warrington and Halton	√	√	X	√
Countess of Chester	√	√	x	√
Clatterbridge Cancer Centre	x	x	x	√
The Walton Centre	N/A	N/A	N/A	√
Wirral University Teaching Hospital	√	√	√	√
Liverpool Women's	N/A	N/A	N/A	√
East Cheshire Trust	x	x	x	√
Mid Cheshire Hospital Trust	x	x	x	√
Liverpool Heart and Chest Hospital	N/A	N/A	N/A	√
Alder Hey Children's Hospital	N/A	N/A	N/A	√*

√= yes x= no *age appropriate "after-cure" service

2.0 Purpose of this document

The purpose of this document is to provide a picture of the improvements made so far across the Alliance. It outlines the current position across all participating units, deliverables in terms of out-patient capacity savings, and resources allocated to implement the pathways at Trust level.

This document may be used to inform discussions between commissioners and providers about the impact and effectiveness of the programme so far, and to reach agreement about local solutions to ensuring sustainability beyond the transformation funding period.

3.0 Data Definitions

At the outset of the project, there was a lack of accepted data definitions for metrics related to delivery of the LWBC agenda. This was addressed in Cheshire and Merseyside by the development of a local CQUIN scheme (appendix 10.2), which included not only data definitions, but also agreed inclusion and exclusion criteria.

These criteria were used to measure improvement across the Trusts involved in the CQUIN, and also as quality measures for the Trusts who were not participating in the local scheme.

Trajectories for improvement were set according to activity data from [CANCERSTATS](#).

In 2018, consultation took place with stakeholders nationally regarding the development of an agreed data set and accompanying definitions to measure the implementation of the LWBC interventions, and these have been adopted by the Alliance since Q3 2018/19.

These data definitions have now been published and form part of the NHSE assurance framework for Alliances (appendix 10.3).

4.0 Finance

In order to support the rollout of the LWBC work streams, each Trust was allocated Cancer Transformation Funding (CTF) during the period 2017-19* . The amount of funding was based on activity levels, and informed by the findings of the [TrueNTH Prostate Cancer Project](#). The funding allocation to Trusts included salaries for Cancer Support Workers and for local data collection. All costs associated with the patient management system, [MyMedicalRecord](#) (MMR) were also covered by the Alliance funding (approximately £104k over 2 years) as were local integration costs (approximately £50k over 2 years). Wirral University Teaching Hospital declined the offer of MMR and instead developed an in-house patient management system as part of their Global Digital Exemplar work streams.

**the earlier implementer sites had been supported by Macmillan funding from 2015-17*

The trust level CTF allocations for 2017-19 are shown below:

Trust	Breast	Prostate	Colorectal	Other	Data collection
Southport and Ormskirk	N/A	£35,937	£31,000	£20,888 QOL	£10,460
Aintree	N/A	£31,000	£31,000	£31,000 QOL	£10,460
Royal Liverpool and Broadgreen	£52,000	£26,000	£52,000	£76,000 Urology CNS	£10,460
St Helens and Knowsley	£31,000	N/A	N/A	£20,888 QOL £10,270 CSW top up	£10,460
Warrington and Halton	£52,000	£31,000	N/A	N/A	£10,460
Countess of Chester	£31,000	£36,028	N/A	N/A	£10,460
The Clatterbridge Cancer Centre	N/A	N/A	N/A	£26,000 H&N CSW	£10,460
The Walton Centre	N/A	N/A	N/A	N/A	£10,460
Wirral University Teaching Hospital	£52,000	£26,000	N/A	N/A	£10,460
Liverpool Women's	N/A	N/A	N/A	£26,000 Gynae CSW	£5,230
East Cheshire Trust	N/A	N/A	N/A	N/A	£10,460
Mid Cheshire Hospital Trust	N/A	N/A	N/A	£18,000 PM extension	£10,460
Liverpool Heart and Chest Hospital	N/A	N/A	N/A	£26,000 Lung CW	£10,460
Alder Hey Children's Hospital	N/A	N/A	N/A	£55,000 Aftercure	N/A

5.0 Data collection and reporting

Data items required to measure the implementation of the LWBC work streams at Trust level were collected quarterly from Q3 2017/18 until Q2 2018/19 (end June 2018). After this point, the data collection frequency was changed to monthly so that it was in line with all other data returns associated with the mandatory Cancer Outcomes Services Dataset (COSD).

