RIGHT BY YOU WESSEX (PHASE 1)
A SERVICE EVALUATION

Produced by CentRIC for the Wessex Cancer Alliance

SPRING 2024

Centre for Psychosocial Research in Cancer: CentRIC+
Understanding the impact of cancer on everyday lives and supporting people to live well

University of Southampton

WCA

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Summary

Context

Traditional oncology aftercare is not effective in meeting the complex needs of people living with cancer. Poor integration across primary, community and secondary care can inhibit the delivery of the personalised care that is needed.

RbY Wessex aim

To enhance patient care by developing an integrated approach to supporting people living with cancer across primary, community and secondary care, from as near to the point of diagnosis as possible and throughout their cancer journey.

RbY Wessex Intervention

A therapeutic dynamic and longitudinal Holistic Needs Assessment (HNA) and support delivered by experienced Cancer Support Workers (CSWs) and Cancer Nurse Specialists (CNSs) who have received Managing Cancer and Living Meaningfully (CALM) training and are trained in Acceptance and Commitment Therapy (ACT) techniques. Delivered in the person living with cancer's preferred location, typically their home, should they have one. The intervention was delivered in Portland and Southampton. Specialist outreach and support was provided to homeless and prison communities.

Evaluation design

Process and outcome evaluation involving multiple methods: 1. quantitative analysis of all people referred to service, 2. >100 qualitative longitudinal interviews with stakeholder groups (people living with cancer, carers, family members, secondary care, primary care, community care, specialist palliative care, commissioners), 3. documentary analysis.

Key findings

RbY Wessex met its key aims: 1. enhanced patient experience and outcomes, 2. effective integrated working between primary, secondary and community care, 3. enhanced healthcare professional (HCP) experience and outcomes, 4. enhanced health service delivery.

It is a resource intensive, personalised community-focussed complex intervention but with potential cost savings through community management and averted admissions and referrals.

Recommendations

Recommendations included: 1. developing referral criteria, 2. clearly articulating what the service adds to current service delivery, 3. continued data collection (particularly health economic data), 4. developing an educational programme for RbY staff and building a cadre of future RbY staff, should it be replicated.

Introduction, Background and Context

RbY Wessex – A People-Led Initiative

Right by You (RbY) Wessex has been driven by people living with cancer and the public from the very start. In 2020, the Health Watch teams in Southampton and Dorset, in collaboration with Macmillan Cancer Support, undertook a listening exercise to understand the experiences of people living with cancer and to identify what they required from cancer services and how services could be improved. The listening exercise reported that:

- For both West Dorset and Southampton, traditional hospital-based care is valued by people living with cancer
- However, most lived experience occurs outside the hospital, and thus supportive care should be available in the community
- A range of effective tailored support should thus be provided in community settings and at hospital, throughout their journey and after treatment has ended
- This support should be provided close to home and be accessible 24/7
- In Southampton, people wanted to be seen within the context of their whole life and thus wished for support to be tailored throughout their cancer care journey
- In Dorset, people highlighted particular support needs, including emotional support, treatment, finances and transport, and the need to ensure effective support for seldom-heard groups
- Support provided should be integrated seamlessly with local communities, networks and health teams.

These findings were firmly rooted in the design of RbY Wessex, formulating a clear vision of what people living with cancer identify as good cancer care.[8, 9]

Background

Half of the UK population will develop cancer, and half of those diagnosed are likely to live at least 10 years.[1] Improvements in diagnosis and treatment mean that cancer is increasingly viewed as a long-term condition. While this is to be celebrated, the long-term impact of living with and beyond cancer is significant. The Colorectal Wellbeing study (CREW) reported that 30% of people with colorectal cancer had poor health and well-being up to five years after initial treatment,[2] 27% had comorbidities that impacted on everyday life,[3] and self-efficacy (confidence to self manage) remained little changed over time.[4]

Traditional aftercare is no longer effective in supporting people's complex needs.[5] As the NHS Long-Term Plan recommends, there is a need to shift to a personalised model of care planning.[6] The Plan set the ambition that, by 2021, everyone diagnosed with cancer will have access to personalised care where appropriate, including HNAs and care plans. To deliver this, integrated care is recommended, which seeks to improve patient care and experience through enhanced coordination of primary and secondary care and community services. Poor service integration across these sectors limits responsiveness to patient-identified need and can inhibit the delivery of personalised care, creating a fragmented care system that is difficult for people living with cancer to navigate. Barriers to service integration include[7]:

- Limited communication and information for people living with cancer
- Lack of GP / primary care knowledge on cancer management
- Excessive workloads / time pressure for those working in primary and secondary care
- Resource constraints, e.g. primary care providers
- Lack of defined professional roles in cancer care, particular the primary care provider role
- Lack of coordination between primary, secondary and community care
- Limited communication and information transfer between care sectors
- Lack of system-wide incentives to deliver integrated care
- Insufficient infrastructure and technology to support integration

In January 2019, Macmillan Cancer Support responded to these challenges by launching a new programme, Right by You, which sought to test models of care that aimed to provide integrated, holistic support across secondary, primary and community settings.

RbY Wessex Logic Model

Context / Need

NHS Long Term Plan
- People living longer with cancer.
- Treatments changing and many are delivered outside hospital
- Target: all people with cancer receive personalised care

NHS Comprehensive Model for Personalised Care
- Aims to deliver better quality, integrated care that improves health and wellbeing

Macmillan Cancer Support
Ambition to:
- improve the lives of everyone with cancer from diagnosis
- everyone offered a conversation about their needs, identifying support that is right for them
- delivered in community and primary care, integrated with acute services.

Wessex Cancer Alliance (WCA)
- By 2024, all people diagnosed with cancer are offered a comprehensive, personalised assessment and care plan

Resources / Inputs

Portland
- 0.8wte Band 7 CNS, 0.4wte Band 4 CSW

Southampton
- 1wte Band 7 + 0.6wte Band 6 CNSs, 0.4wte Band 4 CSW, 0.2wte Band 8b Clinical Nurse Consultant (CNC)

Cross Wessex
- 1wte admin
- Funding from Macmillan Cancer Support / NHS England via WCA

Stakeholder support from:
- Patient & public involvement (PPI) support (Wessex Voices, Healthwatch and Macmillan)
- University Hospitals Southampton and Dorset County Hospital
- Solent NHS Trust
- Southampton Primary Care Networks (PCNs), Royal Manor Healthcare, the Lantern Trust, The Verne Prison, Weldmar
- Somerset cancer registry, Dorset Intelligence & Insight Service (DiiS) data
- HNAs, Cancer care reviews (CCRs), Personalised Care Plan (PCP) and treatment summary

Activities / Intervention

RbY Wessex Approach:
- Therapeutic dynamic assessment and complex support
- HNA conversations at times and location appropriate for the individual
- Personalised care and support plan, codesigned with experts by experience (formerly 'patient advisory group')
- Proactive signposting and advocacy
- Information/services tailored to the lived experience and needs of people living with cancer
- Support for marginalised communities (homeless, prison)
- Mentoring / bespoke education of primary and community care

Activities:
- Identifying / implementing specialist team working arrangements
- Developing policies and protocols
- Mapping opportunities for RbY referrals and promoting offer to people living with cancer, hospital, primary care, community / voluntary sector.
- Identifying barriers to CCRs and offering solutions / resources to encourage meaningful discussions

Outputs

- Promotional materials and care plan co-designed with experts by experience
- Community of Practice enhancing primary care practice, e.g. CCRs
- RbY workshops for people with less complex needs
- CNSs and CSWs delivering a needs-based service for individuals referred
- Workforce (e.g., primary care) learning needs are identified and supported

Outcomes

- Improved patient experience and outcomes, with holistic needs met
- Psychological needs met by ACT techniques / CALM trained CNSs and experienced CSWs support
- Delivery of effective integrated working between primary, secondary and community care
- Improved HCP experience and outcomes, e.g. satisfaction, skills, confidence
- Improved health service delivery, e.g. reduced unplanned care
- People living with cancer better supported to self manage

Impact

An embedded model of integrated holistic care and support that operates across organisational boundaries

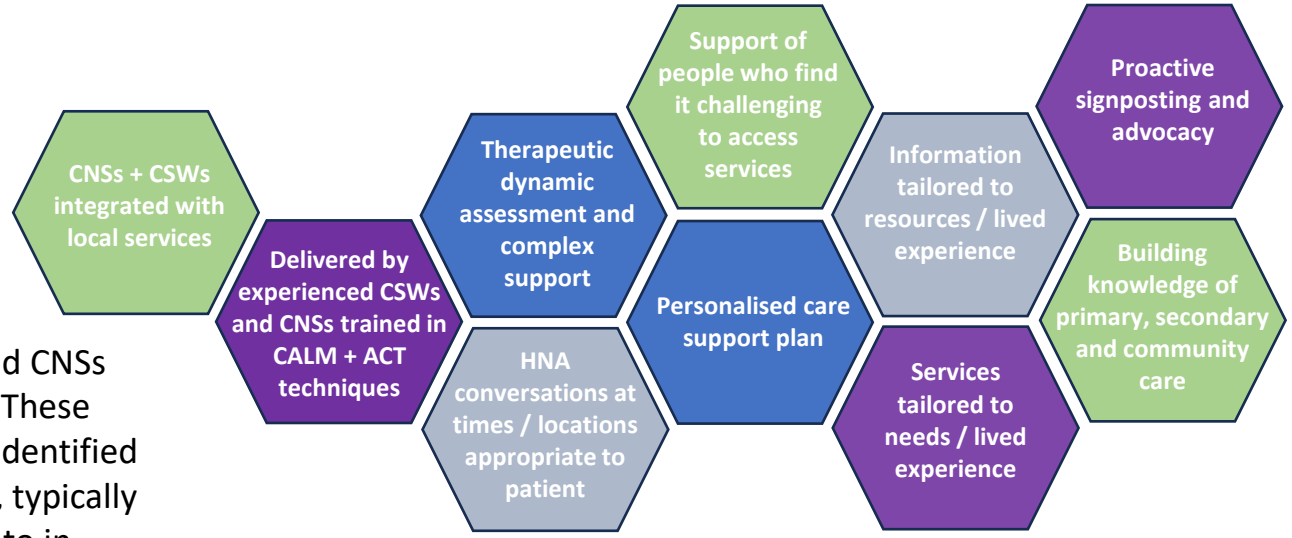
resulting in:

- Proactive management of people living with cancer with complex needs
- PCPs for people living with cancer
- Improved experience for people living with cancer and their families and carers
- Better health and wellbeing outcomes
- More effective use of Health and Social Care resources
- A cultural shift to improved supported self management
- A wider workforce upskilled and confident in supporting people living with cancer (e.g., primary care)
- Improved communication across health and care sectors.
- A model that is affordable, sustainable and can be replicated in other areas

RbY Wessex - Aim & Intervention Description

RbY Wessex Aim…

To enhance patient care through the development and testing of an integrated approach to supporting people living with cancer and carers across primary, community and secondary care, from as near to the point of diagnosis as possible, and throughout their cancer journey.



Therapeutic Dynamic Approach

The RbY Wessex therapeutic dynamic is delivered by experienced CSWs and CNSs with training in psychosocial support using CALM* and ACT** techniques. These staff deliver highly skilled psychosocial interventions to meet service user identified need. Assessments are undertaken in the service users' preferred location, typically their home (for those who have a home). This enables effective responses to in-person verbal and non-verbal cues of needs and concerns. It also helps to establish rapport and build the foundations of a longitudinal therapeutic relationship. Continual, repeated observations and assessment are undertaken with skilled symptom and side-effect management.

**Managing Cancer and Living Meaningfully (CALM)* is a psychotherapeutic intervention to treat and prevent depression and distress in individuals with advanced cancer. The approach facilitates a therapeutic relationship and reflective space to address domains such as symptom management and future-oriented concerns in a tailored, individualized way.[10]

***Acceptance & commitment therapy (ACT)* is a psychotherapy utilising mindfulness techniques to help move through difficult emotions and accept life experiences.[11]

> ***When people are in their own homes or in their own space, things are different. You see more about that real individual patient, and we can only personalise the care as much as we can from a hospital point of view in regards to their initial need while they're actually having treatment. Whereas the RbY team, there's no sort of barrier, so they see things as the person as a whole."***
> *RWS23, Secondary care*

*To ensure participant confidentiality, participants are referred to as 'RWSx' (RbY Wessex + numerical order in which they were recruited to the evaluation).

TIDIER SUMMARY OF RBY WESSEX COMPONENTS[12]

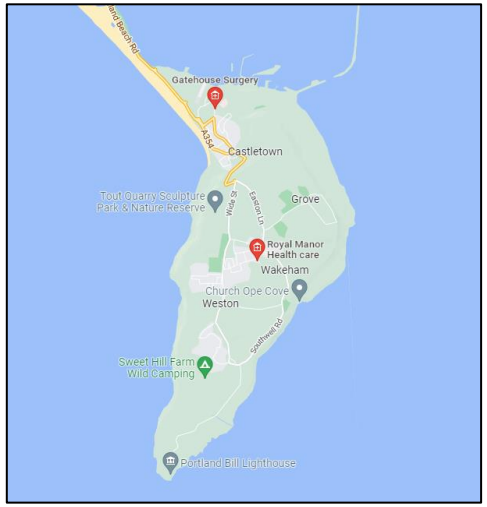
WHAT IS DELIVERED?	• Therapeutic dynamic • Longitudinal HNA and support • Collaboration and shared learning of knowledge and experience with primary, secondary and community care • Proactive signposting and advocacy • NICE level 2+* psychological support[13] *Training in ACT techniques and CALM are in addition to traditional CNS training, thus RbY staff are providing a higher level of psychological support
WHO DELIVERS?	• Community outreach boundary-spanning cancer CNSs with training in CALM and ACT techniques and experienced CSWs, recruited from secondary care but working across acute, primary care and community services settings
TO WHOM?	• People with highly complex support needs • People completing (or who have completed) treatment with curative intent • People living with incurable but stable disease • People at the end of life • People for whom treatment is not an option • People who are pre-diagnosis and are living with the consequences of awaiting tests / results • People who do not wish to / cannot access services (including marginalised communities) • Family, friends and care givers
HOW DELIVERED?	• Face-to-face, telephone, text, email communication for people living with cancer and family members • Telephone, email and letter communication with HCPs
WHERE?	• In the patient's preferred location, typically their own home
WHEN?	• At any stage in the cancer pathway from pre-diagnosis to post-curative treatment or palliative care

Service Delivery Local Population I - Portland

Dorset

Dorset has a population of >822,000[14] with a higher than average population of over 65's (24.7%% compared to the National average of 18.4%)[15]. The Isle of Portland (Portland) is a tied island, forming the southernmost point of the county of Dorset.

Figure 1: Portland & Royal Manor Healthcare Practices[16]



Right by You Offer (during evaluation period)

- 0.8wte Band 7 CNS (from Nov 2021)
- 0.4wte Band 4 CSW (from Nov 2022)

Work one day a week from Royal Manor Health Centre

Who can be referred:

- Individuals residing in Portland
- Individuals accessing The Lantern Trust

Primary Care Services

- Served by Royal Manor Health Care Practice (Weymouth and Portland PCN) which consists of two GP centres (figure 1).
- Total of 12,415 patients (49.6% male)
- 42.6% aged 50-79 years.[17]

Portland

- Predominantly White British (93.9%) population of 13,417 (53% male) with 22.8% aged 65+ years.[18]
- Home to two prisons: Portland Prison and Young Offender Institution (for men aged ≥18)[19], and The Verne Prison for men convicted of a sexual offence[20].
- Population supported by Weldmar Hospice care palliative community services and Dorchester based inpatient unit[21].
- Population supported by The Lantern Trust, a Weymouth based charity who support vulnerable and marginalised people in the Weymouth and Portland area.[22]

Existing Cancer Services

- There is a commissioned community cancer nursing service covering Bournemouth, Poole and West Dorset.[23]
- There are no commissioned specialist cancer services outside of secondary care in West Dorset (including Portland and Weymouth).

