Interim Report

Right by You Wessex

Project period June 2021 - October 2022

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> ***For many years the NHS has talked about the need to shift towards a more personalised approach to health and care. A one-size-fits-all health and care system simply cannot meet the increasing complexity of people's needs and expectations***
>
> **(NHS England 2019)**

Foreword

> ***Right by You Wessex provides our vision for the future delivery of cancer support***
>
> **Jane Winter**
>
> Lead for Nursing & Allied Health Professionals
> Wessex Cancer Alliance

Right by You offers a service which has been co-designed by those with lived experience of the cancer services and seeks to offer integrated, supportive care, across boundaries. It is delivered where individuals and their families will experience the maximum benefit. As well as integration across primary, secondary, community and voluntary services, the team offer psychosocial assessment and intervention at Universal, Targeted and Specialist levels.

Right by You Wessex provides our vision for the future delivery of cancer support – within this project we are creating the blue-print for a model of care that works for all, one that we believe is transferrable beyond the realms of cancer. In this work we aim to see the impact of support when we break down the barriers and boundaries that we know exist in health and social care, when we reach out and work together as one team, and when we start with what really matters – with people and families.

Right by You is about returning to the fundamental values and origins of Cancer Nurse Specialists. Whilst technology and cancer treatments have evolved, so to have many CNS roles, often displacing essential specialist, therapeutic support, to offer a medicalised model of care focused upon complex multimodal treatments over protracted timepoints. Acute services are increasingly juggling the demands placed upon them, with a reality which often leaves those on the receiving end of care feeling unsupported and experiencing fragmentation and poor communication across the system. This model is a return to those original values, one that recognises the impact of a cancer diagnosis on people and families, an impact and meaning for individuals that continues to exist in a way that is unique to cancer. This model is forward thinking in its approach by promoting choice and control for people – giving people freedom to access care when, where and how they want it– redefining how specialist support is provided, offering a consistency of support in a changing world of healthcare.

The team are a highly skilled group of cancer clinicians, equipped to address the rising levels of complexity and multi-morbidity which we know exists. We know that complexity does not imply needs exclusive to cancer, but our team have experience to lead multidisciplinary discussions and skills to integrate across specialities and boundaries. For those who aren't currently being treated RbY-W offers continuation of support to facilitate transition to specialist palliative care (where appropriate). The service offers truly personalised, care at a time when we know people can feel frightened and alone – Right by You offers what is says it does – and what people with lived experience tell us they need.

Introduction

> **_It feels as though you're chucked back into the normal world again after having to adapt. It can be very overwhelming._**
>
> **Expert by experience - participant in Health Watch Southampton Interviews (2019*)**

This report describes the introduction and development of a new model of integrated, specialist support for people affected by cancer (the person with cancer, their families and their support network) - Right by You Wessex (RbY-W).

Finding from an independent evaluation of the service are summarised at this mid-point, outlining the learning and progress from the period June 2021-October 2022, and recommendations for the next phase of this work.

Background:

The origins of this work are founded in the voices of people with lived experience of cancer from across Wessex. This model has evolved in direct response to their words and their experience. In 2019, a broad, 6 month listening/engagement exercise, carried out by HealthWatch* Southampton & Dorset was performed. Whilst the work highlighted the value placed on hospital-based services, there was recognition that this traditional approach led to support that was prescribed, medicalised and system-led. In contrast, what was needed was cancer support that was flexible, personalised and person-led, recognising to the impact cancer has on individuals, their families/friends and sees their diagnosis in the context of their whole lives, combining physical, mental wellbeing and social needs. RbY-W evolved in response to this call for action. It has continued to develop since then in lockstep with the philosophy of co-design to ensure that this future model of support is one that is shaped by and for the communities it services.

This local intelligence coincides with growing evidence and understanding across health services of the benefits of personalisation of care for individuals, organisations and the wider health and social care system. NHS England's Long Term Plan outlined clear ambitions across all sectors, with particular emphasis on cancer, stating that by 2021 everyone with a cancer diagnosis should have "*access to personalised care, including needs assessment, a care plan and health and wellbeing information and support*". Traditionally the delivery of these personalised care interventions has been led by acute providers with limited explicit integration of wider health needs/other services, therefore carving "the whole person approach" into disparate parts.

You can read the Health Watch Southampton & Dorset Reports here

Service Delivery

Specialist nursing roles ensure people with cancer receive care that enables them to live with cancer, not just survive

Macmillan Cancer Support (2021) The Forgotten C

Aims & Objectives:

The RbY-W project is a partnership between Wessex Cancer Alliance (WCA) and Macmillan Cancer Support (MCS).

RbY-W's purpose is it provide personalised, responsive support to people with a confirmed diagnosis of cancer and their families/support network. The service is delivered by experienced Cancer Nurse Specialists (CNS) and Cancer Support Workers (CSW).

CNSs are a valued resource in cancer pathways, central to the delivery of personalised care, but one that is still not universally available. Adequate access to support from a CNS has been linked to improved management of side effects of treatment, reduced likelihood of emergency attendance, increased medication adherence and reduction in serious mental health issues (MCS/You Gov – 2021). The project aims to increase the reach of this critical role.

Whilst the RbY-W team are hosted by acute Trusts, a strength of the model is their freedom to work across boundaries and care settings, not limiting this expert resource to hospital-based support. CNSs are familiar with a multidisciplinary approach to care. Working across boundaries enables care that is truly joined-up. The RbY-W team work in partnership with expert advisors and other health and social care professionals involved in an individual's overall care (not just cancer professionals). They recognize and support social, physical and mental health needs, including those beyond cancer. They enable improved communication amongst teams and provide advocacy for those in the centre of multi-agency care.

This community outreach model enables individuals to have *choice* and *control* over when and where they access support. The service exemplifies the need to acknowledge the complexity which accompanies multimorbidity/ multi sequelae of a cancer diagnosis and the subsequent complexity of interventions that are required to cover the full breath of needs arising in health and social care.

From commencement, the service has deliberately kept a broad inclusion criteria for support - accepting referrals for:

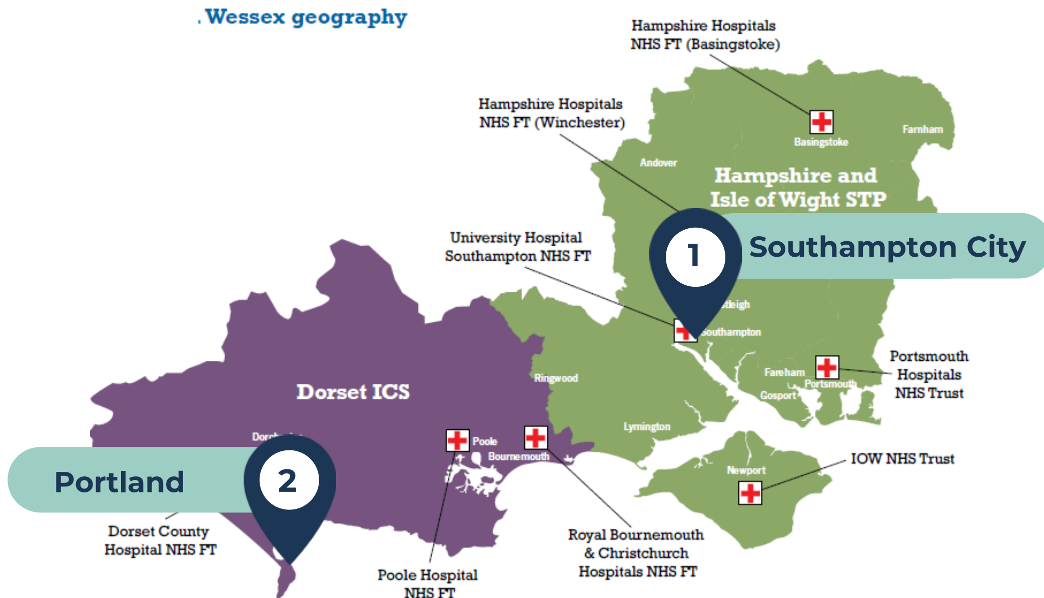
- any person with a confirmed diagnosis of cancer,
- that is living within the project locality areas
- who would like additional support and agrees to referral.