Recovery package data requirements included the number of holistic needs assessments (HNA) carried out at diagnosis, end of treatment summaries issued, and attendances at health and well-being events (HWB). In July 2018, the data for HNA was extended to include assessments carried out at all pathway points, rather than just at diagnosis.

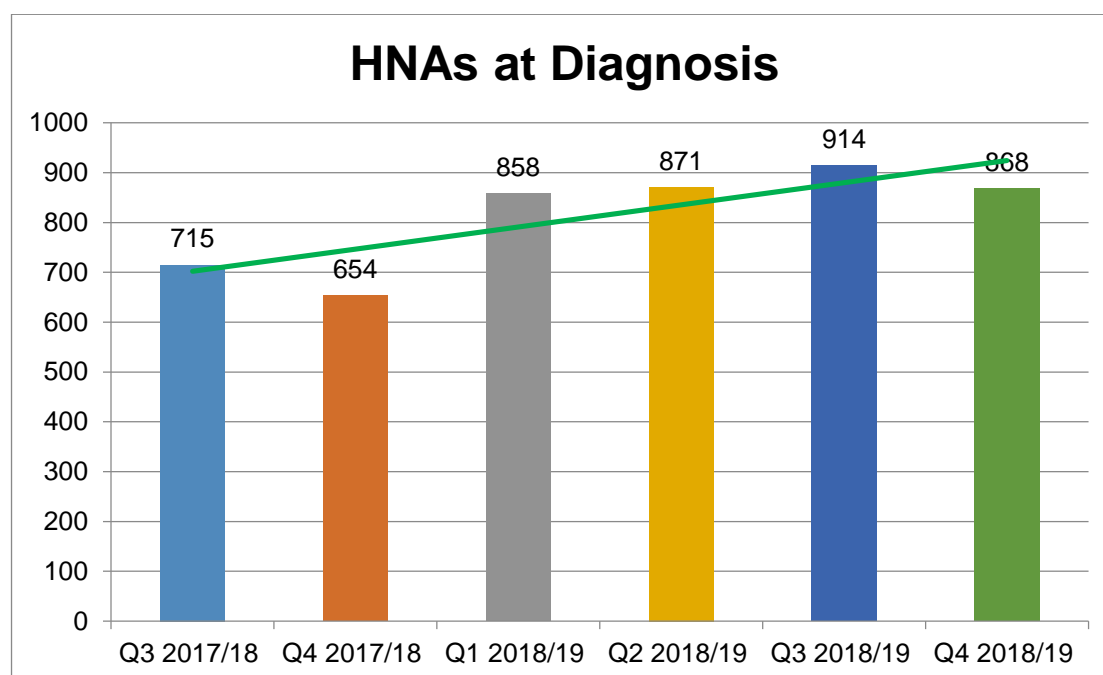
Data submitted from Trusts regarding the numbers of patients enrolled to risk stratified pathways is also cross-referenced with reports received directly from MMR. For the purposes of this report, the MMR data is used (where available) as this allows analysis based on protocol type, and time from diagnosis to enrolment. All patients enrolled since inception are included in this report, and it should be noted that the Aintree Breast Team, and St Helens and Knowsley Prostate team, had already moved a significant number of patients over to remote surveillance (open access) prior to the Alliance project. The data submitted is analysed by the Alliance team and then reported back to Trusts via the Lead Cancer Nurse. This data is also made available to commissioners to inform local quality and improvement plans. The Alliance team reports all elements of the LWBC programme to regional NHSE team, and via temperature check reports to the National Cancer Programme team.