Table 1. Dorset cancer data[15]

	Pop^{N} aged 65+ years (%)	New cancer cases per year	New cancer cases per 100,000 pop^{N}
Royal Manor Healthcare	23.7*	82**	660*
Weymouth & Portland PCN	26.3*	515**	673**
Dorset ICB	24.7*	4,484**	598**
England	17.6*	276,979**	456**

*PHE 2022 data, **PHE 2020-21 data

Service Delivery Local Population II – Southampton

Hampshire

The City of Southampton is a port city in the county of Hampshire. Hampshire has an estimated population of 1.48 million, with an older population of 21.7% (National average, 18.4%).[24]

Southampton

- Entirely urban population of nearly 264,000, 51% male.[25]
- Lower than average older population (14.3% aged over 65).[25]
- University City with approximately 37,800 students.[25]
- Higher than average younger (16-24 years) population of 18.5% (National average, 10.5%).[25]
- Predominantly white British (68.1%) but growing non-white British population with wide variation in ethnic diversity depending on area.[25]
- Population supported by Mountbatten Hampshire palliative community services and the inpatient unit based in West End, Southampton.[26]

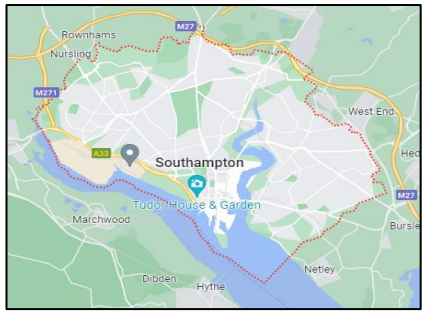


Figure 2: Southampton City[25]

Right by You Offer (during evaluation period)

1FTE Band 7 CNS (from May 2020)
(Covid break Feb-July 2021)
0.6FTE Band 6 CNS (from Oct 2021)
0.4FTE Band 4 CSW (from May 2020)
(Covid break Feb-July 2021 & Jan-March 2022)
0.3FTE Band 8b CNC for homelessness & health inequalities (from Oct 2021)
0.2FTE Band 4 (from Jan 2022), changing to 1FTE Band 5 from Jan 2023
Who can be referred: Individuals residing in any of the six Southampton PCNs

Primary Care Services

- Initial proposal was for RbY to engage with a small number of Southampton City GP practices.
- Early engagement with 4 practices: Burgess Road, Old Fire Station, Stoneham Lane and the Homeless Healthcare Team
- The Homeless Healthcare Team provide care to homeless adults in Southampton.[28] Over 75% of patients are aged 30-59 years.[25]
- As the RbY Wessex service has evolved, there is now wider engagement, with service users from practices across all Southampton PCNs.

Table 1. Southampton cancer data[15]

	Population aged 65+ years (%)	New cancer cases per year	New cancer cases per 100,000 pop[N]
Southampton PCNs *Figures based on mean average across 6 PCNSs*	13.4*	198**	412**
Hampshire & IOW ICB	20.5*	8,757**	545**
England	17.6*	276,979**	456**

*PHE 2022 data, **PHE 2020-21 data

Existing Cancer Services

- There are no commissioned specialist cancer services outside of secondary care other than charitable services.

Evaluation Methods

The evaluation ran from 14th December 2020 – 13th July 2023, pausing from 1st January – 30th June 2021 due to COVID. The design was informed by principles of process and outcome evaluation. The process evaluation assessed the design, set up and delivery of RbY Wessex, the outcome evaluation focused on the experiences and outcomes for people living with cancer, carers or family members (service users), HCPs, and other staff (e.g. commissioners and community services).

METHOD 1

QUANTITATIVE SERVICE DATA

Analysis of data collection on **all people** referred to RbY Wessex in Portland and Southampton *(during the data collection period)*, including:

- Date of current cancer diagnosis
- Site of current cancer diagnosis
- Known number of comorbidities
- Date of referral to RbY Wessex
- Reason for referral to RbY Wessex
- Whether a Holistic Needs Assessment (HNA) had been completed
- To where the service user was referred / signposted
- Time spent with the service user

METHOD 2

QUALITATIVE DATA

Semi structured multi-timepoint interviews with **60 participants** drawn from those in receipt of the RbY Wessex service (from Southampton and Dorset), resulting in qualitative **104 interviews**. Participants included:


10 RbY staff


12 Secondary care staff


9 Community care providers*

12 Service users


10 Primary care staff


7 Commissioners

*Refers to staff working in and providing community-based support, e.g., hostels, homeless charities, those providing financial advice

METHOD 3

DOCUMENTARY REVIEW

Analysis of all documents related to RbY Wessex, including minutes, role descriptions, promotional material, study documentation relating to intervention delivery (e.g. the PCP)

Quantitative Description of Service Delivery

2022/23 Staffing Costs of RbY Wessex Service

Estimated staffing costs of RbY service delivery per 1) each service user supported (active caseload) & 2) each individual contact delivered during the time period Sept 2022 to Feb 2023 (6 months)

Service delivery staff cost estimates are based on data available from the last 6 months of data collection, because….

- This was a new service whose staffing and delivery was impacted by Covid up to and including Q1 of 2022
- This period was deemed more reflective of the service as it currently stands

Portland

- **£441.35 per service user supported by RbY Portland**
- **£55.60 per each RbY contact**

Based on: 1) 516 contacts across an active caseload of 65 service users
2) Staff costs of £28,688
(Bands 7 (0.8wte) + 4 (0.4FTE, for 3months – in post late Nov '23))

Average service user receives 65% of support from a CNS & 31% from a CSW

Average duration of each Portland contact = 22 minutes

Southampton

- **£462.20 per service user supported by RbY Southampton**
- **£33.20 per RbY contact**

Based on: 1) 2,255 contacts across an active caseload of 162 service users
2) Staff costs of £74,876.84
(Bands 7 (1FTE), 8b (0.3FTE), 4 (0.4FTE), 6 (0.6FTE), 4 (0.2FTE for 4 months) + 5 (1FTE for 2 months)) **Band 5 pathway navigator role introduced in January 2023 so band 4 at 0.2FTE relates to administrative support in last 4 months of 2022*

Average service user receives 93% of support from a CNS & 6% from a CSW

Average duration of each Southampton contact = 23 minutes

**Calculations based on 2023/24 Agenda for Change pay scales (top step point) with on-costs*

2022/23 Staffing Costs of RbY Wessex Service

Estimated staffing costs of RbY service delivery during the time period Sept 2022 to Feb 2023 (6 months)

OVERALL ESTIMATED SERVICE DELIVERY STAFFING COSTS

- **£456.23 per service user supported by RbY**
- **£37.37 per RbY contact**

Based on: 1) 2,771 contacts across an active caseload of 227 service users
2) Staff costs of £103,564.84

- As calculations are based on staff salaries, these costings take into account the additional work associated with supporting service users e.g., travel time, case note review and note making, team discussion, data collection, training
- Additional costs associated with delivering the RbY Wessex service (e.g., travel reimbursement, office hire) are not included in these calculations

**Based on 2023/24 Agenda for Change pay scales (top step point) with on-costs*

Moving Forward - Annual RbY Wessex Cost

Potential annual cost of the RbY Wessex Service

This is a *best prediction* based on current and predicted costs

Potential Annual Staff Cost of RbY Wessex

**Based on 2023 staff make-up of RbY service*
***2023/24 Agenda for Change pay scales (top step point) with on-costs*

Portland

- £64,227 staff costs
  Bands 7 (0.8FTE) + 4 (0.4FTE)

Southampton

- £217,513 staff costs
  Bands 7 (2FTE), 4 (1.4FTE) + 5 (1FTE)

Nb. On-costs include National Insurance, pension and apprenticeship levy

Predicted Overall Annual Staff Cost of RbY Wessex

£281,740

Annual Additional Costs breakdown

Mileage reimbursement £9,697
*based on mean average self-reported mileage across RbY staff
**calculated for 2023 RbY staffing at current UHS reimbursement rates (59p for 3,500 miles, 24p thereafter)

Hospital parking permits £1,512
*based on annual University Hospital Southampton (UHS) permit costs (3x band 4 @ £126, 3x band 7 @ £378)

Additional parking charges £110
*based on self-reported mean average cost per month (£2) x 4.6FTE 2023 staffing

Office hire £29,232
*based on annual hire costs for RbY Southampton (£14,616 x2)

People safe device hire £1,051
*based on annual cost for all staff 2023

Printers £257
*based on cost of 2 printers for 2023

Mobile phones £780
*based on UHS unit cost of £130

Laptops £6,432
*based on UHS unit cost of £1,072

Potential Annual Additional Costs of RbY Wessex

**Based on 2023 staff make-up of RbY service*
***Costs included for Portland despite mileage, office hire and parking not currently expended*

Predicted Overall Annual Additional Costs of RbY Wessex (Portland and Southampton Combined)

£49,071

Predicted Overall Annual Cost of RbY Wessex £330,811

Nb. Staffing models and costings differ between RbY Portland and Southampton
Introduction and costings of RbY Wessex to other geographies should take into account that this is not a consistent model of delivery

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RbY Service Data

Data collection

Service data were collected by RbY staff from the start of RbY delivery until pause for data collection and analysis: Southampton: 14/10/20 – 10/05/23
Portland: 24/06/21 - 24/04/23

Patient No	Patient's Name	Hospital Number	Age range	Gender	First four digits of postcode	Date of Current Cancer Diagnosis	GP Surgery	Site of current cancer diagnosis	Known Number of Comorbidities	Date of referral to RbY Wessex	Reason for referral to RbY Wessex	Referred by	HNA Completed	Has Personalised Care Plan been introduced to Patient? Yes/No	Who has the personlised care plan been shared with	Where was the patient referred/signposted to?	Notes

Figure 3: RbY Wessex Service Data Spreadsheet

Background

Macmillan Cancer Support contracted RbY Wessex to collect quarterly performance data. The substantive part of this quantitative service data analysis draws upon these metrics. Additional data were collected to provide context, including location, duration and method of contact.

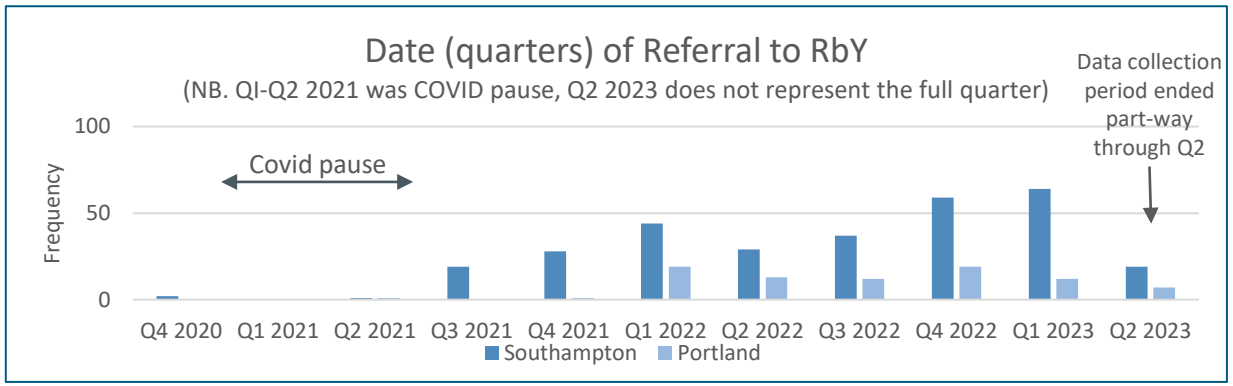
Database

- Data were collected in real time using an excel spreadsheet proforma (figure 3)
- The database was updated during the project to reflect changes in service delivery

Number of referrals

- Total 390 referrals to RbY: 303 in Southampton, 87 in Portland

In Portland, of those referred: 6 declined support, 2 passed away before their first visit, and 1 was uncontactable. Data regarding whether those referred were supported, were unavailable for Southampton.

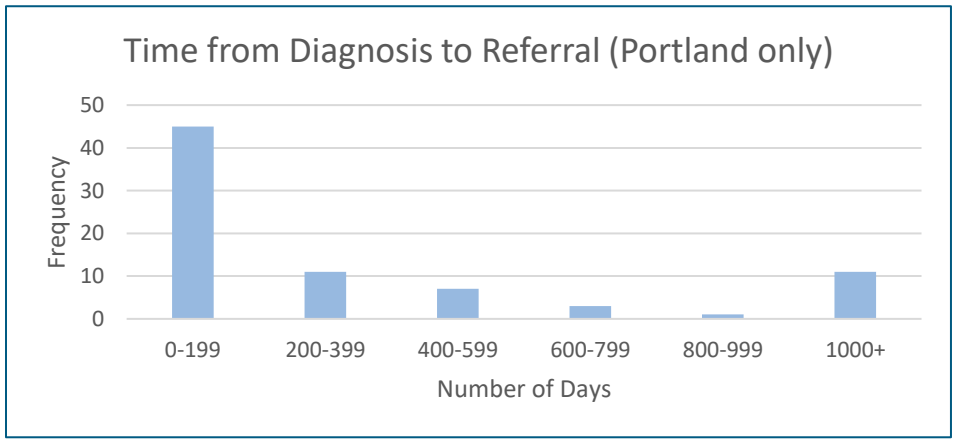


*Q1 runs Jan-March

Time from Diagnosis to Referral

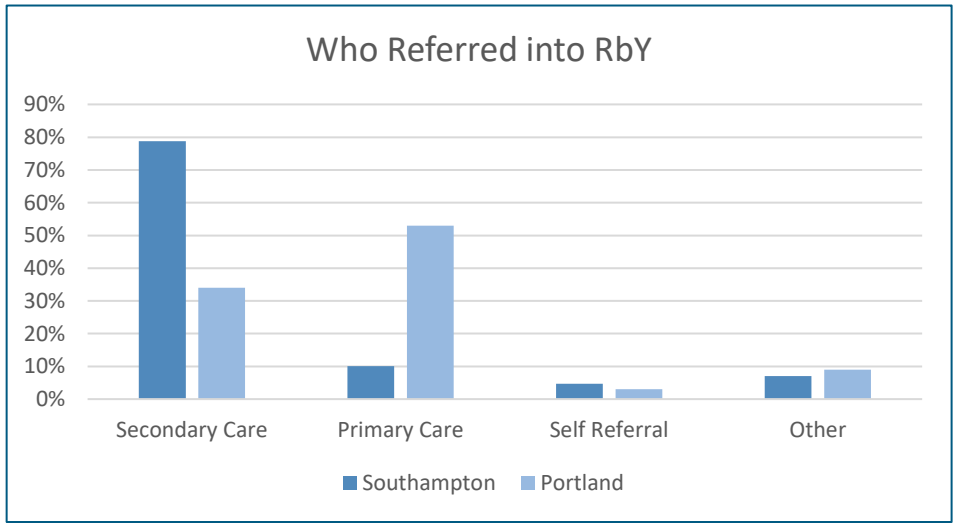
Data available for Portland only

- Mean time from diagnosis to RbY referral: 366 days (range 0-2261 days)
- 45% were referred within 100 days of cancer diagnosis
- 1 referral pre-diagnosis



*Missing data n=9

Who is Referred?