This has allowed RbY-W to explore what referrals (including self-referrals) were generated in response to an open offer. This purposefully enabled the team to offer support based and tailored to individual need and the things that concern/matter to them - rather than clinically defined parameters of need.

RbY-W Local Population & Services

The geographical footprint of Wessex (Dorset, Hampshire and the Isle of Wight) covers a population of approximately 3 million people. Our population represents an expanding and diverse range of communities and needs. Each year within the Wessex region almost 20,000 people will receive a new cancer diagnosis

RbY-W is operating in two sites in Wessex. Southampton City was launched first, with Portland following in December 2021.



Different configurations of the service have been purposefully selected to service local population need.

Portland:

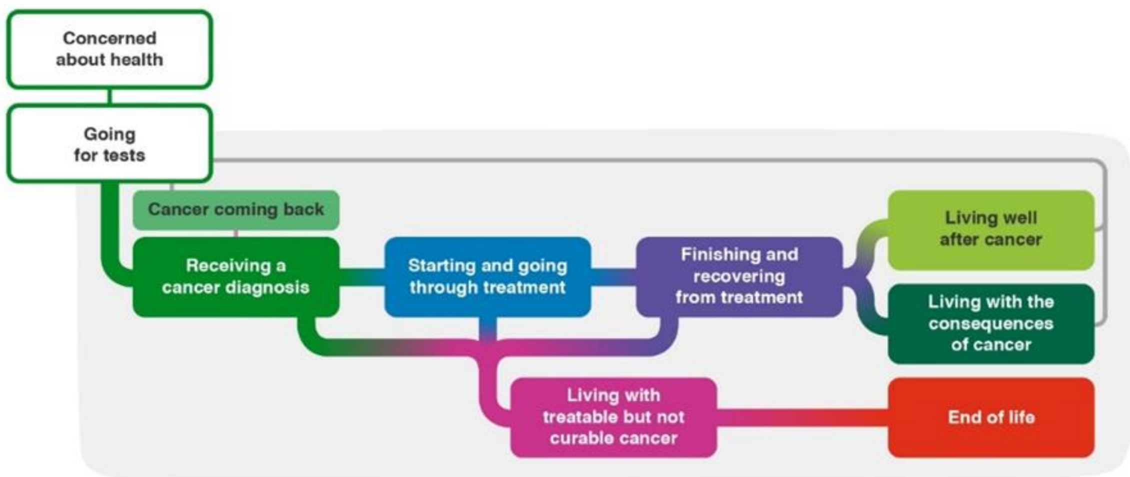
- Population >13,000
- Local situation: tied island, limited transport links
- Local health trends: high levels of social isolation, recognised pre-existing mental health needs (24% of population) and pockets of deprivation (DiiS search May 2021)
- 1 Practice (part of Weymouth & Portland PCN)
- Agreed outreach support to the Lantern Project (supporting homeless community) and Portland Prisons
- Nearest Acute Trust (Dorset County Hospital) - with local service level agreements for treatments carried out at Poole Hospital/University Hospitals Dorset)
- 0.8 WTE CNS - honorary contract with Primary Care team
- Role sits with DCH Macmillan Therapy Team (DCH)

Southampton City:

- Population >250,000
- Local health trends: multimorbidity
- 6 Primary Care Networks (29 GP Practices - including 1 Homeless Healthcare practice, 3 practices managed by community provider Solent NHS Trust)
- 1 Acute Trust (University Hospitals Southampton
- Initial agreement to support 4 GP practices, amended to Southampton City locality during pandemic due to limited primary care time to engage.
- 1 WTE CNS (increased to 1.6WTE Oct 21), 0.4 WTE CSW and 0.2 WTE Expert Advisor for Homeless Healthcare
- Honorary contracts for team with community provider Solent NHS Trust
- Team presence at community multidisciplinary team meetings (Palliative & complex care and virtual ward rounds)

RbY-W bridges a number of gaps in current service provision when mapped against Macmillan's times of need (see below). This includes: -

- people with highly complex support needs during diagnostics or treatment, often missed in the time constraints of secondary care appointments or in primary care that is not sufficiently skilled or resourced to identify and support need
- support for people who have finished treatment with curative intent and are living with and beyond cancer/living with the consequences of cancer
- providing supportive palliative care for those in 'the no-man's-land' of living with incurable but stable disease, who do not 'trigger' specialist palliative care services but have significant unmet need requiring support. Alternatively people may meet the criteria for palliative care services but may not be accepting or ready to make this transition in care. The RbY team is able to facilitate the transition to palliative care services when people situation changes and/or when they elect to receive this support.
- support for family and friends who are unable to access cancer support services.



A supportive holistic therapeutic conversation at multiple time points undertaken in the individual's preferred location (typically their own home) is the core element of the RbY service.

This enables highly complex needs to be identified in contrast to the time-limited needs assessment conducted in hospital by CNSs. Undertaking the conversations in people's homes allows non-verbal as well as verbal needs to be identified (e.g. mobility and access needs).

In contrast to a hospital setting where Holistic Needs Assessments (HNAs) are typically completed at one or a limited number of timepoints in a hospital setting, in RbY-W, needs are identified and supported over many timepoints for as long as is required. Conducting needs assessments in this way maintains a personalised approach as the building of rapport over repeated contacts ensures that information provision and referral to support services is tailored and appropriate to the lived experience of the individual. This helps to reduce inequalities in access to support as referral take into account the resources, opportunities, concerns, fears and wishes of each individual.

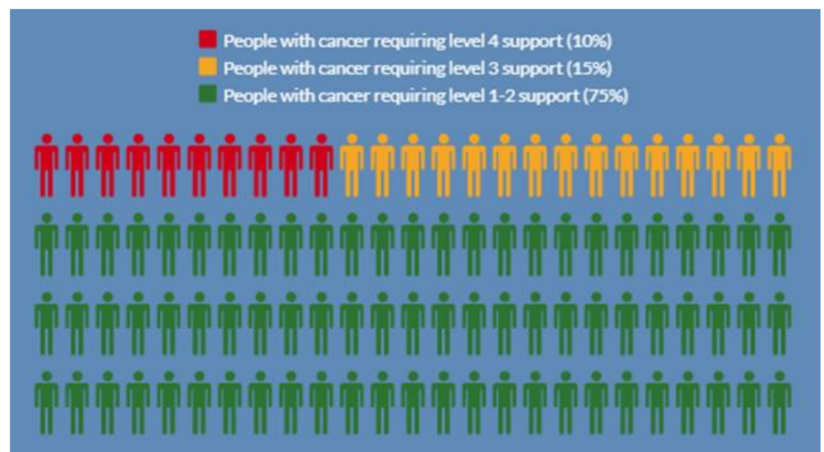
RbY-W has been introduced at a time of major turmoil in all sectors arising from the COVID19 pandemic, resulting in both challenges and opportunities not anticipated at the inception of this project. The impact of COVID19 on people with cancer and their families has been substantial. RbY-W has highlighted the gaps that exist for people and the realities of living with cancer in this time. We are also learning about what it means to people in this situation, when healthcare professionals are given opportunity to adopt an approach to care that stops, listens and hears the challenges individuals are living with, and offers a compassionate care offer based on these issues.

Addressing known unmet needs:

Locally and nationally there are recognised unmet needs relating to psychosocial support – this is evidenced at different times across cancer pathways– as the most highest scoring concern recorded in Holistic Needs Assessments (HNAs) (Data source: MCS eHNA platform – national dataset: concerns raised during 2021 and up to the end of August 2022) and later in the pathway – second highest persisting concern identified regionally and nationally in the new Cancer Quality of life survey (Data set: 2021).

It is recognised that in the year following diagnosis:

•25% of people with cancer will experience symptoms of anxiety and depression severe enough to warrant intervention by specialist psychological/psychiatric services (NICE level 4) or from psychological techniques/ interventions by trained mental health practitioners or Counsellors (NICE level 3).



