



Living with and Beyond Cancer – Summary Report

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1. Executive summary

There are increasing numbers of people who are surviving cancer and living longer within the United Kingdom and in the West Midlands. Currently there are 2.5 million people in the United Kingdom who are living with cancer and 2 million of these live in England. A study by Maddams J. et al (2012) using national cancer registry data indicates that given the current trends in earlier treatment and improved outcomes it is anticipated that the numbers of survivors will increase by 1 million per decade up to 2040 in the United Kingdom. The largest rise will be amongst the over 65 age group where a quarter of this age group will be people living with cancer.

National guidance published by the National Cancer Survivorship Initiative (NCSI) 2013 – www.nsci.org.uk gives recommendations and tools to enable and support the development of services to improve the lives of people living with cancer. West Midlands Strategic Clinical Network identified a need to understand current service commissioning and provision for people living with cancer based on the guidance from the NCSI and a baseline mapping exercise was completed in 2014.

Findings from the project indicate that NCSI and Recovery Package Initiatives such as Holistic Needs Assessment (HNA) Health and Wellbeing (HWB) events are more established within secondary/tertiary provider services and there are several Macmillan Cancer Support funded projects within these provider organisations. They are supporting the development and roll out of the NCSI such as Electronic HNA (eHNA) Other third sector organisations such as Penny Brohn and Prostate UK have more projects based within the community in the West Midlands and there is some joint working between these stakeholders to improve services along pathways such as a joint funded project in Staffordshire. All the Third sector projects are funded for specified period of time. A similar theme was found in the delivery of Health and Wellbeing events that take place in provider services. These mainly rely on charitable funds and have no long term funding streams which have delayed or halted further roll out in the community.

There are very few examples of services that have been commissioned to support people living with cancer within the West Midlands. Commissioning services included cancer within the Long Term Conditions in some Clinical Commissioning Groups (CCG) and cancer was identified in a few CCG`s commissioning priorities in 2014/15. One CCG in Solihull has made real progress in working with its provider services and local authority to provide an integrated pathway for colorectal cancer survivors post-surgery.

There are a number of recommendations made as a result of the project which will require commissioning services to review the current pathway provision for cancer survivors within their CCG area. Commissioning requires support and guidance such as service specifications and more integrated working with local authorities, patient voice, third sector and acute providers. Nationally there may be additional support and leverage provided by the new Cancer Strategy which will be published in 2015. Strategically Cancer Clinical Networks are well placed to provide support and

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guidance to commissioners and provider services. It is envisaged that further project work around the recommendations can be provided by West Midlands Strategic Clinical Network, but this will be dependent on other cancer work priorities and resources available.

1. Introduction

There are a number of significant challenges the NHS faces in managing aspects of the Cancer pathway. One of these is the delivery of good supportive quality services for people who will be living with cancer for many years. Currently many of the cancer survivor population are still managed actively with secondary care in terms of follow up, holistic needs assessment and health and wellbeing sessions. In order to effectively manage cancer survivors now and in the future, Clinical Commissioning Groups (CCGs) will need to change the way they commission services to meet the needs of this population and embed the principles of the National Cancer Survivorship Initiative (NCSI) into future commissioning intentions.

1.1 Context

The number of people Living with and Beyond Cancer is increasing. Nationally there were 1.5 million cancer survivors who were living for more than 5 years in 2010. It has been estimated that this will increase to 4 million by 2030 in England (Macmillan Cancer Support 2012).

Prevalence data collated indicates similar findings. Within the West Midlands the prevalence of people living longer than 20 years with cancer was 159,700 in 2010 and will increase by 50 per cent to 310,300 by 2030. (Cancer Commissioning Toolkit data 2014). The increasing and ageing population nationally and the West Midlands means locally within the region there are significant challenges around meeting the demands and developing capacity within the cancer pathway.

A number of national guidelines/ policies and supporting tool kits have been developed to address cancer survivorship. The National Cancer Survivorship Initiative (NCSI) "Taking action to Improve Outcomes" in 2013 published a toolkit which identified how key interventions such as Recovery Package would improve outcomes for this population of patients. The report recommended the commissioning of a number of initiatives such as the Recovery Package. The Recovery Package and associated elements were seen as key interventions that would support people and carers to live well with their cancer post active treatment.

The Recovery Package Elements:

- Holistic Needs Assessment
- Treatment Summaries
- Cancer Care Reviews
- Education and Support events.

In addition to this it was recognised that Health and Well Being events (including physical activity) and managing Consequences of Treatment plus stratified follow up pathways need to be included in future commissioning intentions. Case studies and evaluation of the Recovery Package published by Macmillan Cancer Support- Recovery Package "Sharing good practice" (2014) http://www.macmillan.org.uk/Documents/AboutUs/Health_professionals/MacVoice/Sharinggoodpractice_TheRecoveryPackage.pdf

indicated that there was greater number of positive patient experiences and larger numbers of empowered patients following interventions such as stratified follow up or care planning. The report however recognised that in order to implement the Recovery Package or other elements such as stratified follow up, a shift in thinking and culture is required by patients and organisations in order to successfully implement service change as well as improve routes back into secondary care if recurrence of cancer occurs for individual patients.