*Missing data n=15

Southampton referrals

- >75% from secondary care
  - 90% from CNSs, also healthcare support workers (6%) and medical secretaries (2%)

May reflect UHS as a regional cancer centre and existing links of RbY Wessex staff

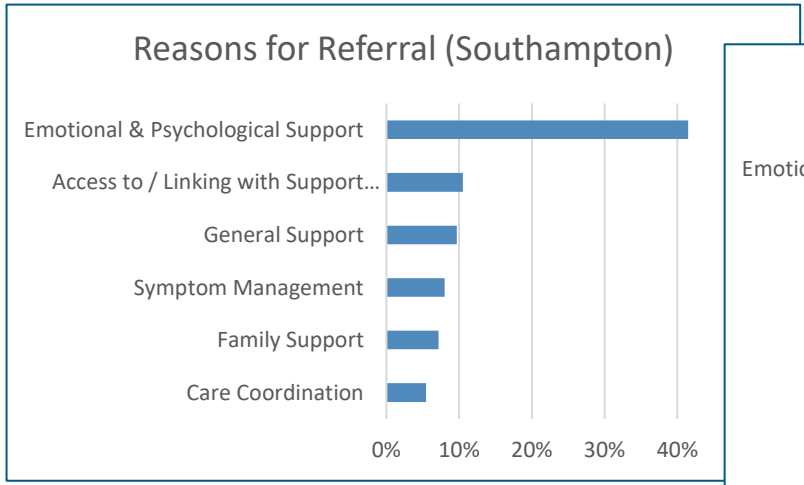
- 10% from primary care
  - Majority from practice nurses (90%), remainder from GPs (10%)
- Self-referrals accounted for 5%
- Others from community care (6%, e.g., CAB, support centres) & specialist palliative care (1%)

Portland referrals

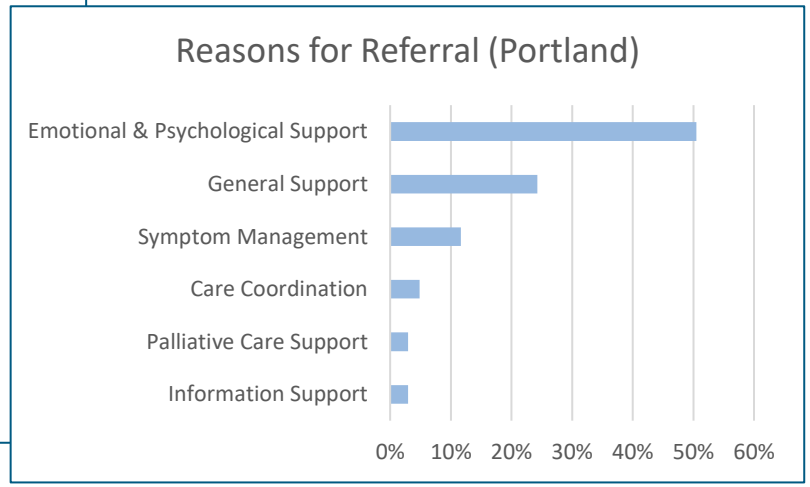
- >50% from primary care
  - Majority from practice nurses (80%), also GPs (20%)

May reflect working with a single GP practice and positioning of RbY team within the practice

- A third from secondary care
  - 59% from CNSs, also lead oncology nurse (28%) and support workers (14%)
- Self-referrals accounted for 3%
- Others limited to the prison healthcare team (9%)



*Missing data n=17, **6 most common reasons displayed



*Missing data n=2, **6 most common reasons displayed

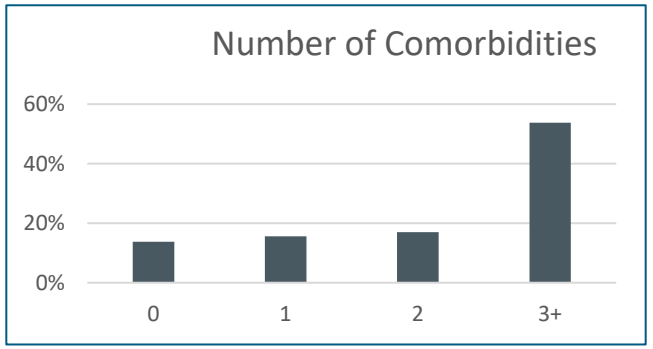
Reasons for referral *Data available for 371 service users (95%)*

- 157 (42%) had ≥2 reasons → total 578 reasons for referral
- Main reason 'emotional and psychological support'
  - 41% Southampton, 50% Portland
- Unspecified 'general support' accounted for 12% across both sites
- In Southampton, 'access to or linking in with support services' accounted for 11%
- In Portland, 'symptom management' third most common reason (12%)
- 'Care coordination' and 'palliative care support' common across both sites
- Less common reasons (<5%): Financial support, social support (e.g. housing) and physical support (e.g. mobility)

CHARACTERISTICS

COMORBIDITIES

- Range of 0-26
- >50% had 3+ comorbidities
- Mean = 3.4 in Southampton,
  3.9 in Portland



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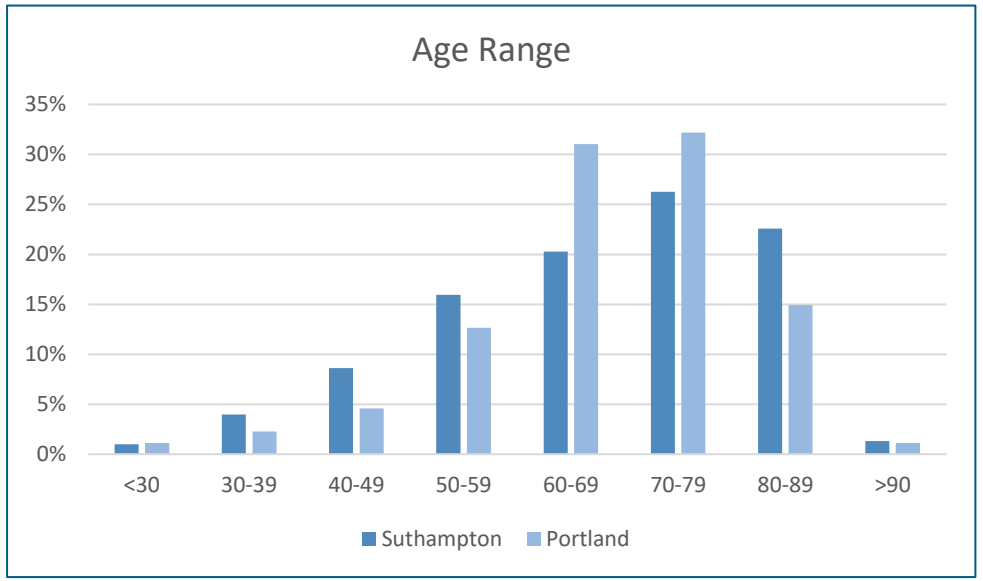

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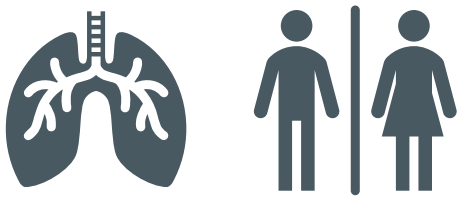
GENDER

- 49% female (54% Portland, 48% Southampton)

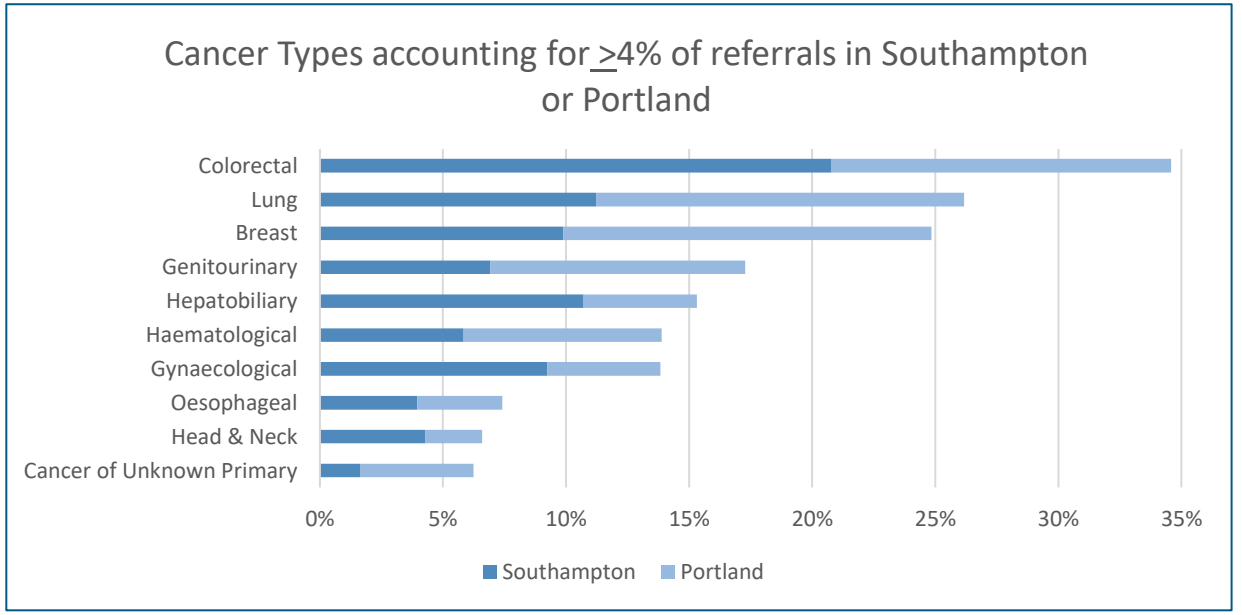
AGE

- 86% aged 50-89 years, 50% aged 60-79 years
- Higher proportion aged 60-79 in Portland (63%, Southampton 47%)
- Higher proportion aged ≤59 years in Southampton (30%, Portland 21%)



CANCER TYPE

- 21% colorectal cancer in Southampton
- In Southampton, lung, breast and hepatobiliary cancers constituted 32%
- Lung, breast and colorectal cancers constituted 44% in Portland
- Across both sites, 5 had no confirmed cancer diagnoses, 7 had dual cancer diagnoses
- Wide range of cancer types including anal (n=7), upper GI (n=4), brain (n=3), mesothelioma (n=3), neuroendocrine (n=3) and peritoneal (n=2) cancers



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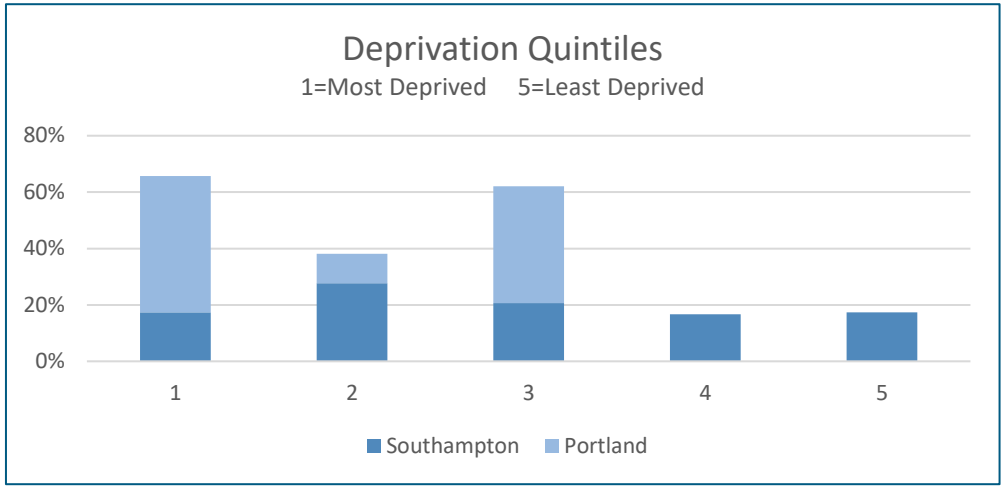
Deprivation

Quintiles of Deprivation

Deprivation quintiles calculated using English Indices of Multiple Deprivation (IMD) 2019, where 1 indicates most deprived and 5 least deprived[29]

- In Southampton, service users supported are fairly equally distributed across all quintiles (>15% from each), with 45% from the lowest two quintiles (most deprived areas) and 34% from the highest two quintiles (least deprived areas)
- In Portland, all service users reside in deprivation indices 1-3, with 48% from quintile 1 (most deprived)
- Overall, 73% of all service users referred to RbY Wessex reside within quintiles 1-3



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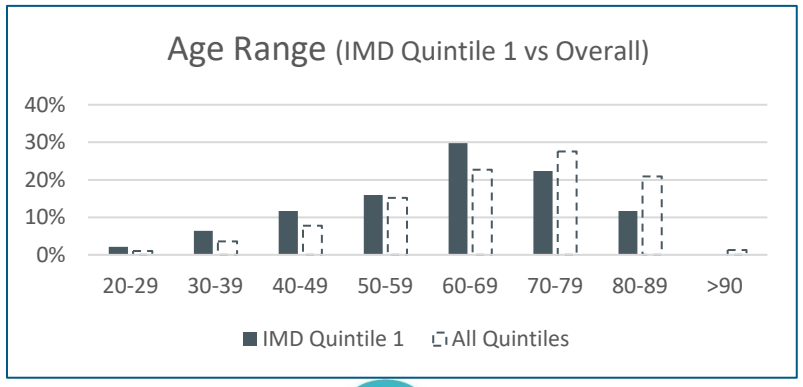
Most Deprived (IMD Quintile 1)

Age

- Similar pattern of age ranges to all service users referred
- Higher percentages of service users aged 20-69 years than overall
- Lower proportion of service users aged 70+ than overall



Locality

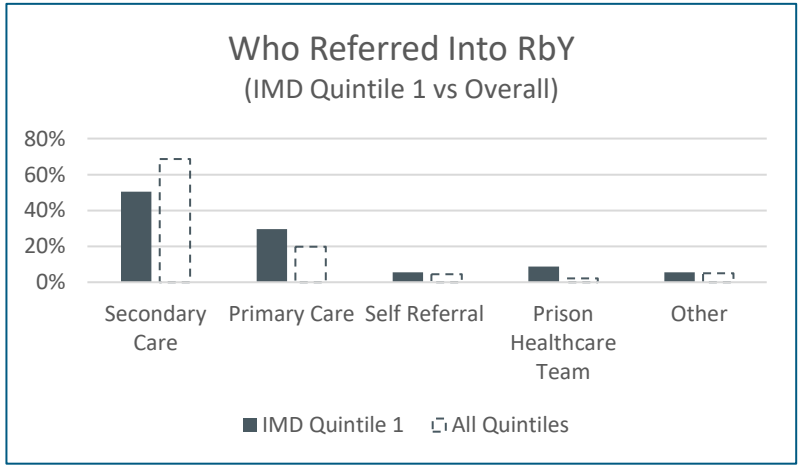
- 24% (n=94) of all referrals to RbY are service users living in the most deprived areas (IMD quintile 1)
- 48% of all Portland referrals are from those living in the most deprived areas
- Overall, Portland-based service users constitute 22% of those supported by RbY, however they constitute 45% of those living in the most deprived areas

Gender

- 53% female (compared to 49% overall)

Who Referred into RbY

- Higher percentage of referrals from primary care reflects the higher proportion of service users from more deprived areas in Portland



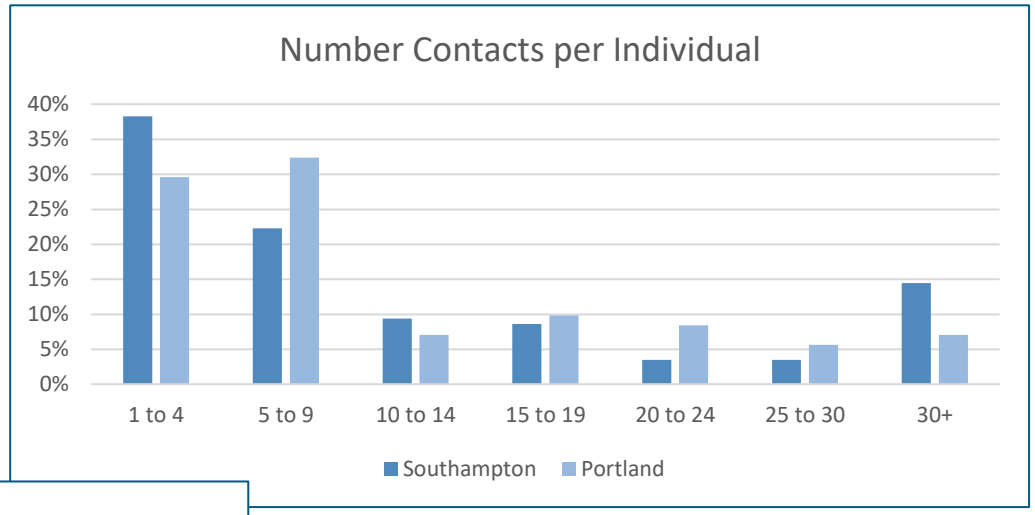
Reasons for Referral

- As per the most common 3 reasons for referral in Portland: Emotional & psychological support (40%)
  General support (14%)
  Symptom management (11%)

CONTACTS

CONTACT METHOD

- 40% of contacts via telephone
  - 51% Portland, 38% Southampton
- 16% of contacts were face to face
  - 26% Portland, 14% Southampton
- Text and email contact more common in Southampton (47%), 18% in Portland



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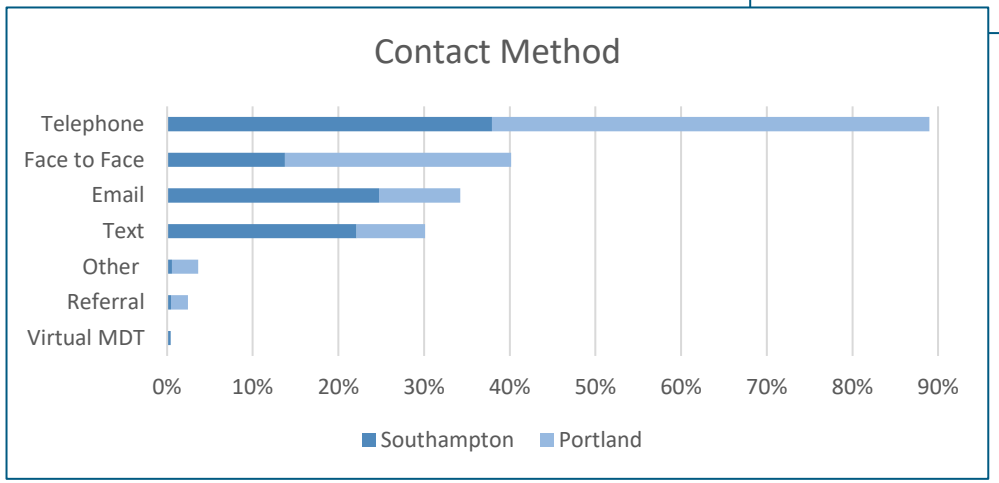