(more details about NICE Level of Psychological Intervention (2004) can be found here:)

However psychological support needs are common within the remaining 75% of people with cancer. Ensuring access to high quality level 2 psychological support (delivered by trained health care professionals with additional expertise) is an essential part of holistic cancer service provision. The need for appropriately skilled and resourced support at level 2 will:

- Identify psychological need and distress early
- Provide skilled intervention to comprehensively assess,
- Provide practical intervention to problem solve, enable adjustment and de-escalate concern
- Promote emotional wellbeing for individuals and families
- Provide appropriate onward escalation via clear pathways to level 3 and 4 provision if required.

A WCA CNS Review within Trusts (2019) showed that provision of NICE levels 2-4 support was inequitable/under-resourced. Not all CNSs had adequate training to support delivery at level 2.

The risk of not adequately addressing these needs is great. People with cancer have a 55% higher risk of suicide, than those without cancer or can live with unresolved psychological issues for long after diagnosis. Even 10 years after treatment, 54% of cancer survivors still suffer from at least one significant psychological issue. The impact of this on individuals, families, health services and wider society cannot be underestimated (the cost impact of suicide equated as £1.5 million).

RbY-W: Provision of Psychological Support

RbY-W is positioned to provide enhanced level 2 (locally described as level 2+) psychological support for people with cancer.

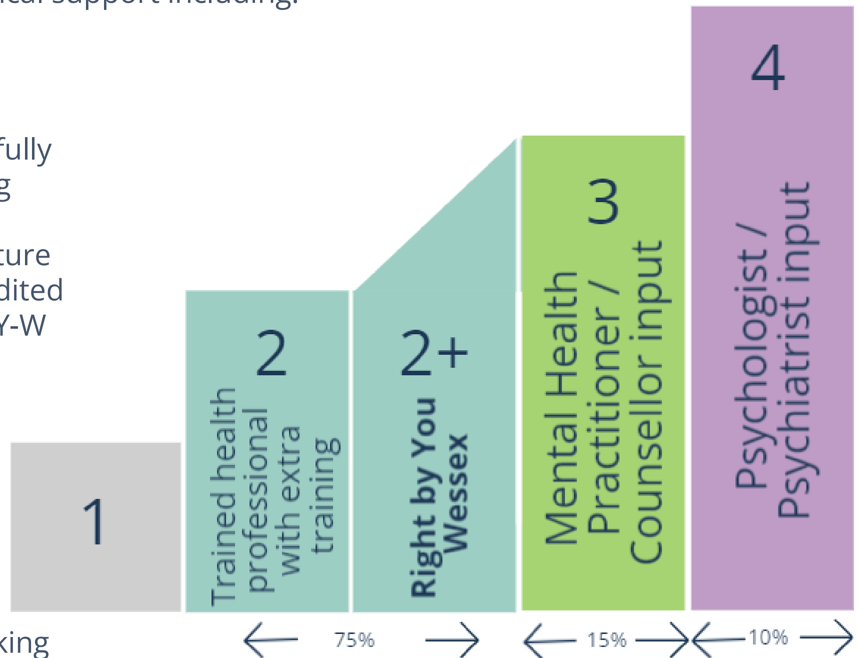
CNSs within Rby-W have completed traditional level 2 psychological support training and advanced communication skills training. In addition they have undergone training in skills to enhance provision of psychological support including:

- Acceptance & Coping Techniques (ACT) therapy
- Coping and Living Meaningfully after Cancer (CALM) training

(There is a plan to consider future skill expansion to EMCC accredited health coaching within the RbY-W skill set).

These skills are in addition to broader CNS and expanded practice skill set including:

- History taking & physical examination
- Critical clinical decision-making
- Knowledge of cancer treatments and symptom management
- Non-medical prescribing



> *In recent years there has been a welcome focus in national policy on achieving 'parity of esteem' for mental health. Colloquially, this phrase has often been interpreted to mean that mental health services should be 'as good as' services for physical health. We argue that there is a greater prize beyond this, in which mental health care is not only 'as good as' but is delivered 'as part of ' an integrated approach to health.*
>
> *Kings Fund (2016) Bringing Together Physical and Mental Health: a new frontier for integrated care*

What RbY-W offers is specialist, skilled level 2+ support as a flexible and timely offer. This approach is provided in an unhurried support environment of the person's choosing.

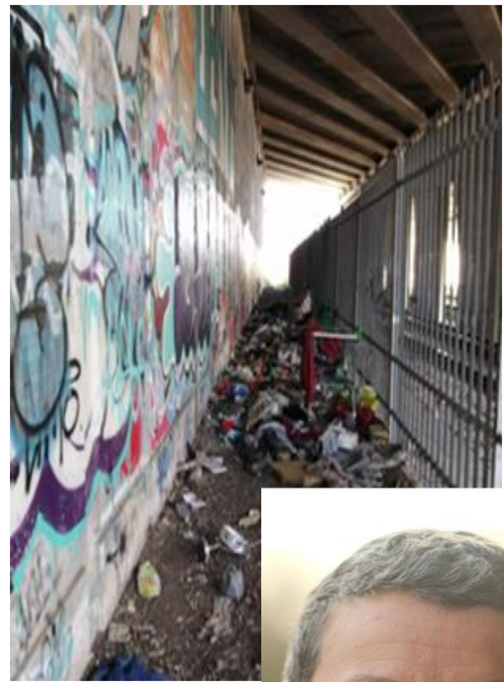
RbY-W endorses a 'whole person' approach, enabling time, expertise and space to discuss and support physical and mental health needs alongside social support needs, including the needs of family members and significant others.

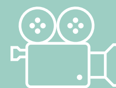
Integration of care in this context is delivered in our philosophy of practice (addressing combined health needs, giving parity of esteem for physical, psychological/mental wellbeing and social needs) and delivering care by cross boundary working in partnership with individuals and other health providers – therefore achieving the 'triple integration' the NHS aspires to (Stevens, 2015)

Addressing local health inequalities:

COVID19 has also put a spotlight on health inequalities. A particular focus of RbY-W is to identify and address the needs of those in our communities who are most vulnerable and often excluded, who typify those most likely to be victims of health inequalities.

The project is proactively supporting people experiencing any degree of homelessness who have a cancer diagnosis, ensuring that the RbY-W service flexes to and is shaped by the needs of all people within our communities. Both sites have links with local homeless healthcare providers (delivered via different models). Our aim is to shine a light on the realities of living with cancer when faced with such extreme challenges and to test of model of integration by proactively working alongside trusted members of each local community. Learning from this work will help inform and shape our service delivery and will consider any learning needs for the cancer workforce, to ensure support is sustainable and fit for purpose.

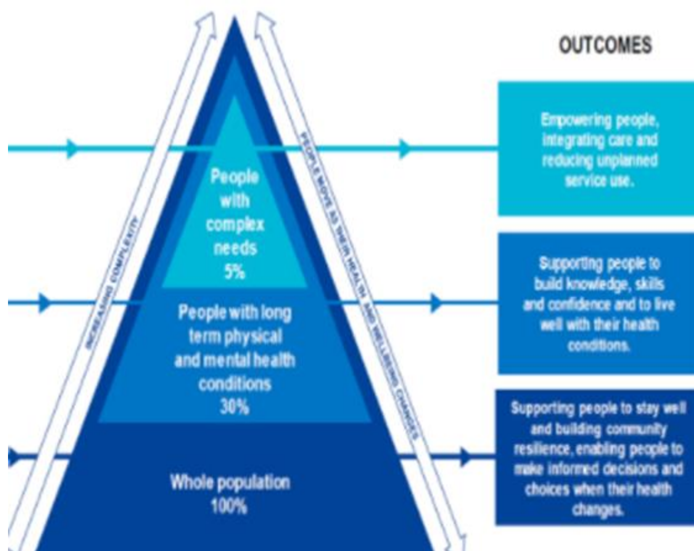




Click here to watch Pam Campbell – Our Expert Advisor for Homeless Healthcare talk about her experiences working within RbY-W and the support provided

Tailored Support Offer:

RbY-W has been set up on the principle that support provided matches individual need and complexity, as demonstrated in NHS England's personalised care model (2019). RbY-W support will therefore be tailored and the amount, duration and focus of support will vary from individual to individual and be person-led. Support may be accessed as and when it is needed.