6.0 Performance to end March 2019

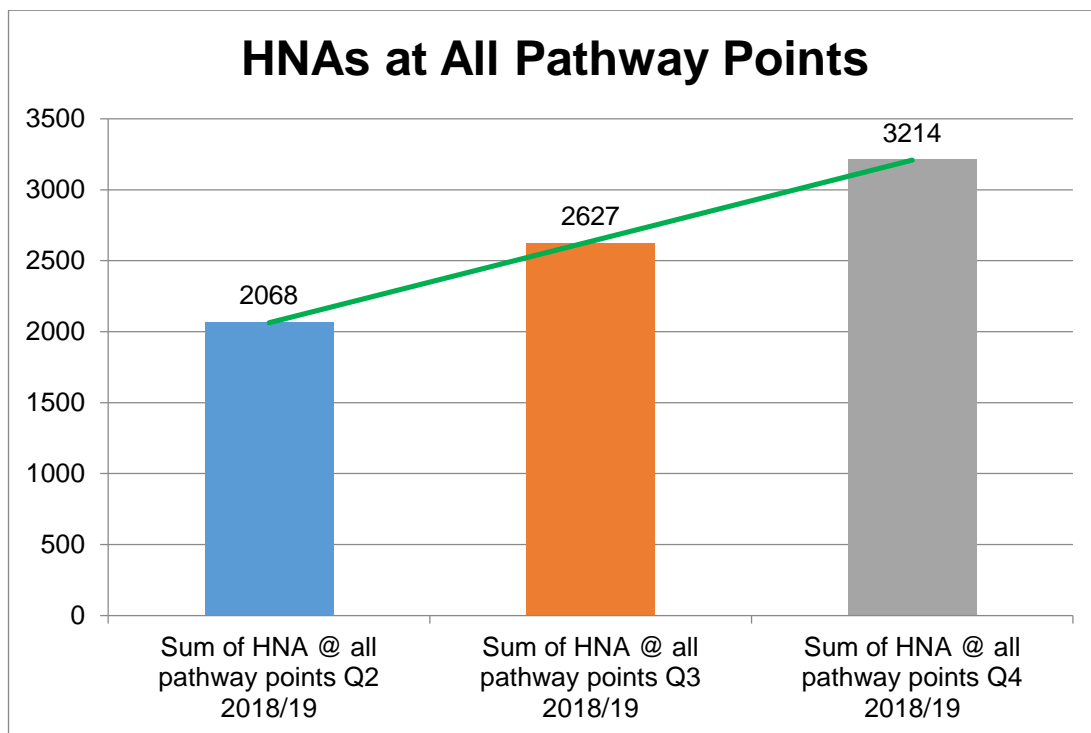
Data is collected from all Trusts on a monthly basis and collated into aggregate quarterly performance for reporting purposes.

6.1 Recovery Package

There has been a consistent rise in the number of Holistic Needs Assessments (HNA) at diagnosis:

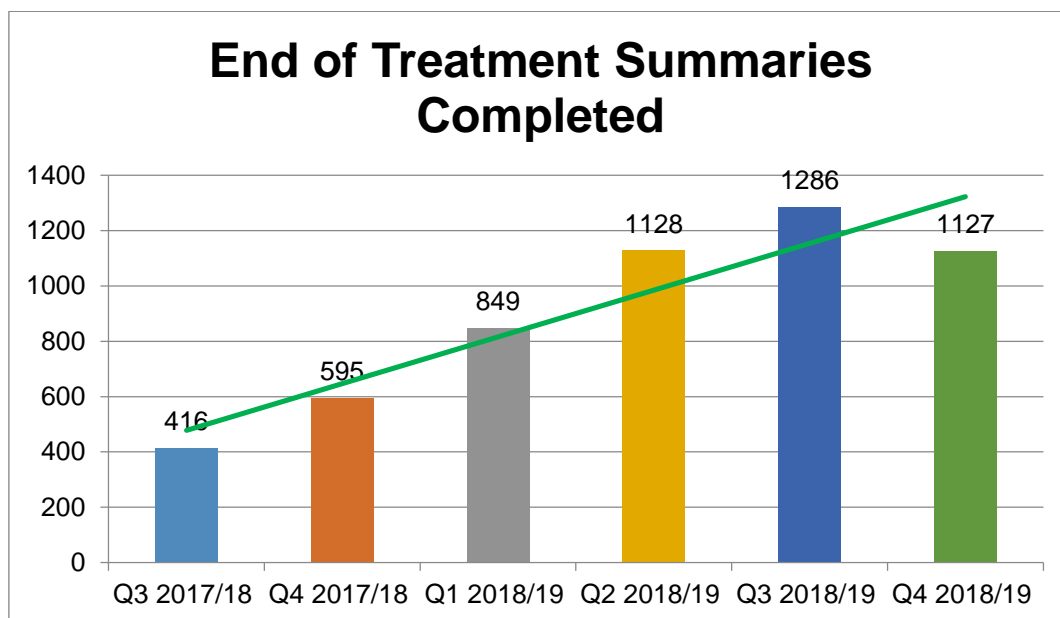


Data collected since July 2018 regarding the number of HNAs at all pathway points has also shown an increase in the number of patients undergoing assessment:



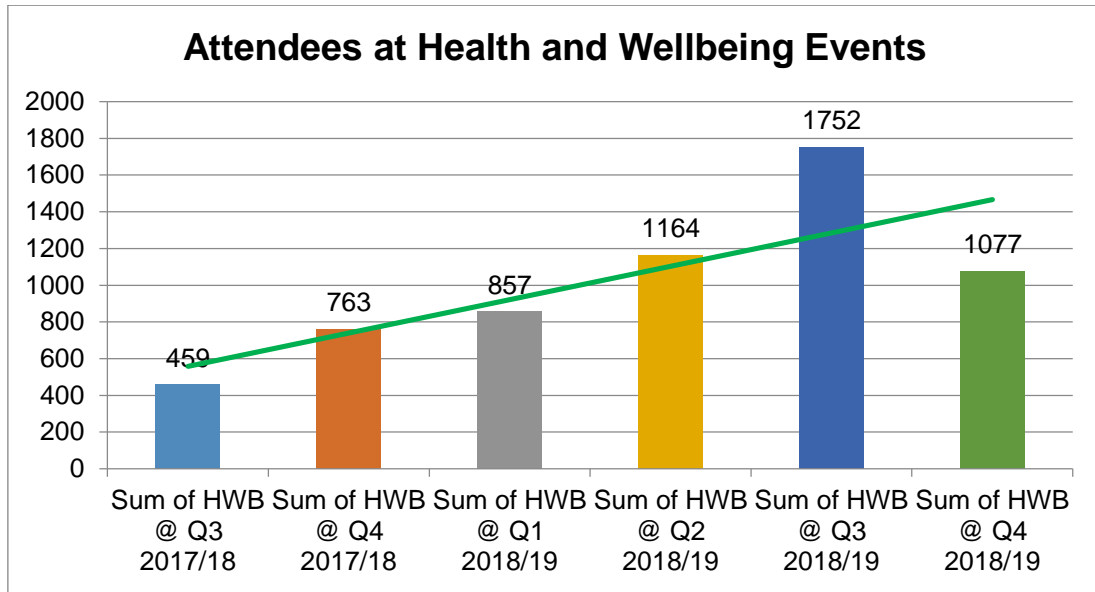
Although end of treatment summaries have posed difficulties, in both completion and data collection across all provider sites, there has been a steady rise in the number of EOTs issued:

NB: No EOTS data has been received from the Royal Liverpool and Broadgreen Hospital for March 2019, and data for Mid Cheshire Hospital is incomplete at the time of reporting; hence the numbers appear to be reduced for Qtr. 4.



More patients are benefitting from Health and Wellbeing interventions:

NB: No HWB data has been received from the Royal Liverpool and Broadgreen Hospital for March 2019; and data for Mid Cheshire Hospital is incomplete at the time of reporting; hence the numbers appear to be reduced for Qtr. 4.