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NUMBER OF CONTACTS

Data available for 327 individuals (84%)

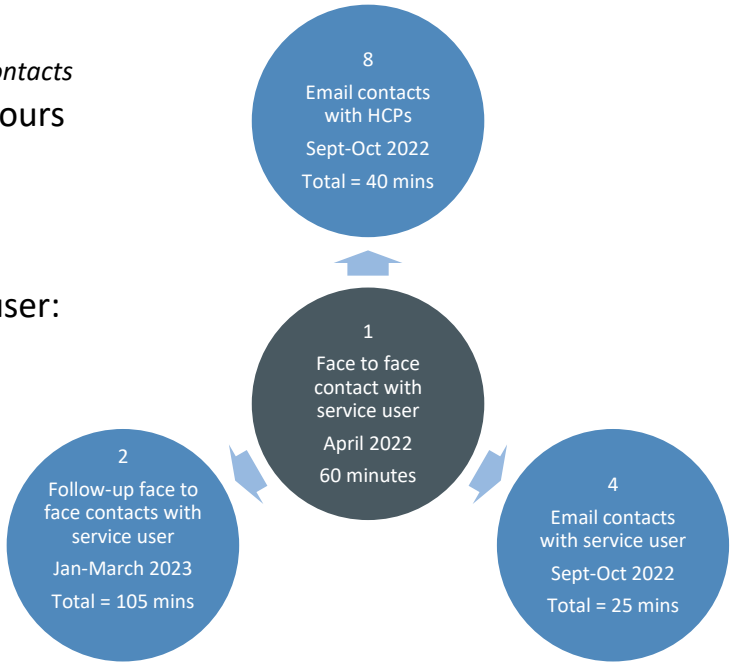
- Total of 5,287 contacts (852 in Portland and 4,435 in Southampton)
- Range 1-298 per service user
- Mean number of contacts 17 in Southampton and 12 in Portland
- 37% had >10 contacts
- 9 service users had >100 contacts

DURATION OF CONTACTS

Data available for 4,067 Southampton & 844 Portland contacts

- Total duration of all contacts = 1,841 hours
- Mean average contact = 22.5 minutes
  - 23 minutes Southampton
  - 22 minutes Portland
- Average contact duration per service user:
  - 6.4 hours Southampton
  - 4.4 hours in Portland

Figure 1: Service user example of relationship between face to face and other contacts



SPOTLIGHT: FACE TO FACE CONTACTS

- When looking at duration, face to face contacts constituted 44% of all service delivery time
- In Portland, 95% were at the service user's home, 5% at hospital
- In Southampton, where specified (n=576), 67% at service user's home, 25% hospital, 7% support centre
- To provide context, each face-to-face contact was preceded by or led to multiple other modes of contact (see figure 1)

CONTACTS

WHO IS DELIVERING?

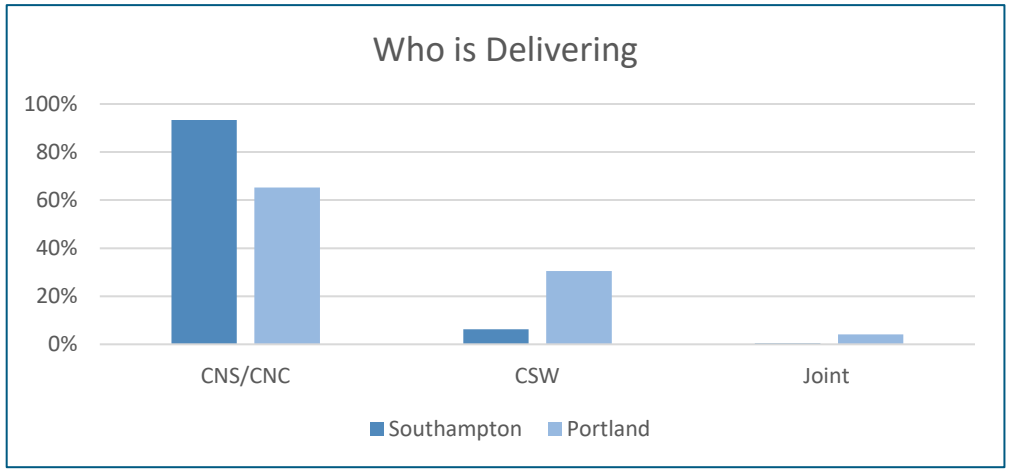
Portland:

- 65% CNS delivery (0.8FTE)
- 31% CSW delivery (0.4FTE)

RbY Portland initially delivered by one CNS
CSW joined team in Nov 2022
Therefore, data limited to 2023 & relates to 383 contacts (01/01/23 – 25/04/23)

Southampton:

- 93% CNS/CNC delivery (equates to 1.9 FTE) (56% CNS, 8% CNC, 36% unspecified)
- 6% CSW delivery (0.4FTE + covid break)
- Patient pathway navigator (post commenced Jan 2023) data not reported as only pertains to 24/02/23 onwards



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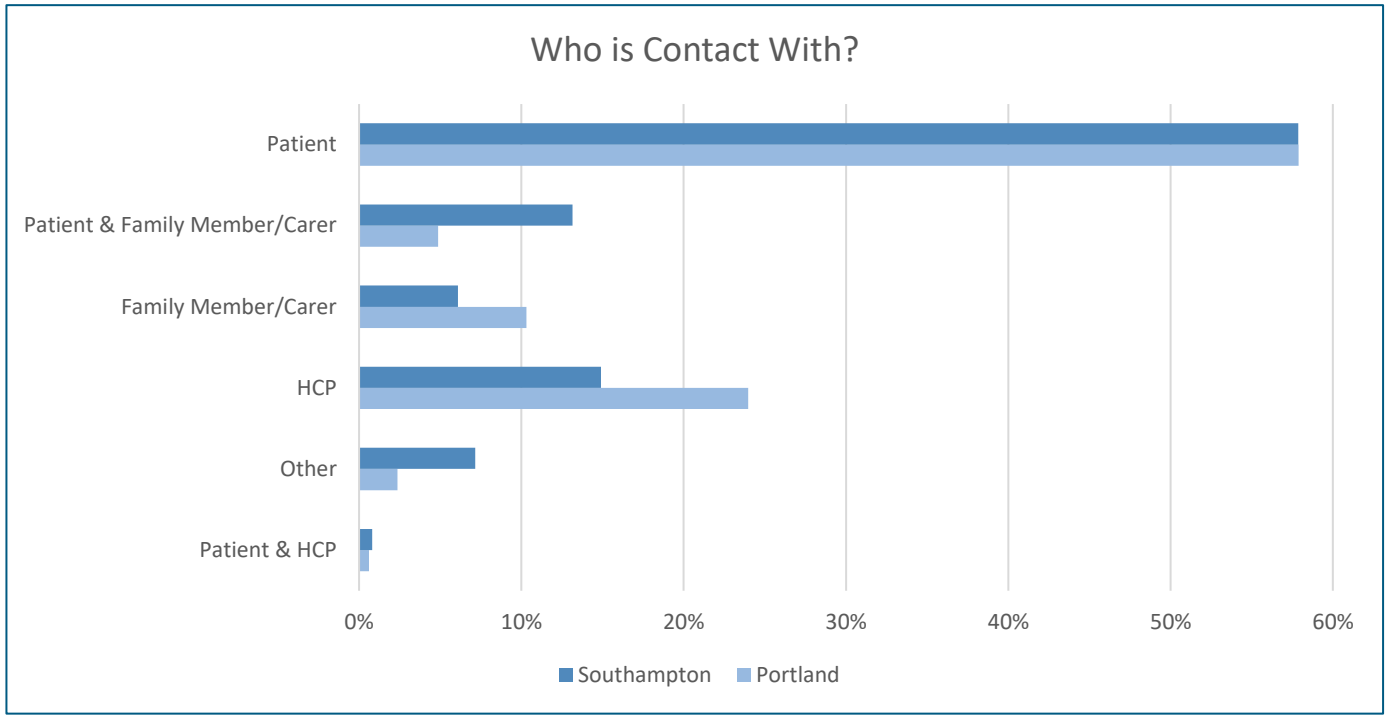


WHO IS CONTACT WITH?

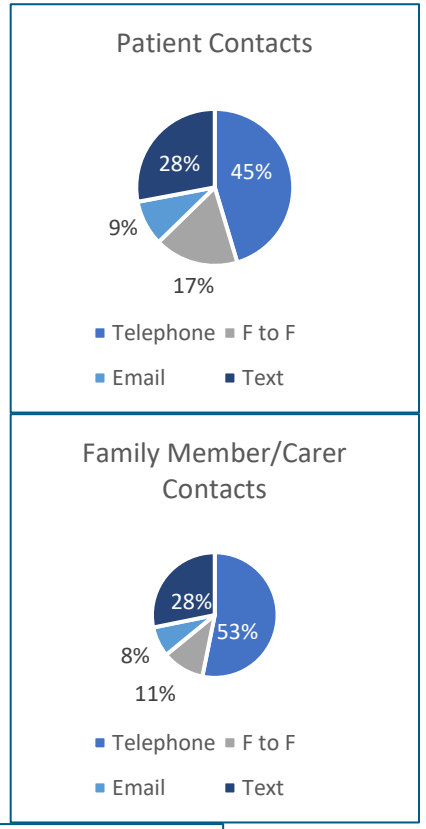
- 58% of contacts with people living with cancer *significant proportion likely includes support of family members alongside, as database amendment to include 'patient & family member' occurred partway through the project
- Contacts with people living with cancer accounted for 63% (Southampton) to 72% (Portland) of contacts when including contacts where family members, carers or HCPs were also present
- Contacts with HCPs accounted for 15% of contacts in Portland, 25% in Southampton
- Contacts with 'others' varied by site and included:
  - 44 attendances at hospice multi-disciplinary team meetings (Southampton)
  - Liaison to arrange prison visits (n=6) and Macmillan CAB contact (n=4) in Portland

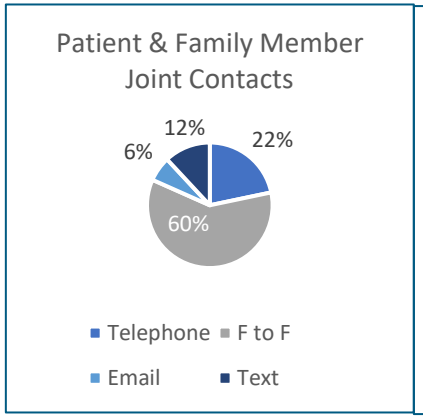
CONTACTS

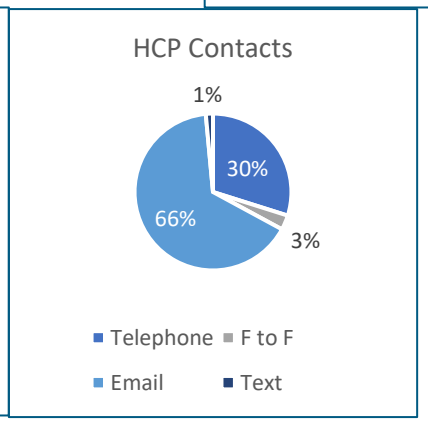
WHO IS CONTACT WITH BY METHOD

Looking at the four main contact methods only

- Telephone was most common method of contact with individuals or family members/carers
  - 45% of individuals contacts
  - 53% of family member/carer contacts
- Joint contacts with individuals and family members mainly held face to face (60%)
- 66% of HCP contacts via email







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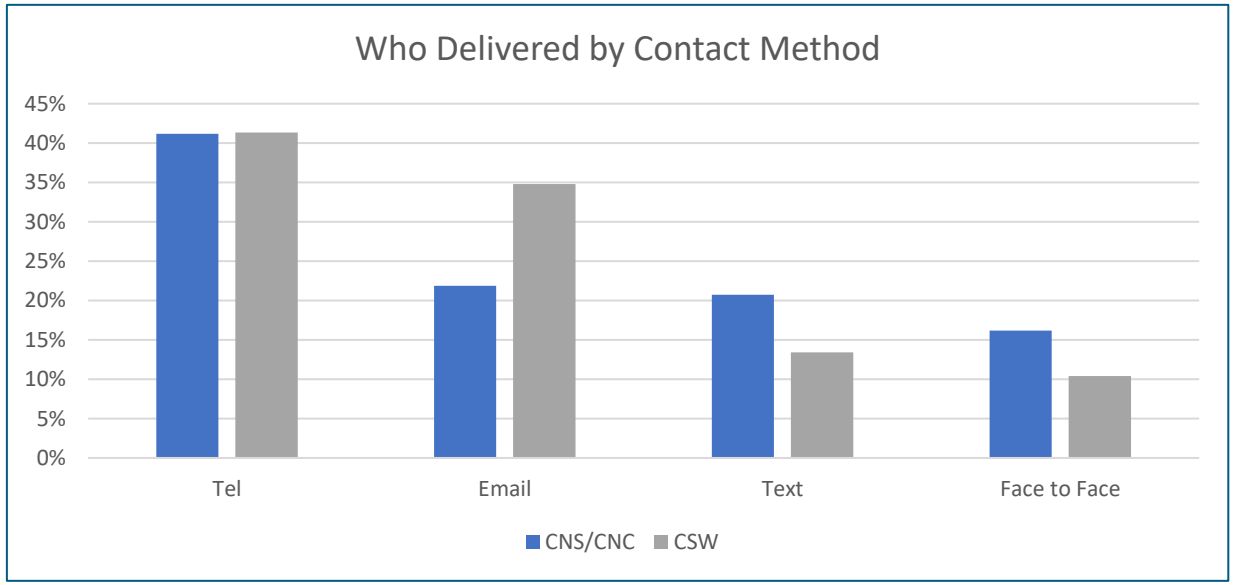


*Missing Data n=47, **Data referring to Virtual MDT, referrals and 'other' not shown
***Data referring to Patient pathway navigator and CNS+CSW not shown

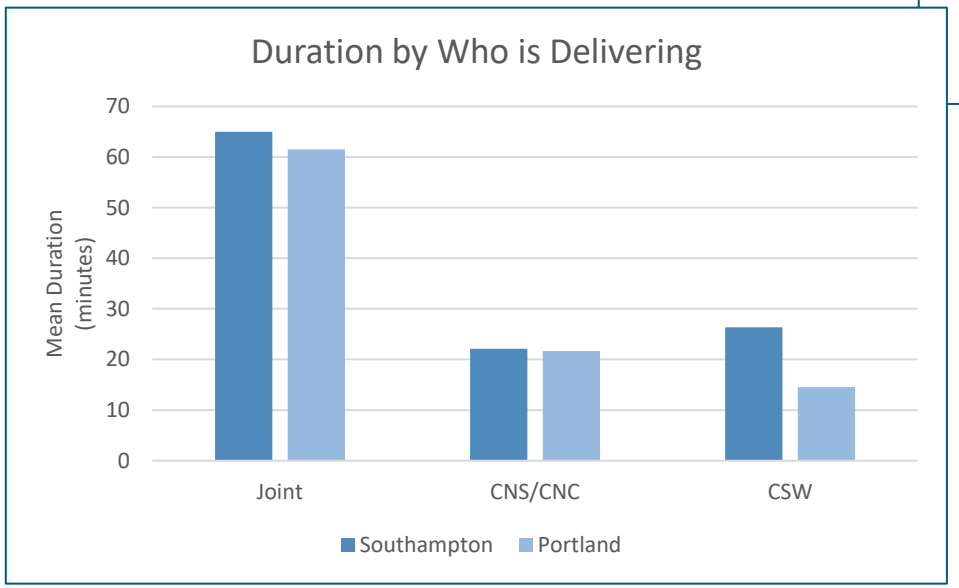
WHO DELIVERED BY METHOD

- Telephone most common contact method for CNSs and CSWs (41%)
  - In Portland, telephone contact more common (71% CSW, 53% CNS delivery)
  - In Southampton, telephone contact 39% of CNS & 29% of CSW delivery
- Email contact more common with CSWs (42% of CSW contact in Southampton)
- Face to face visits accounted for 16% of CNS & 10% of CSW contacts
  - CNS face to face contact more common in Portland (28%, Southampton 14%)
- Text contact used proportionately more by CNSs (21%) than CSWs (13%)
  - Text contact not used at all by Portland CNS
- Joint contacts between the CNS and other RbY team members limited to text contacts in Southampton and face to face contacts in Portland