Right by You:	Level of need:
Cancer Nurse Specialist – coordinating complex psychosocial support / a Supportive care MDT	People with cancer with complex needs or in crisis (e.g. requiring multiple interventions or coordinated MDT support)
Cancer Nurse Specialist creating holistic personalised care & support plans	People with cancer with moderate level support needs or other LTCs (requiring tailored, specialist support)
Cancer Support Worker providing health and wellbeing information, support and coaching	People with cancer with low level support needs (e.g. requiring signposting, general information and support)

Service Delivery: learning to date (SCOT Analysis)

Strengths:

Southampton:
- Team-based approach (brings resilience, peer support, broader cancer expertise & experience, and ability to explore use of different roles e.g. CSW)
- Solent NHS Trust Honorary contracts and relationships (enable integration into community, including community and Palliative Care MDTs and Virtual Ward)
- Homeless Healthcare Expert Advisor – strengthens integration, awareness of health inequalities
- Community of Practice established with RbY team and Primary Care Advisor

Portland:
- Primary care relationships, co-location
- Links with Macmillan Therapy team
- Relationships with Palliative care service
- Building connections with the Lantern Project and Portland Prisons
- Defined geography – centred around 1 GP practice

Both:
- Flexibility and adaptability of support offer
- Benefits of home setting for personalised assessment of needs
- Service reputation and relationships with hospital based CNS
- Additional training of RbY CNS (CALM, ACT)
- Sharing of case studies
- Established Patient Advisory Group contributing to service and resource design

Challenges:

Southampton:
- Large geography – 29 different GP practices – primary care visible presence, relationships and understanding of local teams limited due to stretch of resource
- Primary care engagement due to covid response/competing demands
- Ongoing impact of pandemic remain (e.g. promotional opportunities cancelled – e.g Southampton Target Oct 22) –implications and limitations of virtual promotion sessions (reduced attendance and engagement)
- Geography – travel time and cost
- No team base and infrastructure (challenges for team-working and practical delivery)

Portland:
- Lone post – impact on service resilience
- Delay setting up honorary contract with practice (e.g. impact on non-medical prescribing)
- Complexity of local treatment pathways (working with 2 acute providers)

Both:
- Impact of template Care Plan not yet realised – limitations to universal use needs further development/investment of time
- Limited admin support – impact on quality of data capture (for HNA and PCSP), standardising admin processes
- Setting up local routes to capture service user experience and feedback (due to differing Trust approaches)
- Time – balancing clinical time with other pillars of advanced practice and project development time.
- Non-standardised practice relating to HNA/PCSP

Service Delivery: learning to date (SCOT Analysis)

Opportunities:

Southampton:
- Homeless Healthcare Expert Advisor- scope to focus on team development/skills for future model
- Workshops to promote service post diagnosis for proactive support – linking with lived experience representatives and other support services including CAB
- Successful grant application for 2 x Mental Health Practitioners to work within team to support Level 3 Psychological support provision and integration with Mental Health services/IAPT providers
- Build pathway links with Peri-opFit

Portland:
- Training for expanded practice – e.g. Community DNAR conversations
- Scope to expand/refine support offer to Portland Prisons (e.g. support groups)
- Cancer Support Worker role being introduced
- Use of DiiS Population Health Management dashboard to enable proactive case finding for those most vulnerable

Both:
- Building Community of Practice outside Southampton City
- Build on CCR mentorship and referrals generated via this primary care intervention.
- Further work to understand capacity modelling and skill mix to support caseload management
- Building links with ARRS roles via local connections and WCA ARRS project
- Increased admin support – to formalise processes, improve quality of data capture and standardised practice re: HNA/PCSP and other outcome/experience measures
- Opportunities to build local consensus around what a comprehensive personalised care assessment should include and how performed – potential to influence practice beyond RbY-W service delivery
- Service User feedback pathways now agreed and being tested at both sites – need to standard route for collection.
- Further co-design (service user and PAG input)

Threats:

Southampton:
- Redeployment of CSW due to pressures on acute provider, remains a risk for future pressures

Portland:
- Impact on capacity and quality of service resulting from expanded geography is currently unknown.

Both:
- Potential demand for service and therefore staffing requirement needs further modelling.
- Potential for capacity to be overwhelmed if no step down of support/transition of care
- Need to articulate complexity and ensure understanding of offer and why delegation to other roles (e.g. ARRS, non-cancer workforce) may be inappropriate/sub-optimal (e.g. level of intervention/expertise required)
- Difficulty accessing Business Intelligence systems and collating data to demonstrate economic impact of service
- Current lack of formalised and consistent outcome measures
- System financial pressures – commissioning teams looking for cost savings due to financial deficits

Service Delivery – Informal Feedback

Service Users - testimonials

My support is always contactable, helpful and even proactive in remembering personal things like when I was away and asking how I am (coping etc) and following up on things discussed or suggesting other things which all help to improve and assist people in this stage of life. I've never felt as if anything is too much trouble for them, no matter how small an issue I have.

"as ever we left feeling supported and our footsteps are a little lighter. If you ever ask yourselves "do we make a difference" hold your heads high and with total confidence reply "yes, we really do"

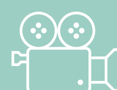
Putting me in touch with some people and organisations which can offer further assistance with social things. Making sure I'm taking my medication and how it's affecting me, more so the side effects - suggesting lifestyle tweaks to make life easier. Even organising a day out through a charity, which will mean a day out for me to take my nephew to a zoo, I won't have to worry about getting around, where's the loo, lunch or anything else as we will be looked after for the day

'I was so worried about all of it and she [RbY staff member] sort of put my mind at rest. She was so good, I don't know what if she hadn't come, you can't get to see the doctor, they don't want to know. You can't keep phoning the hospital because they don't really want to know'

Healthcare Professionals – testimonials:

'[RbY team member] has the background knowledge of all of those agencies that are out there and [she does] a lot of creative thinking to mould what's out there to our clients .... individuals that don't quite fit the usual patient.'

"One patient coming into hospital on a weekly basis – as soon as RbY were involved, he stopped coming back"



Click here to watch some of our stakeholder talk about the benefits of RbY-W

Learning & Development

Within RbY-W overall project aims, there has been a focused commitment on upskilling and supporting primary care staff to better support the needs of people with cancer. A tangible means of fulfilling this commitment was to provide a mentorship and training offer focused on the delivery of high quality Cancer Care Reviews (CCR) in line with QOF requirements.

By doing so, it was anticipated that this would generate referrals to RbY-W for those with specialist or complex needs identified during the CCR.

A programme of Learning and Development for practice staff looking to develop knowledge, skills and confidence in undertaking CCRs has been led by an experienced practice nurse seconded to WCA working alongside the RbY team. Currently the support offer for primary care staff includes:

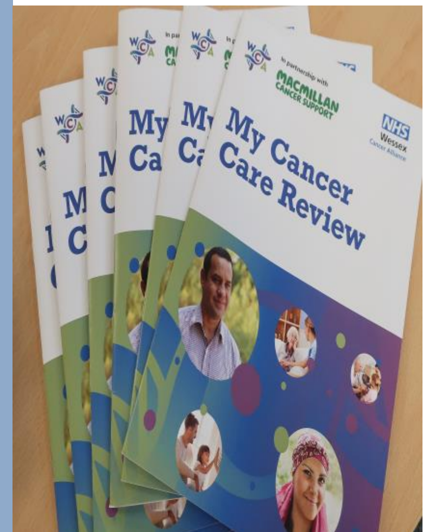
- A bespoke mentorship offer for practice nurses (delivered in person or remotely and offered across Wessex)
- A Community of Practice for a wider cancer workforce established (meeting regularly and brings together hospital/community and primary care staff to share knowledge and experience and foster reciprocal understanding of each other's roles)
- A portfolio of learning resources including those of Macmillan Explore that can be adapted to individual practitioner's needs and as a record of personal development to support revalidation.