1.2 Additional guidance, policies and reports

There are also a number of supporting policies, guidelines and reports that have been published and align to cancer survivorship. The most recent NHS England report “5 year Forward View” includes cancer and cancer survivorship. <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

A new National Cancer taskforce will be developing a Cancer Strategy that will provide additional guidance to organisations in 2015 and is anticipated to include guidance on cancer survivorship service provision and commissioning.

Cancer survivorship is also linked to the National Outcomes Framework (2011) - Domain 2, 3 and 4 as well as the Public Health England Outcomes Framework 2013/16 – Domain 4. Additionally improving survivorship outcomes are linked to CCG Outcomes Indicator set 2013 as part of the 8 outcome indicators of cancer under “Enhancing Quality of life for people with Long Term Conditions”.

The Map of Medicine has published a suggested pathway for Survivorship (appendix 1) which has been used for pathway redesign regionally by one CCG.

The national annual Cancer Patient Experience Survey also reports on patient experience linked to recovery package elements and indicates good patient and improved experience when some elements of Recovery Package are used such as Holistic Needs assessment.

<https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patient-experience-survey/2014-national-cancer-patient-experience-survey-national-reports>

3 Living with and Beyond Cancer Project

The West Midlands Strategic Clinical Network (WMSCN) project commenced in June 2014 and formed part of the WMSCN business planning priorities for 2014/15. The rationale for the project was the need to understand what services had been developed since the National Cancer Survivorship Initiatives – “Stratified pathways”, “Taking Action to Improve Outcomes” guidance (2010, 2013) were published within CCGs and secondary care survivorship services in the region.

The project was supported by the formation of an Expert Advisory Group which is comprised of key stakeholders and patients. The group met quarterly and had terms of reference. It provided oversight and expertise to the project. Governance for project was through the WMSCN Executive team and Oversight group.

3.1 Project scope

The project included all Clinical Commissioning Groups, Acute Trusts, including specialist trusts such as Royal Orthopaedic Hospital, main third sector providers such as Macmillan Cancer Support, Penny Brohn, Prostate UK and hospices within the West Midlands. In the project scope were adult services within these organisations. Children's services were not included for this phase of the project.

3.2 Project Aim

The aim of the project was to review current cancer survivorship management within primary care, acute care and any main third sector provider and identify variation and best practice models. The information gained would provide a baseline of information on how initial recommendations from the National Cancer Survivorship Initiative 2013 have been implemented across the West Midlands region.

The information would be achieved through a mapping exercise that would then review current delivery against defined quality standards. The project will also review areas where the `Recovery Package` has been adopted and the methodologies used. Outputs from the project include a report with recommendations/ options for the potential introduction of elements of Recovery Package/ Living with and Beyond Cancer initiatives package within pilot sites in the West Midlands, as well as tools in the form of frameworks to support commissioning such as CQUIN framework for elements of the recovery package.

3.3 Objectives

1. Scope potential use of recovery package for cancer survivors amongst CCGs and understand methodologies used by London Cancer Alliance in the use of Recovery Package
2. Develop Expert Advisory Group to support and advise project
3. Collaborate with Macmillan Cancer Support work in survivorship
4. Produce a report for CCGs to provide recommendations/options for commissioning "Recovery Package" for cancer survivors
5. Support identification of pilot sites for Living with and Beyond Cancer initiatives within identified CCG`s.

The project timeline commenced in June 2014 – March 2015. The project is part of WMSCN Business plan priorities 2014/15. The project was planned as Phase 1 of WMSCN Cancer Survivorship project, recognising that ongoing work will be required post April 2015 within region to provide strategic support to CCGs to embed elements of Living with and Beyond Cancer in commissioning priorities .

3.4 Project methodology

The project had identified that currently there was no clear understanding of the current context of service delivery in cancer survivorship within CCGs, Acute Trust providers or Third sector within the West Midlands. It was decided to map any implementation of the elements from the NSCI commissioning toolkit within CCGs and acute trusts and third sector. The third sector mapping included the main charities involved within this area of service delivery - Macmillan Cancer Support, Prostate UK and Penny Brohn. The project also identified that Hospices should be included in the mapping as they may provide survivorship services.

The mapping timescales were July – November 2014. A semi structured proforma was designed and used for each organisation. Organisations such as acute trusts were asked to sense check information from interviews to support accuracy of information collated as this is where the most significant activity was based. Each organisation was offered a face to face interview except for Hospices who were contacted by email due to limited workforce capacity within agreed timescales.