CONTACTS

DURATION BY WHO IS DELIVERING

- Joint contacts (CNS + CSW or CNC) had the longest duration of around an hour across both sites.
- The duration of CNS/CNC contacts averaged 22 minutes across both Portland and Southampton
- In Portland, CSW contacts were on average shorter than CNS at 15 minutes
- In Southampton, CSW contacts were on average longer than CNS at 26 minutes



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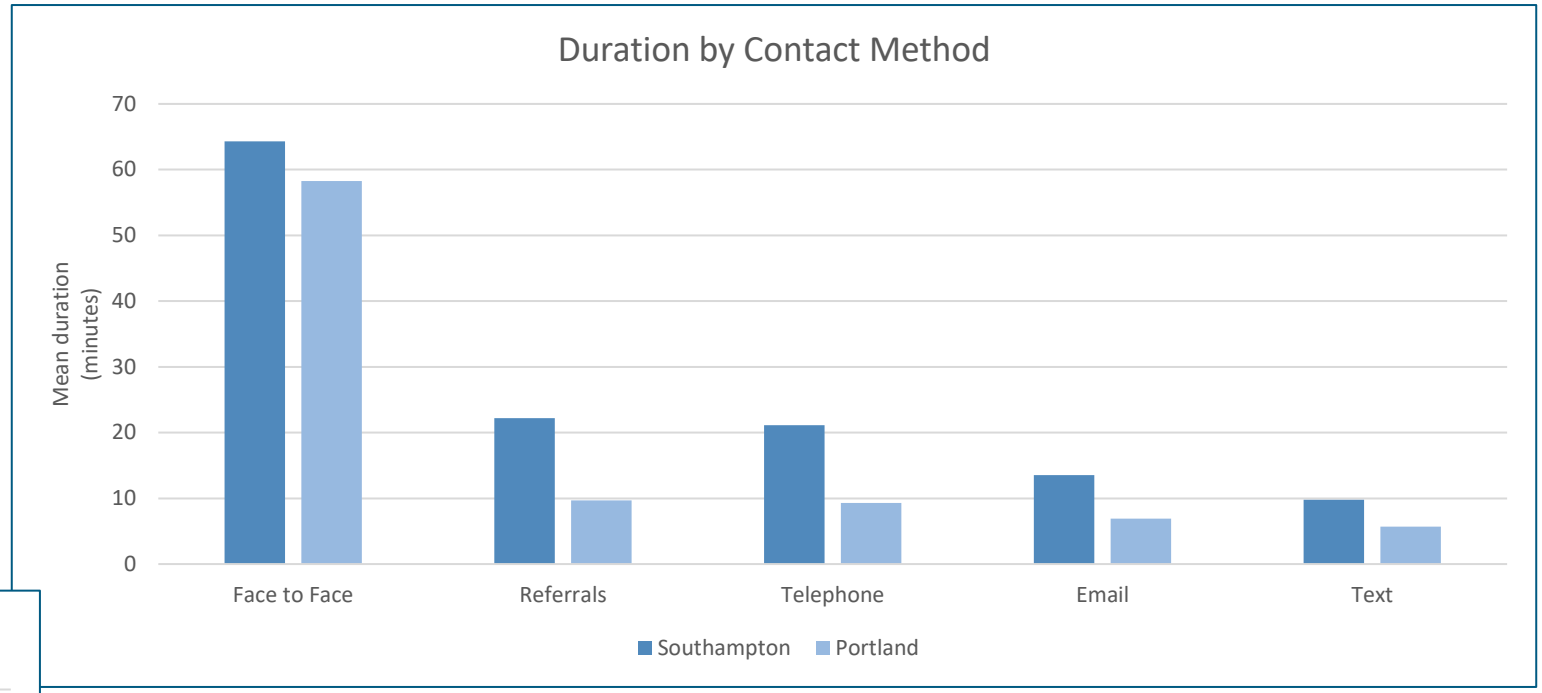


*Missing data n=389, **Data referring to virtual MDTs and 'other' contacts not shown

DURATION OF CONTACTS BY METHOD

- Longest contact = face to face (mean 64 minutes Southampton, 58 minutes Portland)
- Text contacts = shortest contacts (10 minutes Southampton, 6 minutes Portland)
- Across all mediums, contacts in Southampton were longer than Portland
- The difference was greatest for telephone contacts (on average 12 minutes longer in Southampton)

Support Provided

Signposting

Data available for 114 service users (29%), data does not distinguish between signposting and referrals

- Signposting to financial support most common
  e.g., 52 individuals referred to Macmillan CAB services
- Signposting to primary care more common in Southampton (n=30) than Portland (n=2)
- Southampton: 24 signposts to CNS teams, 7 to oncology teams and 12 to non-cancer secondary care teams
- Portland: 4 documented referrals to CNSs or oncologists
- N=19 individuals signposted to specialist palliative care services in Southampton, 8 in Portland
- Also common were signposting to: cancer support centres and groups, housing and local councils, exercise and wellbeing support, counselling, mental health services and psychologists
- Other signposts included: district nurses, pharmacies, dental services, continence services, community physiotherapy

Holistic Needs Assessments

Data recorded whether HNAs had been completed with service users

- In Southampton, 96% (n=289) had a HNA completed with RbY
- In Portland, 63% (n=55) had a HNA completed with RbY

Personalised Care Plans

Data recorded whether PCPs had been introduced to service users

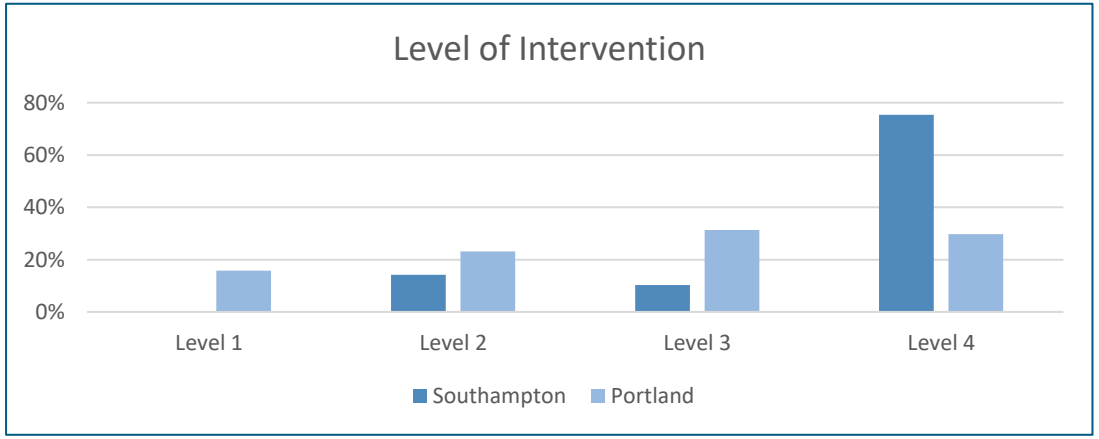
- In Southampton, 93% (n=281) had been introduced to a PCP
  - N=280 shared with others
  - All listed as shared with 'patient, family, primary, secondary & community care'
- In Portland, 64% (n=56) had had been introduced to a PCP
  - 86% (n=48) shared with others
  - Shared with multiple healthcare services: secondary care (n=37), primary care (n=35), community care (n=29)

Level of Intervention

Classified using levels 1-4 as defined by the Somerset Cancer Registry (see figure 4 overleaf)

- Most complex level of intervention (level 4) accounted for
  - 75% of contacts in Southampton
  - 30 % of contacts in Portland
- Least complex (level 1 interactions) accounted for:
  - <1% (n=5) of Southampton contacts
  - 16% of Portland contacts

Differences in levels of intervention may reflect greater proportion of referrals from secondary care in Southampton and from primary care in Portland

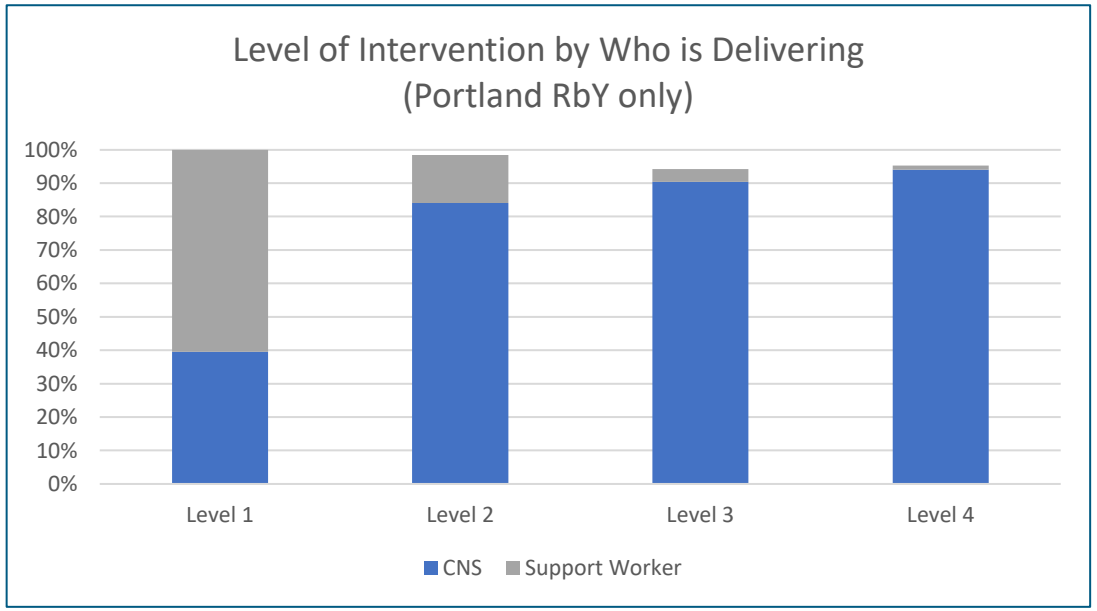


*Missing data n=27

Level of Intervention

Figure 4. Somerset Cancer Registry levels of intervention[30]

Level 1 – Simplest level of intervention on issues relating to patient care Intervention which provides consultancy to others when no direct contact with the patient is made.
Level 2 – Single patient contact to resolve a specific problem The intervention requires a specialist level of knowledge and skill but is easily resolved during a single consultation.
Level 3 – Short-term involvement for multiple problems A more involved level of intervention both in the complexity of the presenting problems and the need for several interventions.
Level 4 – Interventions when patients require ongoing specialist advice and support for complex problems Interventions of the greatest complexity, when there is requirement for long-term specialist involvement, generally for several months both during and after cancer treatment.

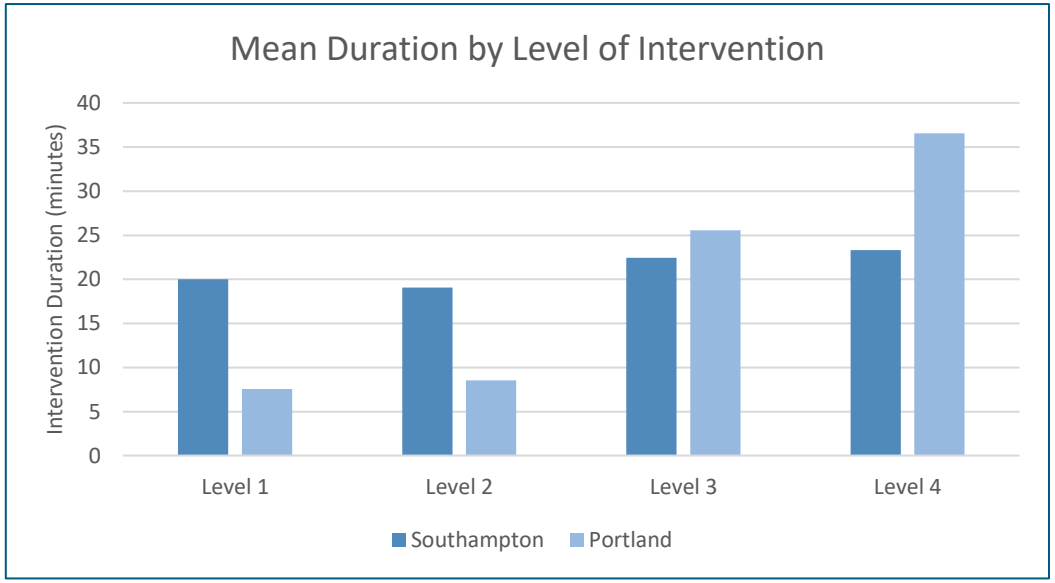


*Missing data n=10, **Data referring to joint CNS+CSW delivery not shown

Duration by level of intervention

Data available for 371 service users (95%)

- Average duration of contact increased with level of intervention in Portland:
  - Level 1: 7.6 minutes average duration
  - Level 4: 36.6 minutes average duration
- In Southampton, the duration of contact was consistent regardless of level of intervention (range 19.1-23.3 minutes)



*Missing data n=383

Level of intervention by Who is Delivering

Data limited to Portland only

- 60% of level 1 interventions are delivered by CSW compared to only 1% of level 4
- CNS delivery accounts for 94% of level 4 delivery, with 5% joint CNS+CSW delivery

‘Deep Dive’ Intervention Data

Aim

In early 2023 a ‘deep-dive’ data collection form was devised by the RbY Wessex project manager to capture:

- Details about the holistic concerns being identified during service user contacts
- The different types of intervention being provided by the RbY team
- The likely positive impact of interventions on patient care
- The likely impact of interventions on healthcare utilisation
- Detail about referrals being made and likely avoided as a result of RbY intervention

The data collection form was trialled by the RbY delivery team. Feedback led to minor amendments (where relevant, explained in results).

Data collection

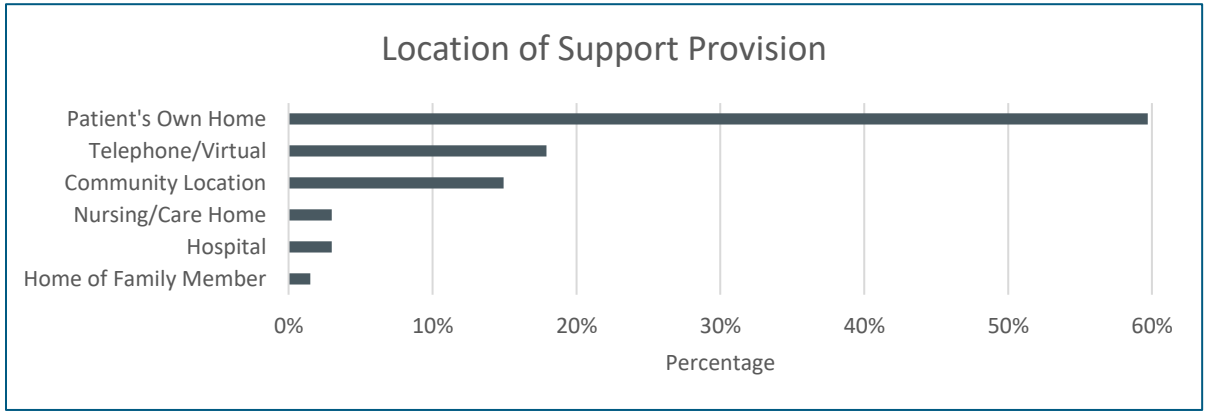
**Data does not represent all RbY contacts, with a total of 503 contacts across the data collection period*

Data collected by RbY staff over 29-day period (18/01/23 – 15/02/23)

- Data were collected in real time using Microsoft forms
- 67 forms completed = 13% of contacts during this period
- 49 completed by CNS / CNC, 18 by CSWs
- 12 first meetings, 55 return visits
- 35 with patients, 24 with patient & others, 8 with family / friends / carers