The offer is now being promoted more widely across Wessex and work with practices outside the geographies of RBY-W are now in the pipeline.

The team have also worked in partnership with a local social prescriber and WCA GPs to develop a training event for social prescribers who may be supporting the delivery of CCRs as part of a primary care team approach to support.

The Learning & Development workstream will also articulate the training and development requirements for future RbY-W CNS/CSWs to support future sustainability of provision and growth.

> *She has been fantastic, mentoring me since September – she comes into the surgery and is always available via email. She has provided a wealth of knowledge and has shared all her contacts with me*
>
> Testimonal: RbY CCR Mentee/Practice Nurse Lisa Lucas



Evaluation

CentRIC+ Evaluation Aims

CentRIC+ are leading the service level quantitative data analysis and qualitative evaluation, due to report in June 2023. Interim findings from the last 12m evaluation are included here in the following sections of this report.

The Evaluation aims are to:

- Describe the intervention design and delivery
- Assess the impact on patient outcomes and experience
- Assess the impact on health professional outcomes and experience
- Assess how health system delivery and pathways adapt to the introduction of the model

The evaluation answers the following questions:

- What is the impact of RbY-W on patient experience and outcomes?
- How is RbY-W's model of integrated, personalised care designed and delivered?
- Does RbY-W deliver effective integrated working between primary, secondary and community care?
- What is the impact of RbY-W on health professional experience and outcomes?
- What is the impact of RbY-W on health service delivery?

Evaluation Design

The evaluation gathers information on RbY-W from patients and carers, health professionals, those providing community support, commissioners and RbY-W members. Data collection methods include qualitative face-to-face / video-conferencing interviews; collection of patient social, demographic, clinical and service-related data; and documentary review. The evaluation examines the design and delivery of RbY-W (process evaluation) and the outcomes of the intervention (outcome evaluation). The evaluation is a large, predominantly qualitative project with over 100 qualitative interviews to be completed by June 2023.

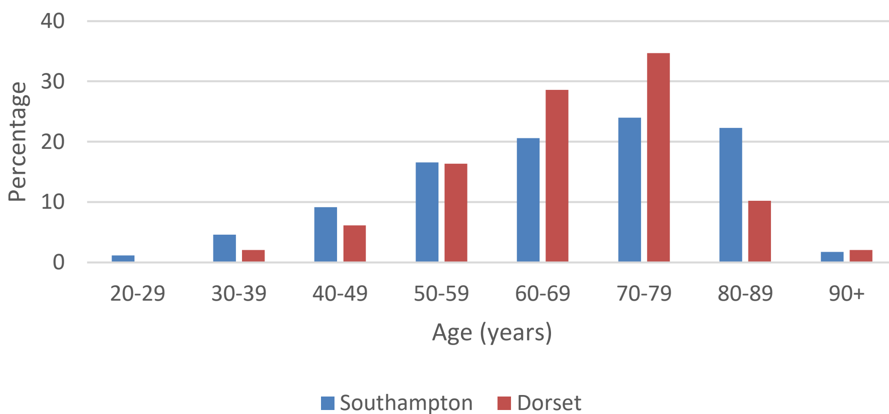
As of November 2022, 63 qualitative interviews have been conducted comprising 11 orientation and 52 project interviews.

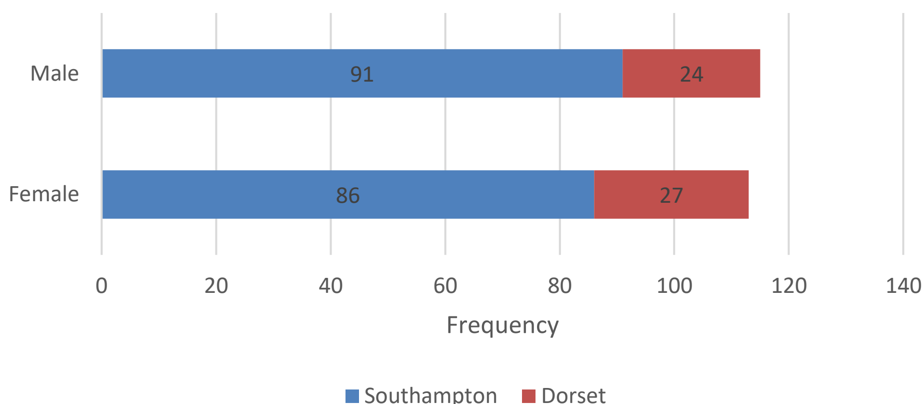
Process Evaluation findings

Description of support to patients and carers by RBY-W

Summary of patient / carer contact by the RbY-W Team

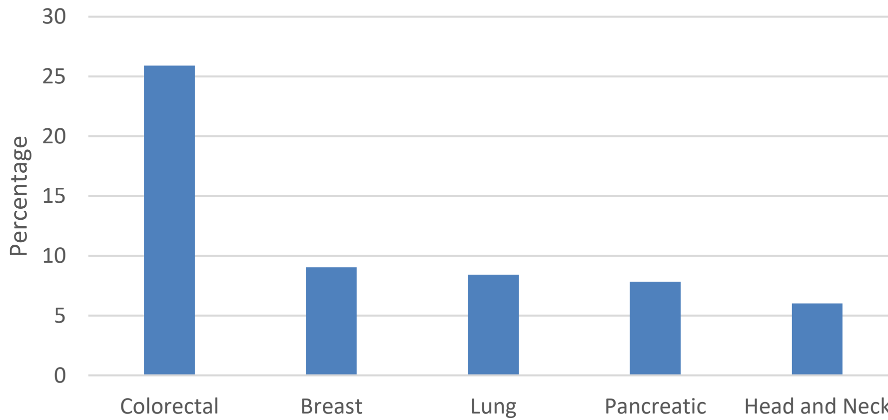
230 people with a cancer diagnosis have had contact with the RbY-W service by mid-October 2022, 179 in the Southampton area (October 2020 to October 2022) and 51 in the Portland area (December 2021 to October 2022). More than half (54%) of patients referred to RbY-W (in Southampton and in Portland) were aged between 60-79 years. Eighty-seven percent of referred patients were aged between 50-89 years (Figure 3). Roughly half of all RbY-W patients were women in both locations (Figure 4). Many RbY-W patients had other comorbidities in addition to their primary cancer. In Southampton, only 17 (10%) had no known comorbidities and 18 (12%) had eight or more known comorbidities.





Patients with a wide variety of primary cancers have been referred to RbY-W, including colorectal, breast, lung, pancreatic, head and neck, prostate, gynaecological and oesophageal (Figure 5), with the largest group of people referred to RbY-W in Southampton being diagnosed with colorectal cancer (26%).

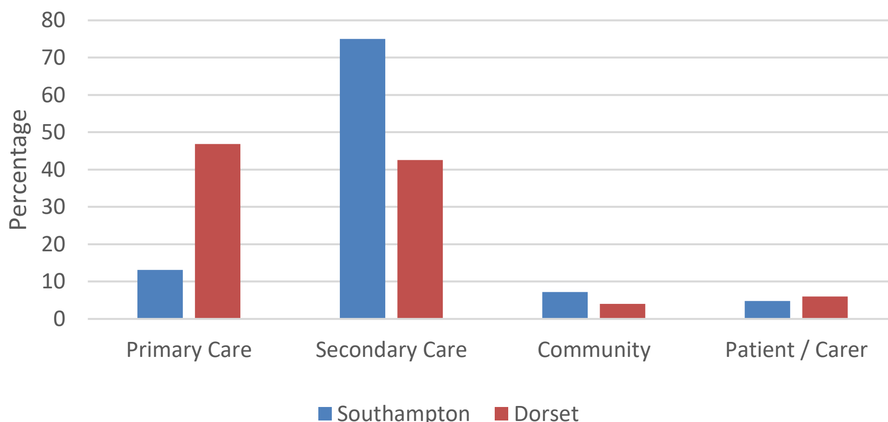
Figure 3 RbY-W patients' most common primary cancer type (Southampton)



Referrals to RbY-W in Southampton and Dorset

In Southampton, 75% of referrals came from staff working in secondary care. In Dorset (Portland and Weymouth), where the RbY-W CNS has closer links with one primary care practice, 47% of referrals came from primary care and 43% from staff working in secondary care (Figure 5).