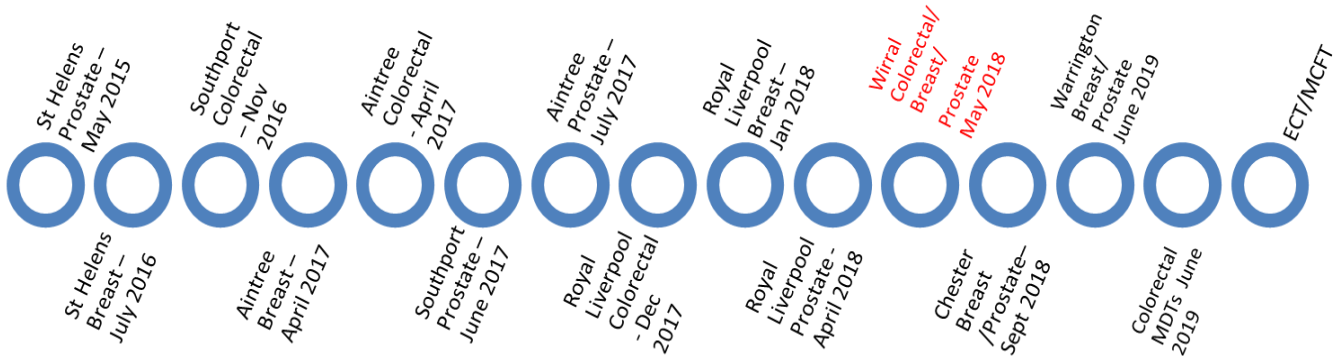
6.2 Risk Stratified Pathways

Data extracted from patient management systems has allowed the recruitment rate to risk stratified follow up pathways at each Trust to be monitored. This data includes all patients registered for remote surveillance since inception of the pathways in CMCA, and up to March 2019.

Implementation took place during a phased programme, with the earliest launch being May 2015 (as part of a national TrueNTH pilot).

The implementation timeline is as follows:

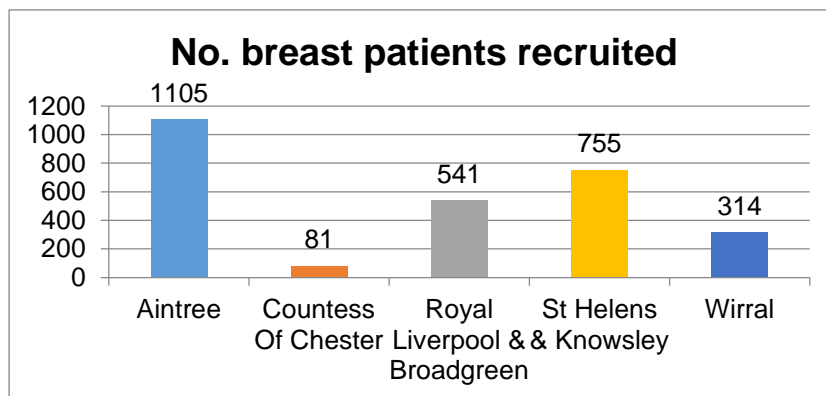
Wirral are not using MMR and have implemented a Trust- designed IT solution



6.2.1 Recruitment to March 2019

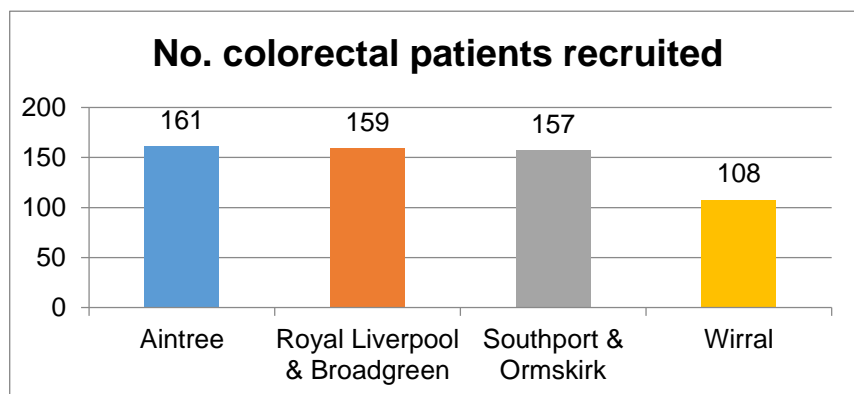
Breast

In the period up to March 2019, a total of 2796 patients from the following Trusts have been recruited to a risk stratified (remote surveillance) pathway for breast cancer:



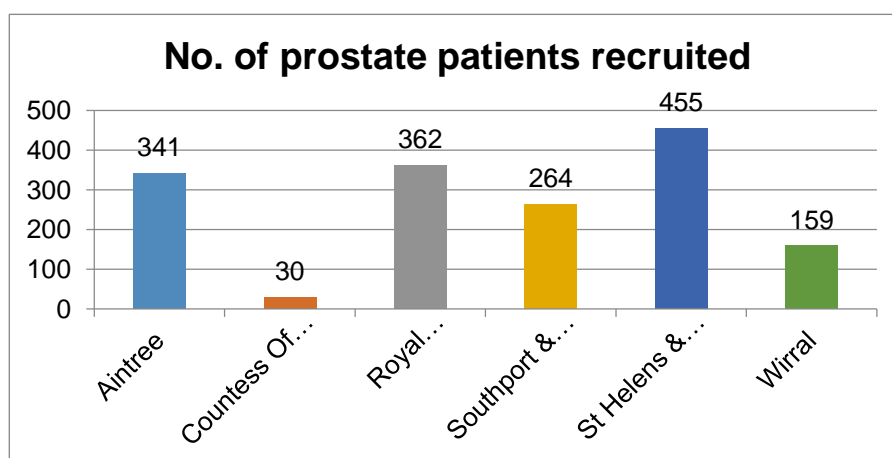
Colorectal

In the period up to March 2019, a total of 585 patients from the following Trusts have been recruited to a risk stratified (remote surveillance) pathway for colorectal cancer:



Prostate

In the period up to March 2019, a total of 1611 patients from the following Trusts have been recruited to a risk stratified (remote surveillance) pathway for Prostate cancer:



6.2.2 Return on investment

Data from MMR and Wirral's in-house system was used to model the 5 year effect of recruiting patients to a remote surveillance pathway on outpatient appointments (see appendix 10.2 OPA savings assumptions).

The number of OPAs saved as a result of the new pathway assumes all "active" patients complete their prescribed protocol remotely, and that each surveillance episode would previously have resulted in a face to face OPA. Those deceased/ recalled/suspended are excluded from the modelling to ensure that projections take into account the activity required more accurately.

Estimated OPAs saved (5 year effect) at each Trust to March 2019 are shown below:

Site	Hospital Name	OPAs Saved
Breast	Aintree	2349
	Countess Of Chester	345
	Royal Liverpool & Broadgreen	2218
	St Helens & Knowsley	2714
	Wirral*	1884
Breast Total		9510
Colorectal	Aintree	1367
	Royal Liverpool & Broadgreen	1059
	Southport & Ormskirk	1200
	Wirral*	608
Colorectal Total		4274
Prostate	Aintree	5010
	Countess Of Chester	420
	Royal Liverpool & Broadgreen	4260
	Southport & Ormskirk	3162
	St Helens & Knowsley	3265
	Wirral*	954
Prostate Total		17071
Grand Total		30855

**Wirral IT systems for recording activity do not provide the same level of data as MMR for the purposes of calculating OPA savings, therefore OPA saving has been calculated using the average OPA saving for all patients registered in MMR (n=6)*

6.2.3 Added benefits

Added benefits from the use of a remote surveillance pathway include:

- Release of Clinician time for more complex activity
- Enhanced safety netting with NO patients being lost to follow up as a result of tracking functionality
- Sustained levels of patient experience- patients report feeling well supported and enjoy having access to a dedicated support worker
- Audit functionality allows recall and relapse rates to be monitored
- Consistency in the adherence to follow up protocols- no deviation from agreed schedule, fully auditable
- Reduction in admin resource needed- all letters and appointments generated directly from the MMR system by support worker leaving medical Secretaries to focus on other priorities
- Enhanced patient information offer with online resources available signposting to local groups and trusted websites
- Communication possible via online secure messaging meaning patient's enquiries can be dealt with in a timely manner

7.0 Summary and Recommendations

There has been a consistent increase in the number of patients being offered recovery package interventions at all pathway points. Identifying patient concerns means that more personalised care can be offered, and appropriate signposting to additional services can be initiated.