Location of Support Provision

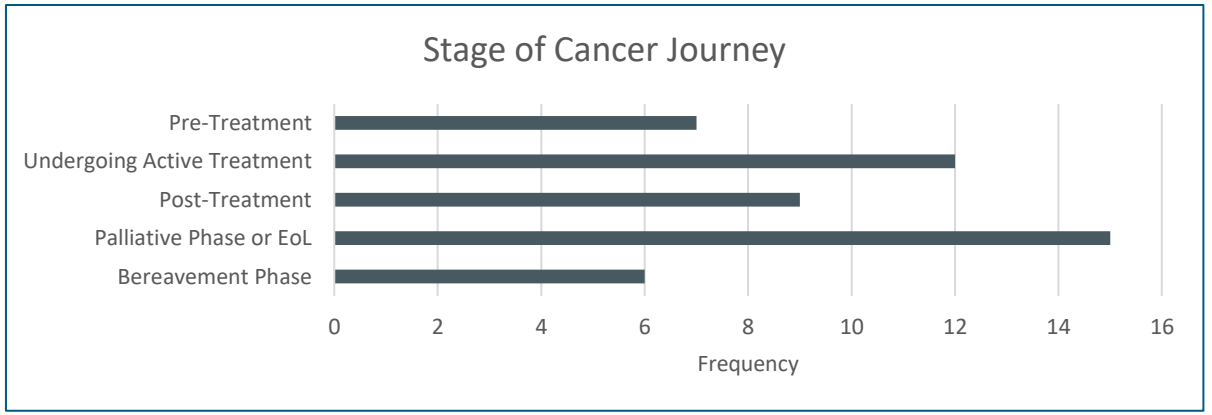
- Most visits face-to-face (82%)
- This constituted 83% of all face-to-face visits during the data collection period
- Most commonly in service users’ own home or a community-based location (e.g., cancer support centre)



Stage of Cancer Journey

Data available for n=49 contacts

- Patients were at a range of stages; many were receiving active treatment (n=12) or were in the palliative or end of life phase (n=15)
- Of the 49 patients, 29 (59%) were recorded as being on a non-curative cancer pathway



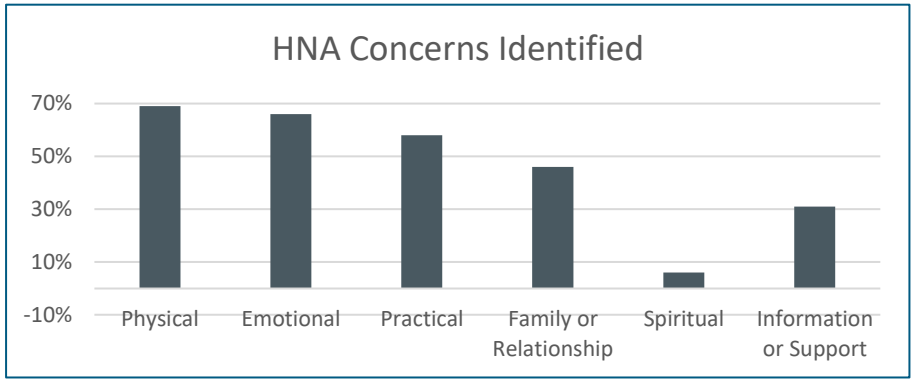
**Missing data n=18, **Some visits recorded more than one cancer stage and not all listed here*

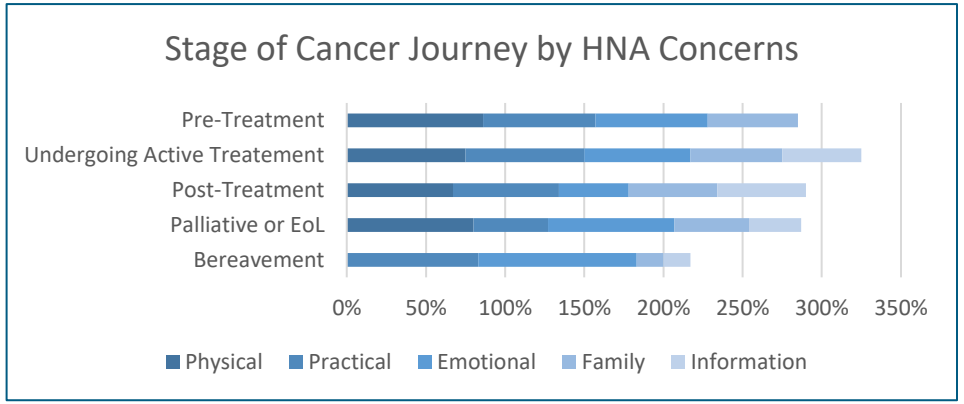
Holistic Needs Assessment

HNA Concerns Identified

RbY staff were asked to outline all HNA concerns identified during each visit using the Macmillan Cancer Support HNA checklist[31]

- ***Physical Concerns*** were the most identified (69% of the service users visited, n=46)
- 148 individual concerns were identified, most commonly: 'tired, exhausted or fatigued' (n=23), 'pain or discomfort' (n=19), 'eating, appetite or taste' (n=19) and 'moving around' (n=13)
- ***Practical Concerns*** were the third most identified (58% of visits identifying concerns, n=39)
- 80 individual concerns identified
- Most common practical concern was 'money or finance', identified in 24% of all visits (n=16)
- Other commonly reported concerns: 'housing' (n=9), 'difficulty making plans' (n=9) and 'taking care of others' (n=8)
- ***Emotional Concerns*** were the second most identified (66% of visits identifying concerns, n=44)
- 145 individual concerns identified, most commonly: 'thinking about the future' (n=25), 'worry, fear or anxiety' (n=22) and 'uncertainty' (n=18)
- 'Sadness or depression' (n=11), 'loneliness or isolation' (n=10) and 'independence' (n=10) were also commonly identified
- ***Family or Relationship Concerns*** were identified 31 times (46% of visits)
- Most concerns were only generally identified under this heading but included 'partner', 'children' and 'person I look after'
- ***Spiritual Concerns*** were the least identified, with 4 concerns identified across 4 (6%) visits
- Of these, 3 were 'feeling at odds with my culture, beliefs, or values'
- ***Information or Support Concerns*** were identified during a third of visits (n=21, 31%)
- 41 individual concerns identified, most commonly: 'managing my symptoms' (n=10), 'diet and nutrition' (n=9), 'planning for my future priorities' (n=8) and 'exercise & activity' (n=7)





Stage of Cancer Journey and HNA Concerns Identified

Data available for n=49 contacts

- Physical concerns were common across all journey stages apart from bereaved service users
- Information or support concerns were most prevalent in service users undergoing or post- treatment
- Emotional concerns were most prevalent in bereaved, palliative or end of life service users
- Practical concerns were most prevalent in bereaved service users, followed by those undergoing active treatment

PSYCHOLOGICAL INTERVENTIONS

PHQ9 & GAD7

Levels of anxiety & depression were assessed for 18 service users using PHQ9[32] and GAD7[33]

- 17 service users had mild-moderate depression
- 15 service users had mild-moderate anxiety symptoms

Figure 6. Levels of anxiety & depression identified

	Minimal (n=)	Mild (n=)	Moderate (n=)	Severe (n=)
Depression (PHQ9)		8	9	1
Anxiety Symptoms (GAD7)	2	12	3	1

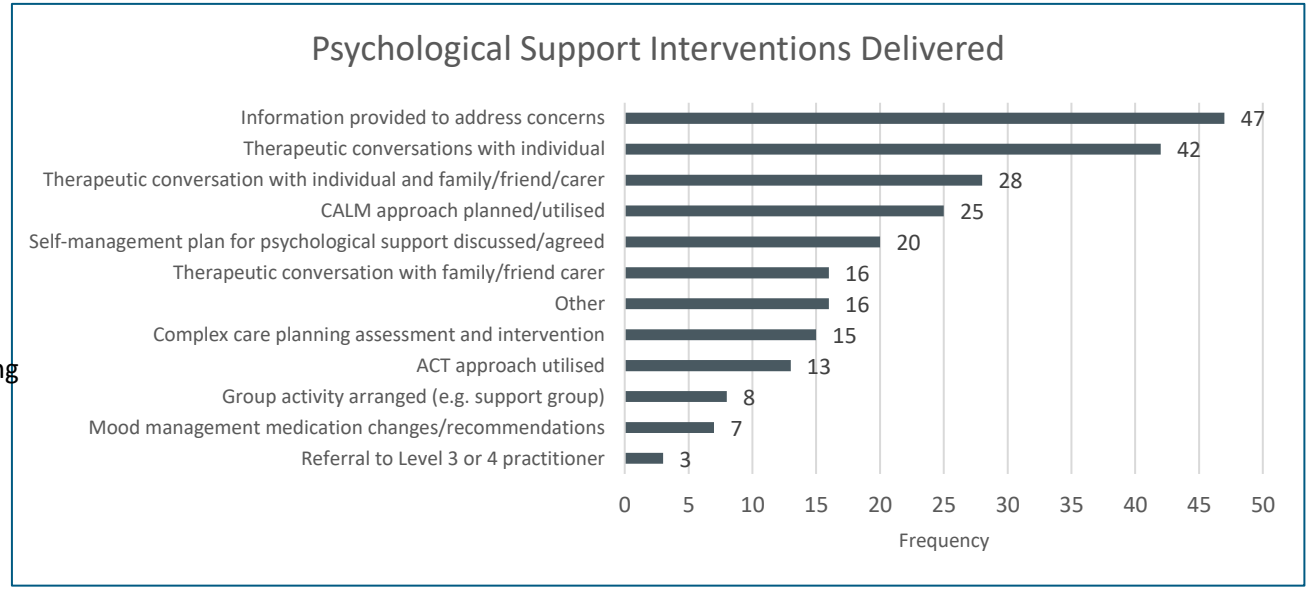
PSYCHOLOGICAL SUPPORT INTERVENTIONS

RbY practitioners were asked to identify psychological interventions provided (shown in adjoining graph)

- Psychological interventions were delivered across 91% of visits (n=61)
- Most service users received >1 intervention, with 240 delivered in total
- Most common were the provision of information to address emotional concerns (n=47), therapeutic conversations with the individual (n=42) or with their family/friend/carer also present (n=28), and utilisation of the CALM approach (n=25)
- Interventions identified as 'other' included bereavement support, provision of a safe reflective space, and accompaniment to third sector organisations
- 'Suicide risk assessment and urgent referral to mental health services' was the only intervention listed to not be delivered

BACKGROUND

RbY staff were asked to identify psychological and non-psychological interventions provided. Options were developed by the RbY Wessex project manager and informed by case studies, domains of personalised care, advanced practice skills and common health assessments.



IMPROVED CARE

- Psychological intervention resulted in 62 instances of improved care
- Most commonly 'avoiding prolonged psychological distress' (n=27)

Figure 7. Instances of improved care

Instance of improved care	n=
Avoided prolonged psychological distress	27
Avoiding prolonged symptoms	12
Avoided delay in care	11
Creating integrated care	12

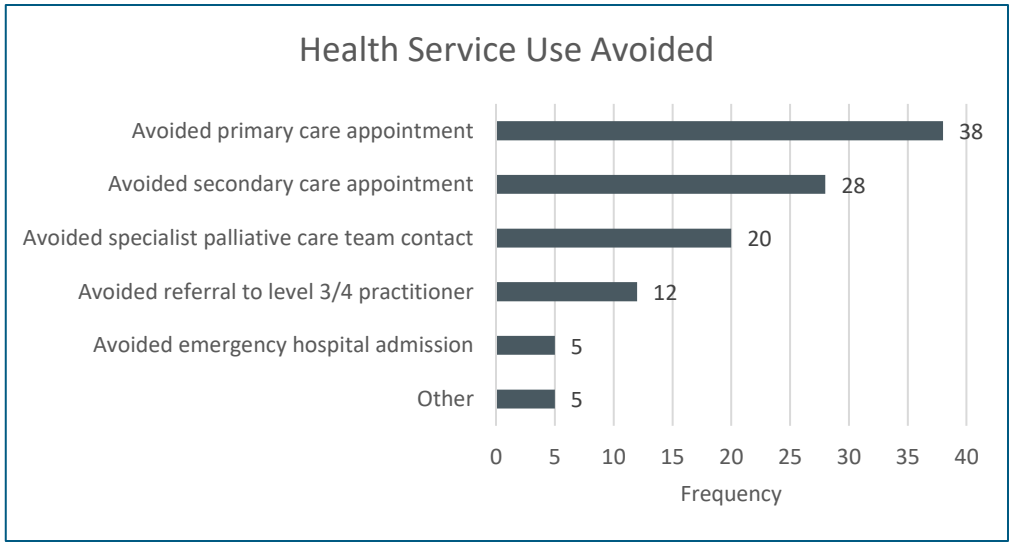
*In the initial data collection form, RbY staff included instances of improved care in the free text 'other' section of the 'what was avoided' question. Thus, an amended second draft included the options listed in figure 7. These data have been combined with secondary analysis and categorisation of 'other' answers from initial data collection forms

Benefit of Psychological Interventions

Health Service Use Avoided

RbY practitioners were asked to identify 'what was avoided' as a result of their psychological support interventions (from an exhaustive list of healthcare services shown in the graph below)

- 103 referrals were deemed avoided, most commonly primary (n=38) and secondary (n=28) care appointments
- 'Other' referrals included to community rehabilitation, the coroner, and housing authority



Limitations:

It should be noted that the data presented have several limitations including:

- Self-reporting by RbY Wessex staff (and thus a potential for bias)
- Presenting a short snap-shot of data within the context of the full length of time over which the service had been running
- Not representing 100% of people seen during the Deep-Dive phase
- Selecting approximate 'best fit tariffs' for the services avoided

Potential Cost Savings to NHS (due to RbY Psychological Intervention)

- 38x GP appointment = £1,596[34]
- 28 x Oncology outpatient attendance £3,948[35]
- 20x Specialist palliative outpatient attendance £3,240[36]
- 12x level 3/4 practitioner £6,471.12[37]
- 5x emergency hospital admission £16,599[37]

*Based on 4x average cost of admission & 1x average cost for end of life care admission (for patients with cancer)

Total £31,854

Cost of Delivery

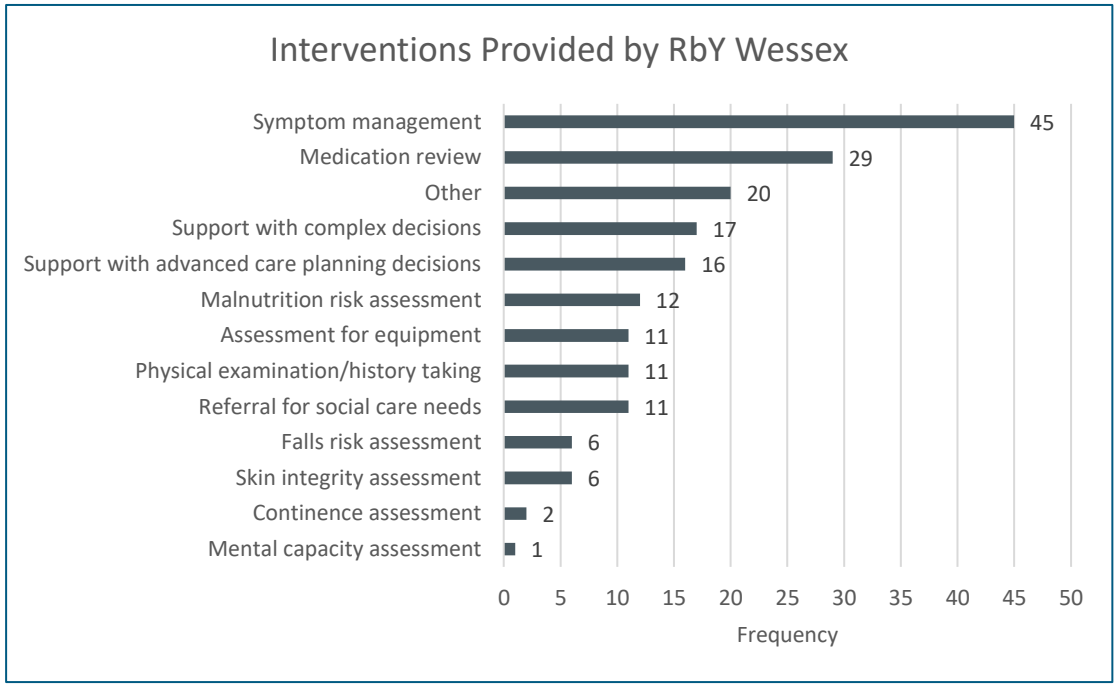
- Across 29 days delivery
- Based on £330,811 annual RbY service cost (moving forward)
- **£26,284**

Other Interventions

Other Support Interventions

RbY practitioners were asked to identify other (non-psychological) interventions provided (shown in adjoining graph)