3.5 Patient voice and insight

Patient voice and insight involvement in the project were sought through the Project Initiation phase of the project and the West Midlands SCN Patient Voice and Insight lead was informed and engaged in identifying patient representatives from the WMSCN region. It was identified that any patient representatives for the project should have a current experience (within last 2 years) of some aspect of cancer survivorship. The patient representatives would be an integral part of the Expert Advisory Group for the project. All organisations were asked about type of patient involvement in service design or delivery. The survey indicated there were varying levels of patient engagement for acute trusts and CCG`s in the cancer survivorship pathway which ranged from being part of trust Cancer Board to very limited patient involvement in the service design and provision of survivorship services. All current transformational regional “Living with and Beyond Cancer” projects appeared to have good patient focus and involvement ,with patients leading several areas of work such as interviewing potential service providers. Some CCGs used focus group input into development and outcomes of local survivorship projects

3.6 Expert Advisory Group

The Expert Advisory Group (EAG) was formed to provide support, guidance and expert insight into cancer survivorship project. All stakeholders were invited to be part of the EAG. The EAG had good representation from many stakeholders across the region and patient representation from cancer survivors who have recent experience of the Living with and Beyond Cancer pathway. The group was fully engaged for phase 1 of the project and provided insight to inform the findings of the project. It is anticipated that the EAG remains engaged with ongoing work in this area.

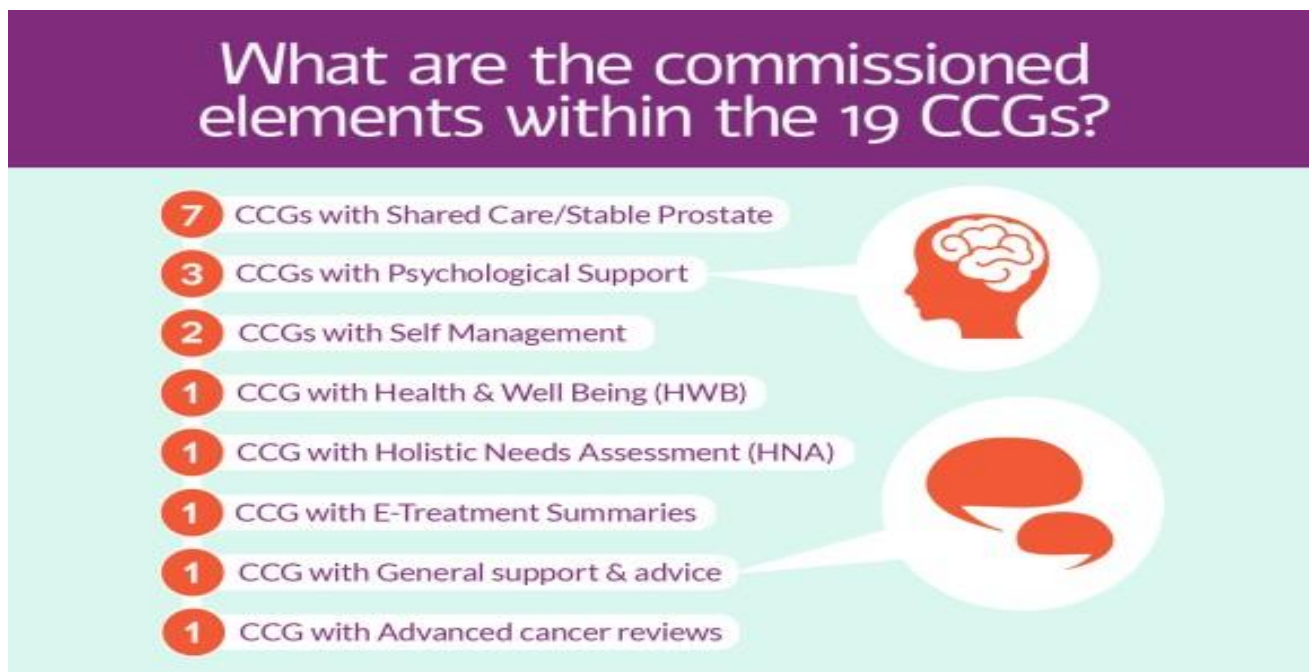
4. Results

The key findings from the mapping exercise were collated and analysed.

4.1 CCG`s

Of the 22 Clinical Commissioning Groups within the West Midlands 19 completed the questionnaires. The questionnaires were completed with the identified person in the CCG who had a link to either commissioning or cancer commissioning. Of the 3 CCGs who did not return questionnaires, there was no identified person within the CCG who had responsibility for cancer commissioning. A number of CCGs did not have a specific person who included cancer as part of their commissioning portfolio, instead it was often part of several commissioning responsibilities such as Long Term Conditions.

Commissioned elements of the Recovery Package/ NSCI



Of the 19 CCG`s returns, 1 CCG has made significant progress in the development of Living with and Beyond Cancer commissioning pathway. Solihull CCG has redesigned the Colorectal pathway with its acute provider Heart of England Foundation NHS Trust. It is currently in process of piloting Electronic Treatment Summaries which will aim to roll out through Birmingham and Sandwell in the future.

The most common commissioned element was risk stratified follow up/shared care for stable prostate within GP practices. Some CCGs used incentivisation such as a Local Incentive Scheme (LIS). There was some variation in the type of follow up used, for example, a number of CCGs used the CNS service for urology as additional guidance and monitoring with GP practices; some CCGs managed stable patients more independently with GP practices.

In addition, psychological support was commissioned by a small number of CCGs with a varying level of service offered. The most common type of service was low level support for all cancer patients at their local acute provider. Walsall CCG had a more developed programme of support which was run in the community by a Clinical Psychologist and was identified by the CCG as an area of good practice.