Figure 5: Routes of referral into RbY-W (Southampton and Dorset)



In Dorset, most patients (60%) referred to RbY-W had been diagnosed with their current cancer within the last year.

Support received by those referred to RbY-W

In Southampton and Dorset, there have been a total of 2719 contacts with patients, carers, health professionals and others in relation to supporting RbY-W patients. The majority of these contacts (71% in Southampton, 45% in Dorset) were classed as Level 4 interventions (Figure 6), meaning that the patients required ongoing specialist advice and support for complex problems.

Contacts were made by telephone, text, email and face-to-face. In Southampton, as shown in Table 2, most patient and carer (family member or friend) contacts were made by telephone, text or email, while most contacts made with other professionals were made by email. Across all types of contact, the average duration was 21 minutes. The total time spent on contacts was more than 938 hours. The shortest contact was text (average 9 minutes), with face-to-face contacts the longest (average 57 minutes). There have been 443 face-to-face contacts across Southampton and Dorset to date, with two thirds of contacts taking place in the individual's own home.

Figure 6: Contacts with RbY-W patients, carers and other professionals – level of intervention (Southampton and Dorset) (see Appendix for definitions)

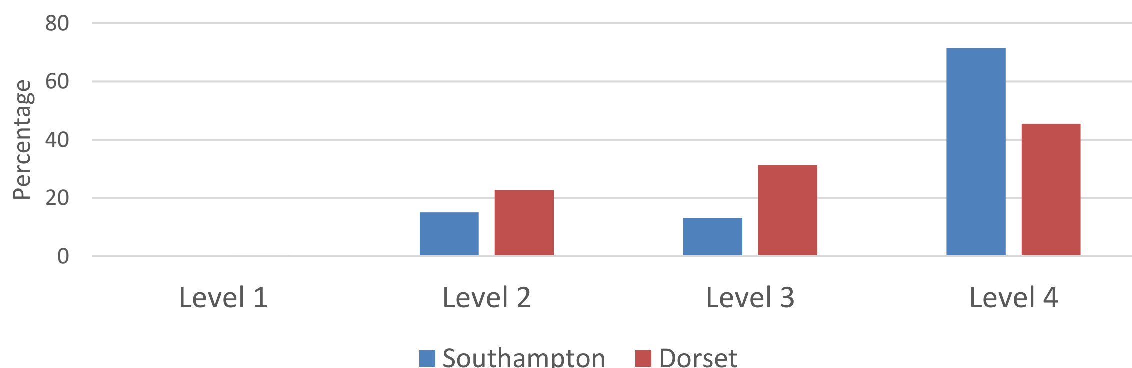


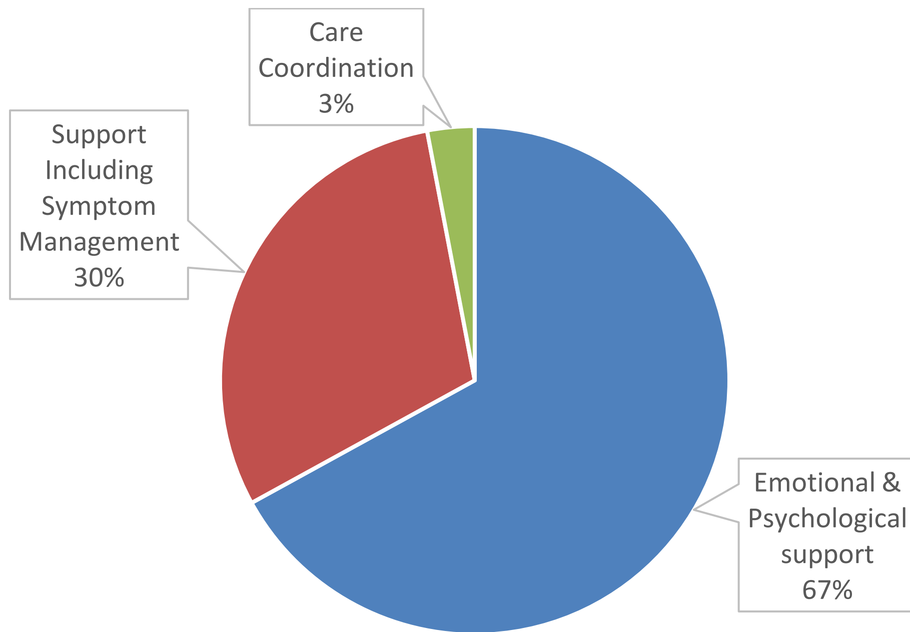
Table 1: Type of contact made by the Southampton RbY-W team*

	Type of contact			
Contact with	**Face to face**	**Telephone**	**Text**	**Email**
Patient	49	362	255	25
Patient and carer	38	26	15	17
Carer	2	36	39	1
Health care professional	5	55	2	101

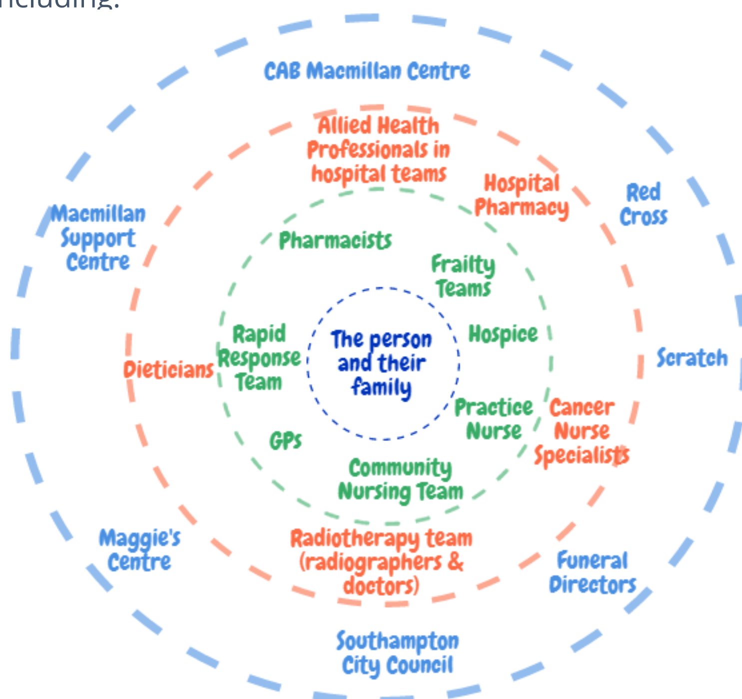
**Data up to July 2022 only*

Psychological support was the main reason for referral into RbY-W in Southampton, forming greater than two thirds of the reasons given for referral (67%). This was followed by the need for support including management of symptoms (30%) (Figure 7).

Figure 7: Reasons for referral to the Southampton and Dorset RbY-W teams



RbY-W patients in Southampton and Dorset were signposted or referred on to a wide variety of services including:



Qualitative analysis of intervention delivery in Dorset and Southampton

Differences between service delivery in Dorset compared to Southampton

RbY-W is delivered differently in the Dorset and Southampton sites. Dorset involves one CNS working with one hospital trust and one primary care practice; Southampton involves two CNSs and one CSW working with all Southampton-area primary care practices and the hospital trust. Interviews indicated that RbY-W staff resourcing was better in Southampton where multiple staff members resulted in greater resilience and peer support. However, Dorset's approach of focussed working with one primary care practice was more effective in enabling targeted engagement and greater opportunities for educational support:

> *'It's just been easier to get in with the one practice… they are very involved and keen to get as much help as they can. For practices that weren't that interested or find it threatening, you might not get the same response.' (Int 5)*

What does RbY-W add to the current provision of services?