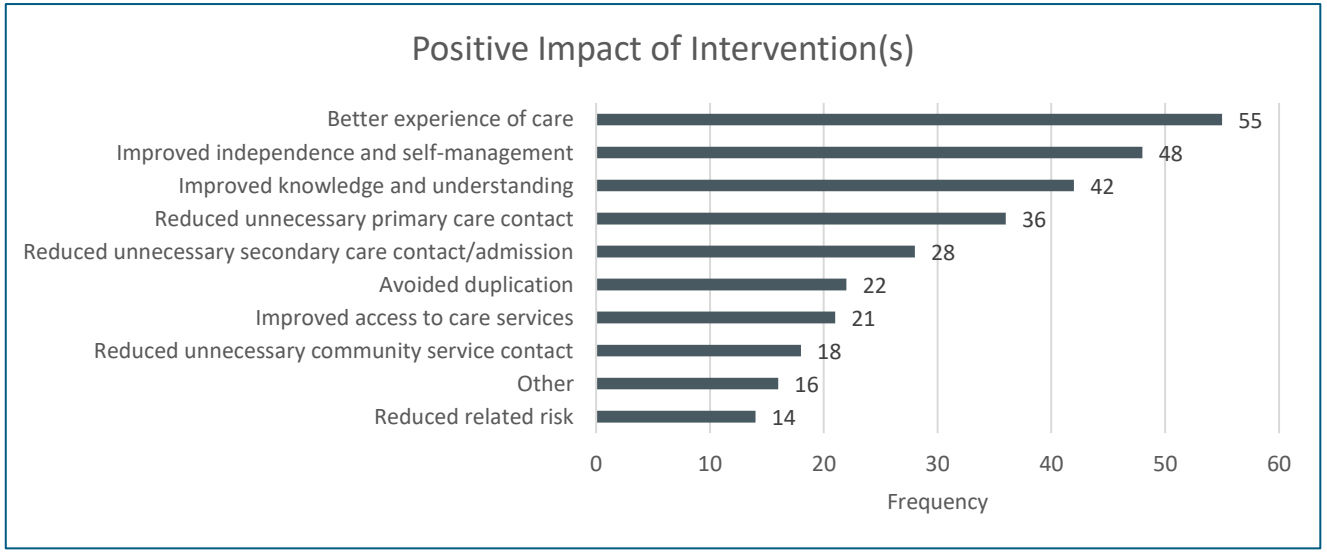
- 187 non-psychological support interventions were delivered across 65 visits (97%)
- The two most common were 'symptom management guidance / self-management plans to support independence/symptom management' (n=45), and 'medications review / suggestions to support management of physical symptoms' (n=29)
- Interventions identified as 'other' included arranging transport, IT support to facilitate online consultations, housing applications and exercise programmes
- 'Frailty assessment' was the only intervention listed to not be delivered



Positive Impact of Interventions

RbY practitioners were asked to identify the likely positive impact of the intervention(s) provided (both psychological and non-psychological) (shown in adjoining graph)

- 300 positive impacts were reported across 67 visits
- The most reported was 'better experience of care (earlier identification & intervention to address concern)' (n=55)
- Other commonly reported benefits included 'improved independence & self-management ability' (n=48) and 'improved knowledge & understanding' (n=42)
- 'Other' impacts included improved confidence, promotion of choice, and food & shelter provision



CASE STUDY EXAMPLE (ID 12.1)

CNS follow-up telephone contact with patient

Main concerns: Symptoms (incl. pain), medication management, ongoing emotional distress (incl. anxiety, sadness and frustration)

Intervention: CALM approach, information provision, therapeutic conversation, symptom management, medication review, liaison with oncologist regarding symptoms & whether further investigation needed

Avoided: GP appointment re. pain management, secondary care appointment & prolonged symptoms

COST SAVING TO NHS = £183, BASED ON:

GP appointment £42[20]

Oncology outpatient attendance £141[21]

COST OF RBY INTERVENTION = £456

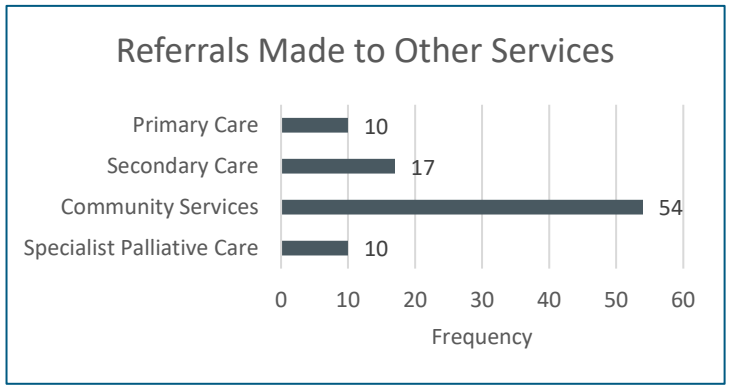
Across duration of support with one individual

40% OF RBY CASELOAD COST FOR THIS INDIVIDUAL OFFSET IN ONE CONTACT

ALSO: BETTER CARE, INTEGRATION & PATIENT EXPERIENCE

REFERRALS MADE

RbY practitioners were asked to list referrals made to other services & referrals that were avoided due to their intervention(s). These were categorised into primary, secondary, specialist palliative and community care



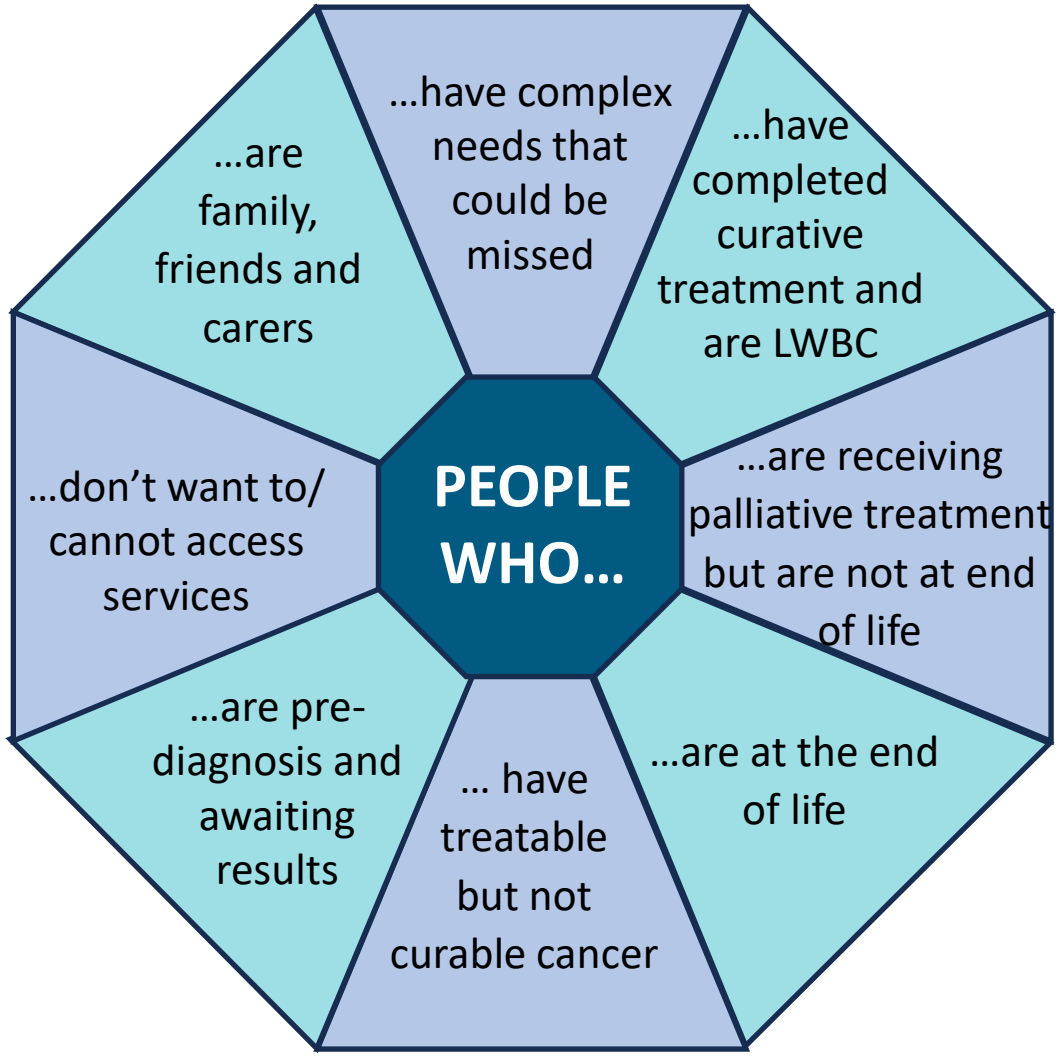
- Total of 91 referrals made across 37 visits (55%)
- 59% of referrals were to community care (n=54)
- Common community care referrals included support centres and groups, exercise and weight-loss schemes, benefits services, housing authorities and voluntary organisations e.g., CLEAR (education and action for refugees)
- Many referrals were made to voluntary and community services and thus did not cost the NHS money
- Referrals to specialist palliative care services were made withing the context of helping individuals navigate the transition to palliative care
- There were evidence of pre-emptive and timely referrals that may have avoided higher levels of care, e.g. to GPs for antibiotic prescriptions
- Not all referrals were formal, some included liaison with secondary care (e.g. to discuss new symptoms and advice regarding indwelling drain management)
- It should be noted the costs incurred through these referrals would have happened regardless of RbY Wessex involvement

Process Evaluation

Population Served

RbY Wessex supported a wide range of service users, including:

- People who are awaiting test results and are thus pre-diagnosis but have significant psychological needs relating to waiting for their diagnosis
- People do not wish to access services (e.g. those who feel that specialist palliative services are 'not for them')
- People who cannot access services (e.g. they may have limited financial resources and are thus unable to attend supportive services regularly, or cannot afford internet or mobile phone costs and thus have limited access to information and online support)
- People from marginalised groups who cannot access services as often or in the same way as the wider population (e.g. people who are homeless and prison communities)
- People with highly complex needs that may only be surfaced in the longitudinal, therapeutic dynamic of RbY Wessex, delivered in the preferred location of the patient / carer



> ***Personalised care in Right by You is about the person, not personalising the care to suit the timing"***
> *RWS18, RbY Wessex staff*

Referral Criteria

It was decided when the service was initially designed that there should be no explicit referral criteria to RbY Wessex. The ethos of the service is that it should be 'right by everyone,' and that people living with and beyond cancer should be 'trusted' to know for themselves when they had a need that could be supported by RbY Wessex. As the service developed, it was increasingly recommended that referral criteria should be put in place to ensure the service is more feasible, economically viable and tailored to those who would most benefit from the intervention. This would help commissioners understand the service as a financially viable model. In addition, it was observed that staff in primary and secondary were applying some form of assessment, intuitively informed, when referring to the service. However, at the end of the pilot phase of service delivery, primary, secondary and RbY staff were equivocal on whether there should be referral criteria. A recommendation to the RbY Wessex team is thus to review the referrals to date and, from this, develop a set of referral criteria for the service. It is noted that RbY Wessex ensured high HNA and care planning completion rates. If referral criteria were put in place, attention needs to be given to ensure that everyone living with cancer has these completed, whether or not they are referred to the service.

FOR…

> ***She's [RbY staff] had quite a loose referral criteria, slightly looser than I'd like and I said to her she was up to 22, 23 patients, which for somebody on the hours doing what she's doing is too much. So, we're going to have to look at the referral criteria"***
> *RWS25, Secondary care*

AGAINST…

> ***It is radical the extent of which that it challenges us not to say these are the groups, these are the people who can access this service. That… explicitly didn't have a set of criteria which said you must be this, this, this and this in order to be able to access those services. I think that was quite a radical act to actually trust that people who came forward would know what their issues were'"***
> *RWS40, RbY Wessex staff*

Participant's rationale for no referral criteria	Participant's rationale for referral criteria
• Needs, distress and trauma not always picked up by referrer • Right by Everyone • Meets Long Term Plan – personalised care for all • Need to adapt to patient's changing needs • Enables self-referral	• Not compelling to commissioners • Difficult to determine resourcing • Risk it becomes a signposting resource only • Universal needs should be met elsewhere in the health system • Limits effectiveness of RbY Wessex service • Sustainability

*Defined by Somerset registry

Health Professional Reasons for Referral

Secondary and primary HCPs were asked why they had referred people living with and beyond cancer to RbY Wessex. In particular, we were interested to know whether this was because RbY Wessex staff were seen to be another 'extra pair of hands' to help support a busy caseload, or whether there were specific skill-sets the RbY Wessex team provided that complemented service provision. For primary care professionals, they typically referred as there were specialist support requirements for complex individuals. Asked what would have happened without RbY Wessex, several participants commented they would have referred to secondary care, possibly to the Emergency Department. Secondary care professionals typically referred people to RbY Wessex as there was a high level of complex psychological need that went beyond what could be supported in secondary care, or there were complex needs that required knowledge of local support services / opportunities that the hospital team could not provide.

Reasons for referral

- Lack of time
- Limited psychological support available
- Limited knowledge of local support services
- Limited physical environment to surface all needs
- Limited experience in supporting marginalised communities (e.g. homeless)
- Limited knowledge of specialist cancer management (for primary care)
- Lack of alternative referral pathways (for primary care)

> ***It's about being able to develop a relationship with that patient to unpick those psychological issues and work with the patient on them. While there is an element of time with that, the psychology of cancer is huge, and we don't do that in secondary care. We deal with the problem that is in front of us now. We can do a little bit of it, but I think predominantly, the whole psychology and support of the patient's emotional wellbeing, that's not dealt with in secondary care. That is something that is definitely added by the Right by You project"***
> RWS54, *Secondary care*

> ***The fact that they could actually visit them in their home. I wouldn't have that opportunity with any other service, so I wouldn't have been able to refer them to district nursing because they've got a really quite set referral standard. And the people that I have referred would not have met that need because actually they were attending hospital appointments so they wouldn't be seen to be housebound"***
> *RWS22, Primary care*

Complementing Specialist Palliative Care

Supporting people living with a terminal diagnosis and in receipt of specialist care was an important component of RbY Wessex's design. It was queried whether RbY Wessex duplicated specialist palliative care services, or whether it provided a service that was distinct but complementary. Interviews with community care providers (including specialist palliative care services), HCPs and RbY Wessex staff reveals that there were aspects of the service that 'shone a light' on where palliative care was not delivering the level of service that was commissioned. However, there were aspects of RbY Wessex that were new and distinct, specifically supporting those who have a stigmatised view of palliative care services and supporting people to transition to these services at the right time and in the right way for individuals.

Where RbY Wessex shines a light	Where RbY Wessex provides as a distinct service offer
RbY staff support people under specialist palliative care who are not yet at end of life	RbY supports people who have a stigma of palliative care services
RbY staff support people who are still independent but have unmet needs	RbY supports the transition of people into palliative care at the right time and in the right way for them
RbY staff facilitate communications with specialist palliative care services and draw the services' attention to people who have yet to be referred	

> ***I spoke with [the RbY staff member] one day and she said to me, she was asked this by a patient, "What's actually happening to me?"… And she said, "I spent a lot of time with that patient just explaining to him what's happening and what the future might look like and the services that would be out there at the right time." And it was way before we'd ever got a referral. We didn't even know about this guy yet… You've got the specialist side of our job and the specialist side of her job just working together'"***
> *RWS27X, Community care*

Outcome Evaluation & Case Studies

Qualitative Outcomes

Outcome Measures

1. What is the impact of RbY Wessex on patient experience and outcomes (e.g. are people's holistic needs met by personalised care and support)?

   Has RbY been effective in:

   a. Identifying and supporting the needs of people living with and beyond cancer?
   b. Improving their health and wellbeing?
   c. Building their knowledge of support available and levels of self-efficacy?
   d. Ensuring people living with cancer experience an integrated service across primary, secondary and community care?

2. Does RbY Wessex deliver effective integrated working between primary, secondary and community care?
3. What is the impact of RbY Wessex on HCP experience and outcomes (e.g. levels of satisfaction, knowledge, skills, confidence)?
4. What is the impact of RbY Wessex on health service delivery (e.g. reduced unplanned care, improved local service provision)?

Service User Outcomes

Identifying and Supporting Needs

People living with cancer, carers and family members told us that meeting their RbY CNS or CSW in their preferred location enabled a better building of rapport, a sense of not being rushed when sharing concerns, and a more productive conversation brought about by the relaxed environment.

All service users said the RbY staff were 'kind', 'gentle', 'empathic' and were skilled in discussing and supporting their needs.

Important areas of need identified by service users included: emotional and psychological support, financial advice, and support for carers and family members. In all cases, participants stated these were being or had been addressed.