Remote surveillance pathways for common cancers have been embraced by clinical teams at Trusts in CMCA. The benefits to both Trusts and to patients have been well documented.

Costs associated with implementation of the pathway are minimal, and are within the envelope that is released from the reduction in Consultant - led outpatient activity. The Alliance would recommend that Trusts:

- Further develop recovery package interventions in line with the NHS Comprehensive Model for Personalised Care and Support, utilising patient activation measures and other KPIs to demonstrate longer term impact
- Ensure complete data is entered to COSD in respect of LWBC interventions
- Continue to expand the risk stratified follow up pathway for common cancers (Breast, Colorectal, Prostate) to achieve the NHSE targets for recruitment (50% Colorectal and Prostate, 66% Breast) in 2019/20
- Test the remote surveillance pathway with other tumour types (advanced colorectal/HPB/Haemato-oncology)
- Audit and monitor patient satisfaction and recall/suspension rate
- Continue to model the cost benefits of the programme
- Refine follow up/surveillance schedules to reflect emerging evidence and best practice
- Work with commissioners to ensure adequate remuneration and sustainability of the service
- Use every opportunity to share learning both within CMCA and with other Cancer Alliances
- Work with commissioners to explore possibilities of remote surveillance for additional non-cancer patient cohorts

8.0 Next Steps

A joint statement of intent regarding the implementation of personalised care and support for people living with Cancer in Cheshire and Merseyside has been developed with Macmillan Cancer Support. This will be taken forward by a Personalised Care Steering Group to ensure that progress made so far continues to be built upon. The NHS Long Term Plan sees emerging Primary Care Networks being tasked with ensuring that more people have access to personalised care for a range of long term conditions, and our work will inform the development of appropriate services for people with cancer. We will work with programme leads at HCP level to embrace findings of the [National Personalised Care Demonstrator sites](#) as they are published.

The Alliance intends to support the continuation of the remote surveillance pathways for common cancers in the financial year 2019/20. The implementation of the pathway for patients with advanced colorectal cancer affecting the liver will also be tested along with a pathway for Gynaecological cancer, and Lung cancer. We will develop a protocol for remote surveillance of selected Haemato-oncology patients at one Trust. The Alliance will also work closely with The Clatterbridge Cancer Centre to implement a follow up pathway with Prostate patients receiving care at the tertiary centre. It is also our intention to implement Breast and Colorectal risk stratified pathways at East Cheshire, and Mid-Cheshire Hospital Trusts. These 2 Cheshire Trusts, along with the Countess of Chester will be early implementers of the newly launched Somerset Cancer Register (SCR) risk stratified follow up module.

Patient management systems (MMR and SCR) will be fully funded for this period, and training for support workers and others using these systems will continue. Resource for local data collection will also be funded, and the Alliance host the personalised care steering group to monitor regional progress against the NHSE metrics. In line with National aspirations, trajectories will be set for Breast, Colorectal and Prostate cancers so that by Q42019/20, recruitment to a risk stratified, personalised follow up pathways will reach 66%, 50% and 50% respectively. It is expected that all of these patients will benefit from development of a personalised care plan, enhanced information and education to enable self-management, and referral to local health and well-being services.

At Trust level, this translates to quarterly recruitment of the following numbers of patients by March 2020:

Trust	Colorectal Q4 Target	Prostate Q4 Target	Breast Q4 Target
Aintree	30	32	51
Countess of Chester	22	5	36
East Cheshire	17	19	45
Mid Cheshire	20	25	43
Royal Liverpool	25	35	73
Southport and Ormskirk	17	21	
St Helens and Knowsley	29	31	49
Warrington and Halton	17	20	44
Wirral	33	67	59
Totals	210	255	400

Trust level trajectories will be set to work towards these targets as part of the 2019/20 funding agreements.

9.0 Contacts

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10.0 Appendices (NB. This report and all of the appendices can be accessed at the [CMCA Website](#))

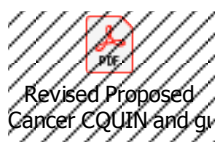
10.1 Protocol



10.2 OPA savings assumptions



10.3 CQUIN



10.4 National metrics