Commissioners stressed the need for a clear description of what RbY-W adds to current service provision, as opposed to being an 'extra pair of hands' for services that should be providing services more effectively. As one commissioner reflected:

> *'This happens quite a lot in the NHS when we put in a new NHS service that is supposed to have a specific role and they end up filling a gap that should be filled by something else that we should properly commission and provide.' (Int 21)*

Interviews with health care professionals, particularly those working in hospitals identified what is distinct about the RbY service offer: a patient-centred supportive therapeutic conversation undertaken in the individual's preferred location (typically their own home); the assessment of holistic needs over multiple timepoints rather than one / few timepoints; the referral of people living with and beyond cancer to tailored, effective and appropriate information and support; support to people who typically 'fall through the gaps' of cancer services (e.g. people with highly complex support needs.

Supportive therapeutic conversations

There was consensus across the interview participants that supportive conversations are effective and a strength of the RbY-W service. Participants spoke of an 'A1' service (Int5) in which the supported conversation was a key asset:

> *'I think the therapeutic supported conversation is the primary tool in the toolbox, myself… it's probably a little bit unique to RbY… because it is so much about the person…, the things that they value, the things that upset them, where they've been, how they come to be upset, their current circumstances. … it's called a conversation but often it's more listening to a few hints and there's lots of things that are said that give you a real picture of the patient. For me that's the primary and the most important thing' [Int 18]*

Undertaking supportive conversations in the patient or carer's home was a strong factor in the tool's success. As one RbY-W staff member explained:

> *'I feel people do open up more. I get a sense much easier of how they are coping because you are looking at their surroundings... When I go into people's homes, some of what I am observing, I would never have that insight from the hospital' [Int4]*

Information sharing

Information sharing in RbY-W is proceeding well with RbY-W staff providing relevant and useful information to patients and carers. The identification and provision of information to those referred to RbY-W has not solely been identified with the patient alone but has also been identified through close working relationships with other health professionals. The planned RbY-W community workshops, to be delivered by two CSWs, and open to those recently diagnosed in Southampton (including those not referred to RbY-W), is a further means to share information. It has been suggested this may diversify the levels of support provided to include more individuals with lower levels of support need, and would be a further route to promoting RBY and encouraging self-referral.

Referrals to support services

Patient feedback reveals that the support services and resources to which they are referred are relevant, timely and effective in addressing identified need. Support services and resources are varied, ranging from pharmacy support over medication use to financial services. One patient commented on the effectiveness of the financial support he had received following the intervention of their RbY-W contact:

> *'She's been there for me, and she's done phoning up on my behalf and got some results.........she's got some help from the Macmillan - she got some money for me from there and she filled out a form and got help for me for a PIP [Personal Independence Payment], I've got an extra £30 a week for that, which pays for the food' [Int 30]*

It is evident that the RbY-W team are at times serving the role of patient advocates. This includes attending health care appointments with the patient, ensuring the timing of appointments is appropriate for the individual, or visiting pharmacies to ensure medications are appropriately provided.

Reflections on the RbY-W approach

There was consensus among participants of the problem RbY-W was seeking to fix. One commissioner summed up the views of many, commenting:

> *'we find a lot in health services in the NHS things can be quite fragmented. For example, a cancer patient will, as they go through their journey, see lots of different people, probably working for lots of different organisations, not always communicating well and sharing information. So, I think patients can feel they are a bit on their own, or stuck, falling in between the gaps between some of these services.' (Int 21)*

The need for an integrated system, working across hospital, primary and community care was important, as was building confidence and knowledge amongst health professionals for cancer management. There was broad agreement from hospital, primary, community care, commissioners and those delivering the service that the RbY-W approach is the right one. As commissioners reflected:

> *'Right by You is what it means, being patient-centred, developing the personalised care plan. You can't bring this into one place, so having the signposting is really important.' (Int21)*

Fundamentally, it was the patient-centred nature of the intervention that was well-respected by participants. The quality of care provided was viewed as a 'Gold Standard' service by commissioners and professionals in secondary care. *[Int 25]*

Specialist, Targeted, Universal

The original intention of RbY-W was to ensure a range of needs were met, as defined by the NHS England Comprehensive Model of Universal Personalised Care (2019). Process evaluation findings suggest that Dorset has a wider cross-section of levels of support provided, ranging from newly diagnosed people undergoing treatment with curative intent requiring one phone-call only to people in the palliative stage of disease with highly complex needs. In Southampton, interviewees reported a higher proportion of people requiring targeted or specialist support being seen. Such a focus on high levels of support need was deemed appropriate, particularly given the pressures of living with cancer at a time of COVID 19 and the related impact on cancer care delivery. Commissioners and health care providers were not surprised by this as it was people who 'fell through the gaps' due to complex needs that were in greatest need of support: 'It ends up being people from a complex group, but not necessarily complex cancer.' [Int 29].

Enablers and challenges to delivering RbY-W

Enablers

RbY-W Team:

The skills and experience of the RbY-W team were an important factor to its success. These qualities included leadership skills, enthusiasm, in-depth knowledge, communication skills and dedication. Many interviewees, especially commissioners, queried whether RbY-W staff should be based in the hospital or could be based in primary care. There is a need to articulate precisely why hospital-based nurses and support workers are needed to deliver RbY-W in light of these other roles, such as PCN DES and ARRS. RbY-W staff and health care professionals identified two important reasons by CNSs and CSWs are needed:

1: Hospital-based CNSs and CSWs have the experience and expertise relating to cancer, cancer treatment, cancer-related information and support services, and holistic care knowledge and support.

2: Allocating aspects of the RbY-W service to specific roles in primary care (e.g. care navigators) would fragment the support provided, which would undermine the Integrated care currently provided.

Adaptability and flexibility

The adaptability and flexibility of the RbY service was appreciated by patients and interviewees in primary and hospital care:

> *‘[It] doesn’t have any parameters: ‘oh, I can only see you twice’ or ‘I can only see you here or there’, [They have] the flexibility to work around the patient and around the GP surgery. I think that works really well’ [Int 25]*

RbY-W staff commented on the need to respond to highly complex issues not previously experienced in prior clinical practice. Enabling more time with the individual, typically in their home, resulted in more complex needs surfacing (e.g. safe-guarding issues) than would otherwise be raised in the time-pressured context of hospital-based discussions with the patient and / or carer.

Adaptability was seen to be a necessary feature of RbY-W ‘s design, recognising, for example, that primary care services are hugely varied (e.g. the presence of Macmillan GP, size, populations served, readiness for new ways of working). The adaptability of RbY-W was thus seen as a strength by commissioners to ‘lift and shift’ the approach to other areas and conditions (Int28).

Challenges
Working with diverse Primary care services

Emerging evaluation findings suggest that RbY-W engagement is strongest where there are effective champions. In Dorset, for example, the practice nurse is a strong advocate for the project. Other practices have been more reticent, sometimes due to a sense of 'tribalism' and an initial fear of treading on practice nurses' territory [Int5]. Time with each practice has helped to secure buy in, and this was easier in Dorset with a dedicated space one day a week in the practice. In Southampton, a lack of a base has made such engagement difficult.

Referring out of RbY-W

A challenge for RbY-W staff was that people referred to the service may build such a rapport with their RbY nurse or support worker that they do not wish to be referred to other professional teams when it is appropriate to do so. Continuity of care with professionals was paramount. There is thus an issue about moving people out of RbY-W when appropriate to do so to manage the increasing number of referrals:

'How do we move people on from the service? Are we fostering unnecessary dependence on the team, or are there other people out there that the team can hand over to?' (Int 5)

Sustainability

Interviewees had mixed views over how sustainable RbY-W is. Some participants agreed that the resourcing of a CNS working across a number of practices was effective and sustainable, although the recommended ratio between the number of practices supported by each CNS remains uncalculated. There was concern that the RbY-W team could quickly 'get completely overwhelmed', particularly as the understanding and reputation of the service develops [Int21]. Other interviewees discussed the challenges of recruiting RbY staff to post, recognising that many experienced CNSs are close to retirement. There is therefore a need to make the RbY role attractive and to market 'grow your own' professionals [Int20].