4.2 Other Living with and Beyond cancer projects

Further work around improving services for cancer survivors were planned in some CCGs.



It was recognised that other cancer pathways such as breast and colorectal could be followed up in primary care in some CCGs but none of these pathways had been fully implemented due to a number of reasons such as agreement about diagnostic reviews and GP workload. Some CCGs also recognised that GPs would require additional education and peer support in order to carry out more of this type of follow up. There were examples of CCGs providing education sessions such as Herefordshire CCG who were working with the local acute trust clinician to provide guidance and information to GP colleagues.

The “Transforming Cancer Care and End of Life Programme” in North Staffordshire, Stafford, Stoke and Cannock Chase CCG had adopted a different approach to commissioning cancer survivorship based on outcomes. Using a prime provider model for parts of the cancer pathway, it had developed a commissioning outcomes framework that incorporates the elements of the National Cancer Survivorship Initiative. This involved a large amount of public consultation and patient involvement

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in the development of the services with the aim of providing a whole cancer pathway approach across Breast, Lung, Bladder and Prostate pathways in adults. The project was being run by Macmillan Cancer Support and 4 Staffordshire CCGs. NHS England is a stakeholder.

<http://staffordshirecancerandcol.com/>

Health and wellbeing events had been piloted in several CCGs. These ranged from annual seminars for all types of cancer survivors, to attending a specific health and wellbeing follow up event for prostate survivors run in conjunction with Prostate UK and Dudley CCG. The common challenge around the continuation of these events was sustainability, with third sector, CCG or charity funding usually providing one off funding. All events that were held had reported excellent feedback from patients.

All cancer survivors have access to a cancer review at their GP practice post six months from diagnosis. The NCSI has identified that this review can provide additional self - management support for patients and signposting as well as advice on healthy living and exercise. The cancer review forms part of the Quality Outcomes Framework for GP`s and there is no standard format for delivery. Many CCGs were not aware of how these reviews were administered by GP practices as there is no reporting requirement to CCGs about this. Macmillan Cancer Support currently funds 2 projects to develop advanced cancer reviews within GP practice which will be delivered by practice nurses in Solihull and Birmingham South Central CCG. It is running a workforce development programme with both projects rolled out over 2 years in each CCG.

The survey asked if future commissioning would include cancer and elements of the NCSI/Recovery package. Just over half of CCGs in the region (55%) stated that they would be considering and trying to build this area into future commissioning priorities. Most CCGs did not have a cancer strategy to support commissioning and many did not mention it as part of their published current and future CCG Priorities. The CCG`s that did not indicate they would be commissioning cancer survivorship services cited reasons as “not part of priorities” or a “lack of need to improve survivorship service delivery in the community as they did not have capacity” and there were “no national levers”. It was highlighted that a lack of credible financial national modelling to demonstrate how funding could be moved from secondary to primary care was also not available. It was felt that this contributed towards a lack of development in LWBC services.

4.3 Acute trusts

Living with and Beyond Cancer service development and provision was more embedded across the region within secondary/tertiary care providers. The project found that there are a number of trusts who are working in partnership with Macmillan Cancer Support to develop tools such as electronic Health Needs Assessments or scoping projects and funding Exercise and Rehab courses in trusts or the community .

Holistic Needs Assessment (HNA) was reasonably well embedded into many cancer pathways. Some trusts such as Worcester Hospitals NHS trust were in process of

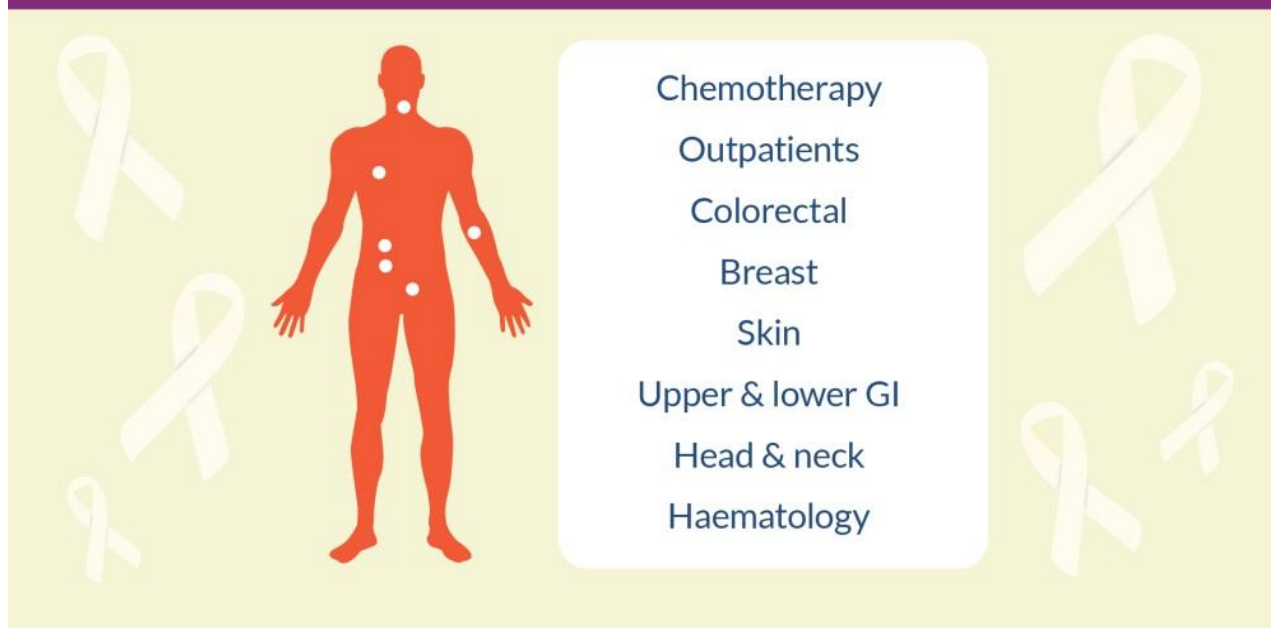
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extending HNA across all pathways within Multi-Disciplinary Teams (MDT's). Worcester had also trained Clinical Nurse Specialists in level 2 psychology to use as part of the HNA. Ongoing electronic HNA projects in trusts such as University Hospital Coventry and Warwickshire NHS Trust were being further extended into additional cancer MDTs. The use of Distress thermometer and patient concerns inventory were present in a number of trusts. Stafford Hospital had used trained volunteers to perform HNAs on patients which were reported to work successfully.