Recommendations for improving the sustainability of RbY-W included:

- Greater use of Cancer Support Workers
- Use of accredited volunteers (people who have received RbY-W support who could have a 'patient-facing presence across the whole system' [Int28])
- Clearer processes for referrals out of RbY-W
- Targeted working with primary care practices, with recommendations on the size of population seen in primary care for each RbY-W CNS
- Developing an education programme to skill up future RbY-W professionals

Replicability

Participants agreed that RbY-W was highly replicable for other conditions and geographical areas. As one commissioner reflected, ‘The question is, “Why just cancer?”, “Why can't this model be bigger than cancer?”.’ [Int21]. A key attribute of RbY-W is its flexibility and adaptability, qualities that are important in enabling replication across different Trusts and primary care practices with differing size, complexity and configuration. Recommendations to enhance the replicability of RbY-W included:

- Early and effective engagement of commissioners to help ‘lift and shift’ the approach (Int 28)
- Creating a toolkit of plans, assessments, structured resources to support RbY-W-style delivery of services
- Detailed descriptions of all roles that can support delivery of RbY-W (including CNSs, CSWs, plus other potential roles, e.g. practice nurses)
- Clear, consistent communication of the RbY-W approach, articulating how this integrates and supports current service provision, e.g. Supportive and Palliative Care

Emerging outcome evaluation

Improved patient outcomes (e.g., holistic needs and experience of care)

Meeting holistic needs

Feedback from patients, carers and primary care is that patients are receiving effective and enhanced personalised care that meets their holistic needs. Health professional interviewees reflected that, 'There is no opportunity to express them [needs] for a lot of people. People are worried people are too busy in the hospital and there is never an environment to discuss.' [Int 4] Participants spoke of a 'good deal' and having a 'beneficial impact', helping the patient navigate 'through that absolute maze of services, appointments and people' [Int 5].
The support provided by RbY-W to those receiving support from the Homeless Help Team in Southampton reveals the extent to which complex holistic needs are being supported. As one homeless hostel service leader commented:

> *'[RBY-W team member] has the background knowledge of all of those agencies that are out there and [she does] a lot of creative thinking to mould what's out there to our clients .... individuals that don't quite fit the usual patient.*

> *'[patient/client name] has a history of using drugs and... that scares a lot of agencies off. [RBY-W team member is] someone that understands that and [knows] where we can pull in support,... knows how to word it for us to get a bit more support.' [Int 11]*

Improved experience of care

Patients and carers have described experiences of improved care that are directly attributable to the interventions of RbY-W staff. Often, this involved building the awareness, understanding and confidence in accessing services, such as Palliative Care services. In this regard, the RBY-W team were not duplicating the services provided elsewhere, but helping the individual navigate the services available, ensuring they were accessed appropriately and at the right time. In the following example, a carer describes how her RbY-W staff member ensured GP services responded appropriately to someone at the palliative phase of illness:

> *'Right towards the end, the doctor came out and gave him some end of life pills, sort of thing, I think there was five. That was through [RbY-W team member] because the doctor wouldn't come out when we phoned him. As soon as [she] stepped in and phoned up and said I think you need to come out and see [name] the doctor came out, if we tried we couldn't even get past the receptionist, it was 'we'll get you a telephone consultation' [Int 26]*

Delivering integrated care

Emerging evidence indicates that RbY-W staff are fostering integration between primary, secondary and community care. As RbY-W staff explained:

> *‘There is better integration of care because we are that middle-man. Instead of them trying desperately to get hold of a GP or struggling to know what other services are around, we help by helping them feel confident that they can bring it to us and we will go from there.' [Int 4]*

Of significance is emerging evidence of greater integration between health services arising from RbY-W, independent of RbY-W staff. As one primary care participant reflected:

> *'A CNS came out last week who has never been into primary care, and she was amazed about what we juggle and see and do, and we know a bit about everything.' [Int 14]*

Impact on Health Professional knowledge

Improved health professional knowledge included opportunities to contact and link with other parts of the healthcare system. In primary care, RbY-W has helped instil greater awareness and confidence in liaising with health professionals at the hospital, facilitating the delivery of integrated care. As one GP put it: ‘I am not afraid, I will pick up the phone and speak to the CNS’ [Int 14]. Furthermore, RbY-W has also increased cancer confidence in primary care knowledge and confidence in supporting people with cancer. One primary care practice nurse explained:

> *‘cancer support was very new to me even though I've been nursing a long time and seen lots of people with cancer, I've never needed to have more than a three-minute conversation about it, I haven't really been involved in more than that... it's a big learning curve for me. [RbY-W team member] came and worked a shift and observed what I do in a normal day ... and then she was with me at the very beginning when I was making phone calls, not really knowing how to introduce myself, and it just helped me gain confidence really.’ [Int 19]*

Interim recommendations for next steps

The following are emerging, ongoing recommendations intended to guide the next steps of service delivery. They are based on early findings and thus should be used in an advisory rather than definitive manner.

☐ In discussion/planning

☑ In progress

Service delivery

1.Establish consistent base(s) for the Southampton RbY-W team in selected primary care practices to raise the profile of RbY-W and improve the confidence and knowledge of primary care staff in cancer management ☐

2.Determine whether and how people referred into the service are moved on from the service. (Is continuity of care more important than the number of people that the service can support?) ☐

3.Improve consistency on data collection including whether, how and when RbY-W components (e.g. the Personalised Care Plan) are delivered to aid replication of the service ☑

4.Consider whether RbY-W should address a whole range of needs. Currently it focuses predominantly on complex needs. Should it also support lower levels of need experienced by patients? ☑

5.If the remit of RbY-W includes lower levels of support needs, consider the best way in which these are to be supported through RbY-W (e.g. the planned Workshops) ☑

6.Consider aligning RbY-W activity with other primary care developments currently under way (e.g. health and wellbeing coaches, social prescribers and care coordinators) ☐

7.Ensure opportunities for GP engagement are promoted by Alliance GPs by early and effective involvement of commissioners to support GP engagement ☐

Future replicability and sustainability

8.Review and revise content of the data collected to ensure it reflects needs of a business case ☐

9.Consider what skill-mix of staff is needed to deliver RbY-W in the future (e.g. CNS, CSW, primary care roles) ☐

10.Develop a complete description of the RbY-W service, using standard checklists and role descriptions, incorporating lessons learned from the different modes of engagement between Dorset and Southampton ☐

11.Ensure any description of the intervention articulates how RbY-W supports and complements current service provision, e.g. Supportive and Palliative Care ☐

12.Develop a commissioning toolkit including role descriptions to support the replication of RbY-W to other conditions / geographical regions ☐

13.Develop a pathways to impact strategy, including a communications / educational plan to upskill potential future RbY-W staff ☐

14.Ensure early and effective involvement of commissioners to aid replication of RbY-W. ☑

Appendix

Levels of Intervention (linked to page 17:

Level	Definition
2	Single patient contact to resolve a specific problem This intervention would include a one-off review of a patient in the clinic who has a specific need, such as a symptom control issue or a concern about their disease progression. The intervention requires a specialist level of knowledge and skill but is easily resolved during a single consultation.
3	Short-term involvement for multiple problems Level 3 is a more involved level of intervention both in the complexity of the presenting problems and the need for several interventions by the CNS. Examples include provision of support and information when a patient has just been given bad news, assessment and management of needs when associated with more complex aetiology whether physical, psychological or social. There are also patients for whom care is shared with another healthcare team involving several updates with one another such as telephone communication with the relevant palliative care team.
4	Interventions when patients require ongoing specialist advice and support for complex problems The fourth level describes interventions of the greatest complexity, when there is requirement for long-term specialist involvement, generally for several months both during and after cancer treatment. The intervention may involve assessment and management of multiple problems, which may reflect patients with rapidly changing disease status, additional health problems, and/or challenging family dynamics. Level 4 may also be used to reflect patient referrals which required Level 3 direct care, but then due to continuing support and advice to other health and social care agencies, CNS involvement becomes more complex and involved. For example, liaison with district nursing teams, the GP, and Marie Curie and community palliative care teams looking after the patient.

To find out more about this work:

Right By You Wessex - Welcome to Wessex Cancer Alliance