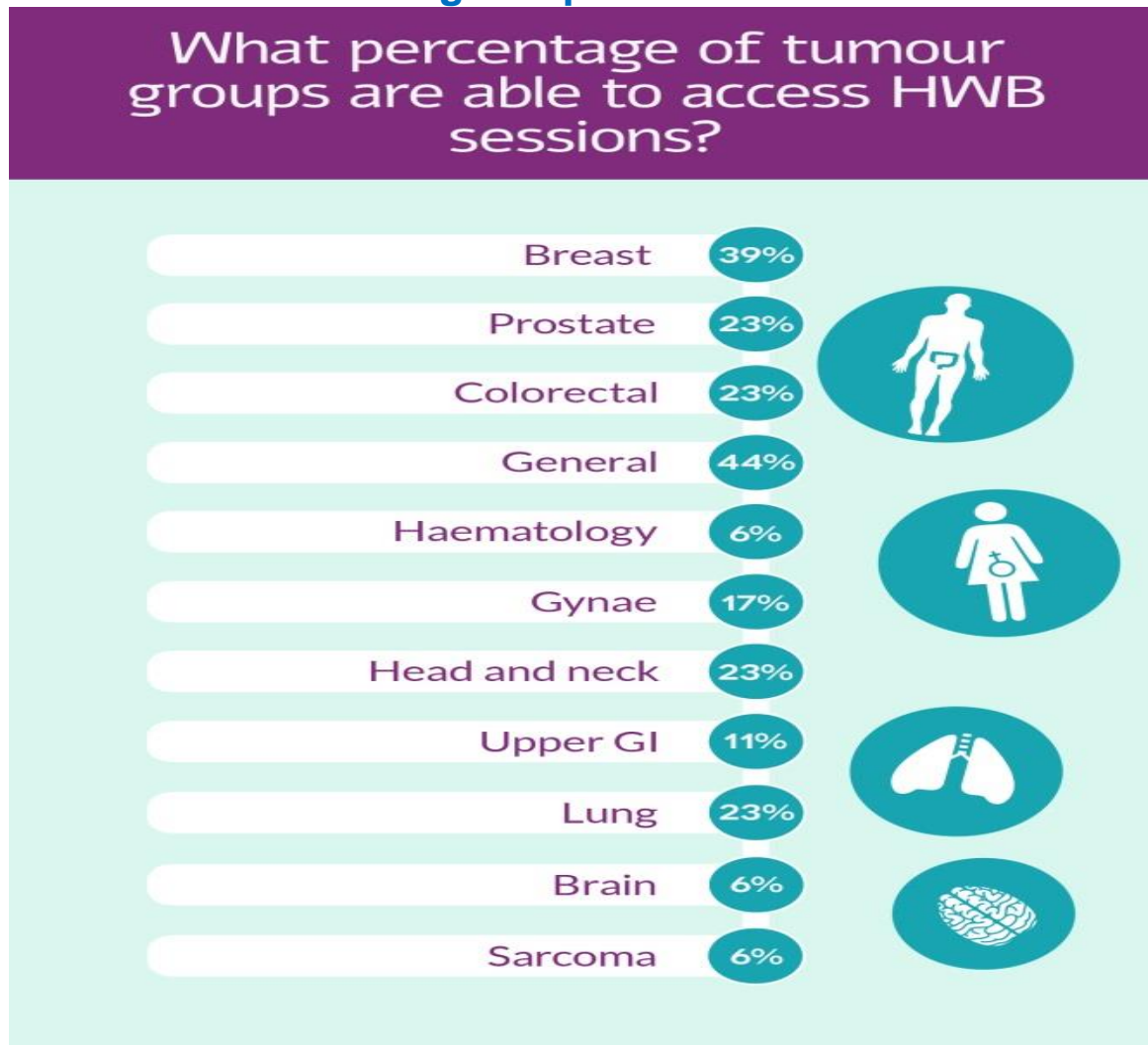
The use of Treatment Summaries (TRS) as a tool was variable across the region. Many trusts were using discharge letters that had a standard format or each MDT had a different format. A number of trusts adopted a format from the Somerset register. One trust had developed health care plans that incorporated Treatment Summaries as a model of good practice. Breast patients were most likely to have a TRS completed in the region. Several trusts identified that they would like to use Electronic Treatment summaries but had encountered issues around IT systems not being compatible with GP IT systems. Regionally some GPs have identified that TRS would support and inform them to manage patients once they were discharged from hospital.

Heart of England Foundation NHS Trust was piloting the use of electronic Treatment Summaries within the colorectal pathway. The pilot was due to commence in June 2015 and the aspiration was that the format could be transferred to all other tumour groups in the future.

Which tumour groups are using treatment summaries? (Standardised template)



Promotion of wellbeing and patient education



There were a variety of types of Health and Well being provision within acute care providers. Many of the events were similar to CCG events and had the same challenges in that they were 1 day events for all types of cancer survivors that were funded by charitable or third sector funds. They were not happening as often as MDTs would like or and none were sustainably funded. Breast cancer survivors had the most established provision in the form of regular Health and Well being sessions. These varied from a series of planned sessions to one day events. Heart of England NHS Trust were running regular block sessions for colorectal and breast patients with a CQUIN incentivisation from Solihull CCG until 2015.

Macmillan Cancer Support funded exercise programmes were used in Dudley. Penny Bohn provision in the form of Living Well/ Mindfulness courses was present in a number of areas such as Staffordshire and Sandwell. Some hospices in areas such as Hereford also ran support groups and living well courses that survivors could access. The development of a cancer exercise rehab 12 week programmes based on the cardiac rehab model used in leisure centres was being piloted in Sandwell.

Lung cancer survivors were able to access a local specific “Odyssey outdoor living course” that is run by third sector over 1 week in Wolverhampton.

Stratified Follow up pathways

Very few acute trusts had made progress in developing stratified follow up pathways outside the trust apart from stable prostate. Many recognised that increasing demand and capacity challenges were being faced and there was a need to address this. Some trusts were working with primary care colleagues in supporting stable prostate management in GP practices, but no other risk stratified follow up pathway for areas such as breast or colorectal had been established .

4.4 Other types of Living with and Beyond Cancer initiatives

Psychological support/ support groups

The availability of psychological support for survivors varied, with some tumour groups such as Breast being able to seek low level psychology support in Burton to Walsall’s more intensive Psychology support programme. Many Cancer lead nurses wanted to improve the availability of provision and work was planned as part of the remit of several Macmillan Cancer Support funded project posts within acute trusts regionally. Sandwell CCG funded a support centre in the community “Bridges Project” to provide advice and help to families and carers.

Many survivors were sign posted to mindfulness courses in the community run by Penny Bohn to provide additional support within the region. Prostate UK was running a male prostate support group at John Taylor Hospice in Birmingham.

Exercise rehab pilots

South Warwickshire cancer survivors were being identified by MDTs and invited to take part in research project “Pro rehab” run by Coventry University. It was seeking patients to take part in a 12 week programme and extended to all tumour groups.

5.0 Joint working

5.1 CCGs/ Local Authorities/ Acute Trusts

Many trusts did not have joint working or regular links with commissioners around cancer services for people living with cancer.. There were some CCG`s involved with acute trust cancer boards, but these were mainly focused on urgent priorities relating to cancer such as waiting times and not Living with and Beyond Cancer. There were very few cancer steering groups or examples were trusts and CCG`s were working together. The best example of work was Solihull CCG and Heart of England NHS Foundation Trust. A number of elements of NSCI were being piloted and they were also closely involved with Solihull Council in developing services for Living with and Beyond Cancer and cancer prevention agenda.

5.2 Third Sector

Three main third sector providers were involved across the West Midlands in a variety of projects with in CCGs or acute trusts. Macmillan Cancer Support had the largest involvement in survivorship with a variety of stakeholders and projects ranging from E treatment summary projects to workforce education for practice nurses to undertake advanced cancer reviews in GP surgeries. There was also a survivorship education forum for acute trust nurse professionals who were involved in Macmillan projects in Birmingham and Coventry area. This was run by Macmillan Cancer Support. There was also a joint project with Penny Brohn to provide a programme of health & wellbeing events, Living Well courses and on-going support for patients and carers in Staffordshire.

Prostate UK was involved in some work with Dudley CCG around Living with Prostate Cancer in the form of health and wellbeing sessions at a local hospice. Penny Brohn had a number of Living Well, Health and Well Being and self-management courses that people can self-refer or be sign posted to throughout the region; some are based within hospices. There were reported to be a number of joint working projects they were involved in with Prostate UK and Macmillan Cancer Support that looked at various aspects of the Living with and beyond cancer pathway.

All Hospices were asked about services they may offer to people who are not palliative and require support and living well courses. There was a poor response rate to the short survey. Of the responses received (40%) it was found that there was very little work taking place in these settings currently but some hospices did express interest in developing this aspect in the future. Marie Curie Hospice in Solihull did run some health and wellbeing events. Herefordshire also had some mindfulness and living well events that were run by Haven and Yelani.

6.0 Recommendations

The project has provided a baseline of information for organisations and raised the profile of Living with and Beyond Cancer within CCGs and acute trusts.

With an increasing number of people surviving cancer for longer, there is a need to review service pathways and improve provision with the community. Acute Trusts are challenged with increasing demands in numbers of referrals and treatment of cancer. In order to free capacity within acute trusts, a number of tumour pathways could be followed and managed within community with an appropriately skilled workforce and resourced pathway.

There are a number of recommendations that can be made as a result of the study.

	Recommendation	Recommended Lead
1	<p>Financial levers</p> <ul style="list-style-type: none"> • There are some examples of financial models that have been developed for example South West Strategic Clinical Network “Survivorship Recovery Package Implementation Plan” which provide some insight into financial models that could be adopted by CCGs regionally. • Regional work from the West Midlands Strategic Clinical Network will provide some tools and frameworks such as CQUIN templates and service specifications for elements of the Recovery Package for commissioning leads to include in future commissioning plans in 2016/17. • Regional work in this area needs to link to any recommendations and guidance published by the new NHS England Cancer Strategy that was published in 2015 • The adoption of national commissioning guidance from NHS England that is due to be published late 2015 will help strengthen commissioning and contracting for elements of the recovery package stratified follow up and health and wellbeing events 	<p>CCGs</p> <p>WMSCN/CCGs</p> <p>WMSCN</p> <p>CCG`s</p>
2	<p>Joint Working</p> <ul style="list-style-type: none"> • In order to improve the Living with and Beyond Cancer pathway there needs to be closer/ more integrated/joint working with CCGs, secondary care, Local Authorities, Patient Voice and Third Sector to pool resources and finance. 	<p>CCG, Provider services, Local Authorities, Cancer LITs.</p>

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	<ul style="list-style-type: none"> GP Macmillan leads and lead clinicians within secondary care are able provide expertise and clinical leadership to redesign elements of the patient pathway post discharge from active phases of cancer treatment 	CCGs and acute trusts
3	<p>Cancer Care Reviews</p> <ul style="list-style-type: none"> A number of CCGs are not aware of the quality of the reviews being conducted in GP surgeries. There are examples of pilots of to develop best practice in Solihull and Birmingham South Central CCGs. This can be strengthened through the contracting process in primary care. 	CCGs, Primary Care
4	<p>Data and Intelligence</p> <ul style="list-style-type: none"> No data is collated for cancer survivorship apart from 1 and 5 year mortality rates nationally. Locally CCGs could develop audit and monitoring of service delivery and quality that can link to local patient experience of use of elements of the Recovery Package such as attending a Health and Wellbeing Event. 	CCG, Provider services
5	<p>Embedding elements of the National Cancer Survivorship Initiative (including Recovery Package)</p> <ul style="list-style-type: none"> Elements such as Risk stratified follow up have national stratified pathways defined such as Colorectal, Breast and Prostate. Expert Advisory Groups within WMSCN can advise and provide expert opinion of the development of any risk stratified pathways in tumour groups and link with commissioning to devolve more follow up from traditional consultant lead hospital outpatient models to GPs/ primary care. Clinical leadership within the CCG can be provided by GP Macmillan Facilitator and local acute trust cancer clinical lead The standardising of the use of Treatment Summaries within trusts across cancer pathways would enable patients, GP`s and acute trusts to manage patients more effectively at various stages post active treatment, promote self-management as well as inform GP cancer reviews 	GP Macmillan Facilitators/CCGs/ Primary Care/ acute trusts CCGs/ acute trusts

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	<ul style="list-style-type: none">• Health and Wellbeing events provide valuable support and improve patient outcomes post active treatment .It can improve patient self management These can be used to instead of attending follow up clinics. There is a number of good examples run by acute trusts, third sector and CCGs regionally. For them to remain sustainable more joint working between key stakeholders will be required plus financial commitment by CCGs to maintain funding for ongoing events in the community	CCGs/ sector/ trusts/ LA Third Acute
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7.0. Summary

Living with and Beyond Cancer (LWBC) services have made some progress since the inception of the National Cancer Survivorship Initiative but do require support and further national guidance to move improvement forward. The new Cancer Strategy should provide some support and guidance. It will be published in July 2015. There are some examples of work within South West Strategic Clinical Network that have financially modelled follow up pathways that could be adopted by CCG`s (Appendix 2).

Regionally 1 CCG has 3 elements of the NSCI/ Recovery Package elements which include stratified follow up in General Practice for stable prostate. There are in addition 6 other CCGs who have 1 element – Stratified Follow up for stable prostate embedded. There are a number of expressions of interest within other CCGs in developing this follow up pathway. Further work will be required by CCG`s and acute trusts to move this area of work forward. Examples of additional work relating to survivorship were shared at a regional workshop in January 2015.

The link to resources from this event follows:

<http://www.wmscnsenate.nhs.uk/strategic-clinical-networks/our-network/cancer/resources/living-and-beyond-cancer-event/>

Clinical Commissioning Groups within the region have engaged in the discussion and work around LWBC but require strategic support and guidance from Clinical Networks to further the area of work. There also needs to be recognition that a more joined up working approach with acute trusts, patient voice, third sector and local authorities will improve the LWBC pathway and shift the emphasis from all services being provided within acute care settings. It will be important to ensure that the workforce is appropriately skilled to deliver these services within community settings.

Further guidance to support CCG`s locally will be published in the form of national commissioning guidance from NHS England in late November 2015 .

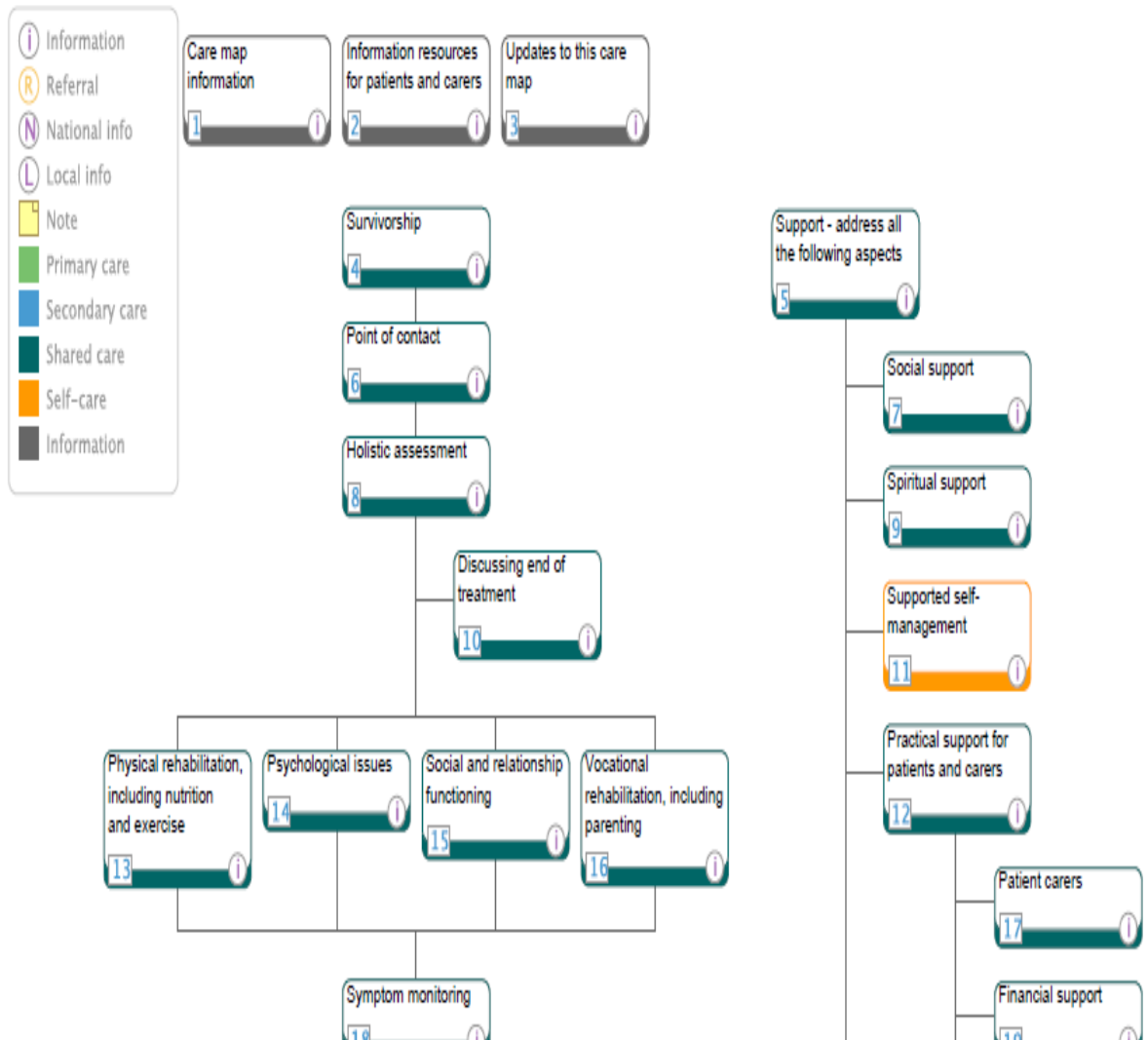
Patient user groups within the region have been supportive of the initial findings of the project and have included some areas of the Recovery Package within their work plans for 2015/16.

Appendix 1

Survivorship map of medicine

Journey into survivorship

Oncology > Patient experience > Improving cancer patient experience



Appendix 2

South West Strategic Clinical Network Implementation plan

[SW Implementation Plan v5.pdf](#)

Achieving world class outcomes: a strategy for England 2015-2020

<http://www.cancerresearchuk.org/about-us/cancer-taskforce>

References

Maddams J, Utley M, Miller H (2012). Projections of Cancer Prevalence in United Kingdom 2010 -2040. British Journal of Cancer 107 (7)