For example

One carer described how RbY supported the pain relief and incontinence difficulties of her dying father. Most importantly, RbY facilitated his preferred place of death:

"She listened! If you told her something she would act on it. She actually listened to what my Dad wanted… he trusted her 100%. He was adamant that he wasn't going into hospital, he was going to die at home. And she said, 'that's your wishes, we will respect that'"

RWS26, Service user

> **Financially they totally saved us…. I know I now have everything that I could have"**
> *RWS44, Service user*

> ***They've helped me relax and talk about things that I've never talked about before"***
> *RWS43, Service user*

> **I couldn't have asked for a better person. She explains anything if I want to know something. She's very good, she's been there for me and she's done phoning up on my behalf… she 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. I've got an extra £30 per week which pays for my food"**
> *RWS30, Service user*

Service User Outcomes

Improving Health and Wellbeing

People living with cancer, carers and family members provided many examples of how the support they had received from RbY had improved their health and wellbeing. These included:

- Arranging and adjusting prescriptions, e.g. for effective pain management
- Identifying, addressing and reviewing patient symptoms, some of which were not identified by other HCPs, e.g. oral thrush and anaemia
- Making recommendations for specialty referrals, such as psychological support services, with a successful outcome in reducing health needs
- Improved psychological wellbeing resulting directly from ACT / CALM-informed conversations with the RbY CNS or CSW
- Initiating dialogue with secondary care for review and/or further investigation
- Enabling people to live a "normal life" with the reassurance and trust that someone was there
- Providing a source of support for carers / family members

> ***Emotionally you are overwhelmed, and so anything on top of that, the straw has already broken the camels back, so anything you…….your ability to cope just seems to spiral downward and you're, like, "Damn, God what happened to me?"… I was fairly robust…..and then yes crumpled into a little heap and the girls where there and have been you know right throughout"***
> *RWS44, Service user*

> ***She sorted out this comfortable chair [which is] comfortable, because before that I sat in that chair…because I am in this position all day …so I really find hard that wooden chair… this one is big … I feel much, much more comfortable …what I like about [RbY] - when I ask about something, she reacts straightaway, she starts doing that straightaway, practically running somewhere… if someone needs help… she starts doing immediately, she starts running and finding and doing everything. She's like 100%. I am positively surprised over such a person"***
> *RWS34, Service user*

> ***When the whole thing just seems to be a vortex that you are simply sucked down into and you have no idea… It would have been infinitely tougher, so much tougher without them"***
> *RWS44, Service user*

Service User Outcomes

Improved Knowledge and Self-Efficacy

People living with cancer, carers and family members reported gaining knowledge about their cancer, symptoms, treatments and support services available as result of their interactions with RbY. RbY staff were seen to 'go the extra-mile' in advocating for the patient, providing a proactive approach to information and support provision. This entailed organising and facilitating access to support by accompanying people to first meetings, where appropriate, and providing telephone follow up. This helped build the confidence of service users, increasing the likelihood of effective uptake of services.

As a result of the support provided by RbY staff, service users reported:

- Increased self-efficacy (confidence to self-manage problems related to cancer and its treatment)
- Increased confidence in asking for and accepting help
- Increased confidence in accessing new support services
- Increased activation related to their cancer and cancer care
- Family members feeling better able to continue looking after loved ones

> ***When you are in that space and when you are that frenetic, the chances of you driving something are low, hugely low…. I just did not have it in me to seek out [support]"***
> *RWS44, Service user*

> ***I feel confident that I can cope with it with her help. I don't think I'd be coping so well if she hadn't been there"***
> *RWS42, Service user*

> **She made me much more confident… It's almost like a Guardian Angel floating in, and they know everything, and you feel as if, "Oh, I'm in safe hands now," and I think that gives you confidence… When she came, everything calmed down a bit and I feel confident that I can cope with it with her help"**
> *RWS42, Service user*

Service User Outcomes

Impact on Experiences of Service Integration

Before RbY Wessex

Prior to referrals to RbY Wessex, most service users reported limited integration between primary, secondary and community care. For example, one patient described how treatment regimens recommended by their oncologist were not shared with her GP, and therefore she had to communicate the information directly. Similarly, several service users commented on a perceived lack of communication between secondary and primary care and specialist palliative care services. Where they felt a breakdown in communication had occurred, service users often directly intervened, sharing letters and information with their health care provider.

> ***When it's end of life, and the hospice, we phoned them and they said, 'He hasn't been assessed yet, we can't do anything.' They didn't talk to the GP, nobody seemed to talk to each other. You just didn't feel like anybody was listening to each other or talking to each other"***
> *RWS26, Service user*

> ***[The hospital] said that before my husband started his radiotherapy, he had to have this toothpaste. I took the letter to the GP receptionist... They didn't really take any notice of that letter. So, one morning I went for myself and I said to the receptionist, 'I brought this form in a week ago, my husband starts next week and I still haven't got any.' I had to get quite upset about it... So that's not joined up, even though I knew that letter had got there because I took it"***
> *RWS16, Service user*

> ***They [RbY] have been joining quite a few of the dots for us"***
> *RWS56, Service user*

> ***I didn't really have a huge expectation from the GP surgery from doing frontline work... They [RbY staff members] are going into battle for me... When you don't feel as though you really can pick that sword up"***
> *RWS44, Service user*

After RbY Wessex

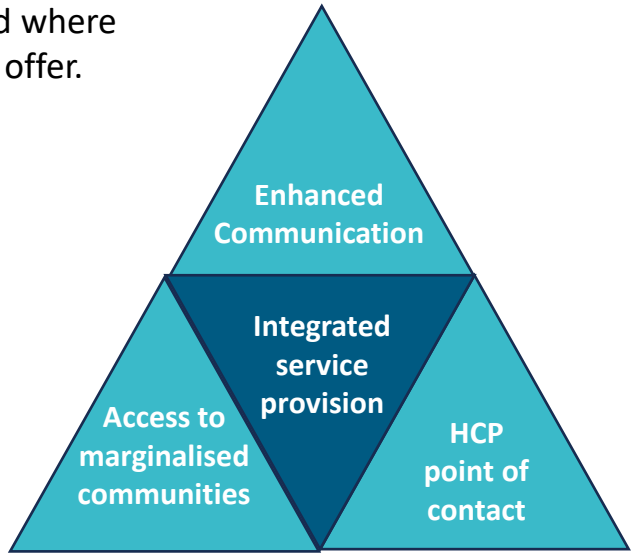
Following referrals to RbY Wessex, service users typically reported experiencing improved integration of services. An important part of this was the proactive approach of RbY staff in bringing services together in the delivery of patient-centred care. Through the advocacy role, service users gave examples of how RbY Wessex staff facilitated follow-up up care by ensuring needs identified in secondary care were communicated and supported by community providers, such as the provision of tailored exercise programmes. The support provided by RbY Wessex staff for referrals to Specialist Palliative Care was noted by service users.

Health Service Outcomes

RbY Wessex Impact on Integration between primary, secondary and community care

Interviews with professionals from primary, secondary and community care identified enhanced communication, improved access to marginalised communities, and acting as a point of contact for HCPs to be the principal ways RbY Wessex facilitated and improved service integration. RbY Wessex enhanced channels of communication by both acting as a conduit for sharing information and facilitating improved relationships between care sectors. Access to marginalised communities is considered in detail in two case studies (pages 47 – 50). Participants highlighted where RbY Wessex 'shines a light' on where services can be improved and areas where it provides a new and distinct service offer.

Where RbY Wessex shines a light…	Where RbY Wessex provides as a distinct service offer
RbY Wessex staff have become a point of contact for HCPs to get information on the patient's current health status	Cancer CNSs are upskilled on the role of primary care in managing the consequences of cancer and cancer treatment
RbY Wessex staff pass on details of patient's wellbeing and care from one party to another, e.g., regarding specialist palliative care provision	Primary care professions are upskilled on the specialist management of cancer in secondary care
	Sharing detailed knowledge of local / regional community links
	Providing direct numbers of cancer CNSs for primary care staff and GP bypass numbers for secondary care



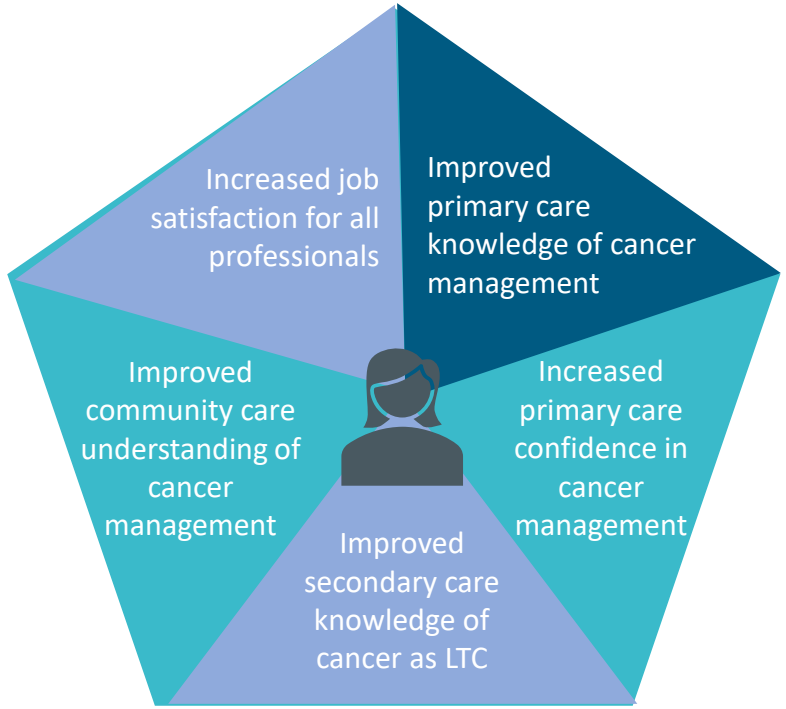
> ***The communications we get from the hospital are much quicker. So, when I phone them up, I can have a quick look through, I can see the palliative care have been involved, I can see the district nurses have. I can read all their notes… I feel like I really know what is going on with the patient. For me, that communication side of things was much better than it was"***
> *RWS19, Primary care*

> ***The GP practice was quite challenging… it was quite difficult to engage with them and it's completely revolutionised it. We've got a much, much better relationship with the GP practice and much better lines of communication, and you now feel that if we have a problem with one of our patients, we can get it sorted immediately"***
> *RWS54, Secondary care*

Health Service Outcomes

Impact on Health Professional Experience

Healthcare professionals within primary and secondary were asked if the introduction of RbY Wessex had any impact on their professional experience or delivery of care, whether good or bad. No participant felt that any aspect of their care had been adversely affected and all were able to provide examples of where it had been enhanced. Staff recruited from primary care practices described how knowledge on cancer management had improved as a result of RbY Wessex, particularly on cancer care reviews, the support of the RbY Practice Nurse and the Community of Practice. Primary care staff also spoke of improved confidence in supporting people living with cancer, particularly in end of life care and pain management. Community care staff (e.g. hostels, prisons) similarly reported improved understanding of cancer management, e.g. the appropriate provision of pain medication and end of life care. Secondary care staff reported enhanced understanding of the management in the community and as a long term condition. Staff across secondary, primary and community care described how RbY had improved job satisfaction as they felt the complex needs of the people living with cancer they see could now be adequately supported.



> ***"They have practically taught me everything I know"***
> *RWS51, Primary care*

> ***"I'm still coming across clinical situations I have not been in before. This was a valuable experience of managing a palliative care patient. To have her support and knowledge was really helpful immediately"***
> *RWS60, Primary care*

> ***What I've learnt from [RbY]… because they have that link with the community, I've learnt a lot from what the practice nurses do, I've learnt a lot about other services out there that I wasn't necessarily aware of… like social prescribers"***
> *RWS23, Secondary care*

Health Service Outcomes

Impact on Health Service Delivery

> ***That contribution of a therapy component is helping in that they are pre-empting those conversations… pre-empting somebody not being able to manage the stairs. So, when it comes to the end of life, where do they want the bed?… they are having those anticipatory conversations with family members and getting things sorted out so that that particular individual doesn't hit crisis, doesn't end up getting admitted"***
> *RWS25, Secondary care*

> ***Without Right by You, the patient would have bounced back into hospital most definitely. It would have been a failed discharge… Someone would have missed them and that patient would have come back into hospital and we would have struggled to get them back out again"***
> *RWS27X, Community care*

Health professionals in secondary and primary care were asked whether the introduction of RbY Wessex had resulted in any improvements or efficiencies to the delivery of health systems. Staff identified four principal areas where RbY had been making a difference:

Reduced attendance – Secondary care HCPs provided examples where 'serial attendees' to the Emergency Department did not return once referred to RbY Wessex. Primary care staff similarly stated they observed fewer GP appointments being made following RbY referral.

Increased efficiencies in the delivery of care – As a result of improved communications and sharing of information between primary, secondary and community care, secondary care staff reported they spent less time phoning GPs and others requesting information. This enabled them to see more people living with cancer in clinic compared to before the introduction of RbY.

Preventing unmet needs escalating to a crisis – Participants described how RbY Wessex staff supported service users through the cancer pathway, proactively identifying and responding to need. This meant certain needs (e.g. equipment at home) were met early, preventing a crisis that could have resulted in an admission to hospital.

Preventing inappropriate referrals – It was recognised that, while primary care roles were important in the delivery, they were less experienced than RbY staff. The RbY team were thus able to use their skills to recommend that people living with cancer were supported in the community rather than be referred inappropriately to hospital.

Case Study I (Homeless – context)

Before RbY Wessex, those working with homeless communities said health support was limited for homeless people. It was difficult to access the right care and support due to bureaucracy, a lack of knowledge of cancer management and prejudice. This meant that people may not have received the treatment required and were unable to secure their preferred place of death. Homeless communities included asylum seekers and those vulnerably housed.

> ***"They are the knotty issues that have prevented people in these situations from feeling they have any agency over their life or death. They are the difference between, 'Can I pick up my methadone today and be alright?,' or 'Do I do I get to my chemo?'… I think this group of people in the situations I am describing were deemed to be difficult patients because they wouldn't comply with the wishes. If we turn that on its head and say, 'Actually the services are being far too rigid. How do we make it possible for individuals in these situations to get both their treatment and to know that, to get their treatment, they need to have had their methadone'"***
> *RWS12, RbY Wessex staff*

Current RbY support

- Band 8 homeless specialist nursing working closely with Homeless Health team (Southampton); Band 7 CNS working with Lantern Trust (Portland)
- Upskilling of homeless teams of cancer management, e.g. end of life care for hostel staff
- Effective patient advocacy, e.g. attending appointment with the oncologist
- Effective communication skills and ability to adapt to rapidly shifting patient circumstances
- Detailed knowledge of local agencies and organisations that can support patient needs
- An active link to connect different part of the health system, e.g. hospital, hostel and specialist palliative care team.

Issues affecting support for homeless communities

- Prejudice resulting in reticence to provide equipment, e.g. reluctance from charities to provide wheelchairs
- Fear of homeless communities and hostels, e.g. reluctance of night-sitters to sit with patient
- More likely to have alcohol and drug dependency
- Financial challenges, e.g. lack of back account, ability to attend hospital for chemotherapy treatment
- Inability to receive information, e.g. no abode, no mobile through which to receive messages
- Cancer services too rigid, e.g. collecting methadone meant unable to meet chemotherapy appointments
- Challenging to ensure preferred place of death, e.g. hostels feeling ill-resourced to support dying residents
- Hostels ill-equipped to deal with consequences of cancer, e.g. incontinence, pain management

> ***"What we can offer is often just on things such as benefits, housing, advice on those things… which is helpful for people in those situations, but we don't have a category necessarily that's health and those issues, though we can book appointments and we can book things but couldn't go"***
> *RWS59, Community care*

Case Study 1 – Homeless

38 year old woman
Ovarian cancer
Palliative treatment & supportive care
Drug dependency

Issues affecting patient

- Wishes to die in the hostel, but the hostel feels ill-equipped to support this
- Struggles to attend hospital for treatment as she is unable to pick up methadone medication
- Wishes to have greater mobility, but charity will not release wheelchair for fear it will not be returned
- Requires morphine, but not reliably administered in hospice as often taken by other residents

Main support provided

- Advocacy:

- Attending oncologist appointments whilst maintaining methadone regime – Liaising with charities to obtain wheelchair
- Facilitating preferred place of death

- Specific training to hostel on end of life care management
- Financial support
- Devised system of pain-relief dispensing within complexity of hostel setting
- Liaison with multiple healthcare teams and agencies to ensure seamless, coordinated system of care in a complex case

> ***"I think if we didn't have the support of [RbY] at the moment, we as a service wouldn't have been able to keep her with us and she very much does not want to go to a hospice. So it would have been a really hard decision, but I didn't really know what was out there, what support we could have had, how we go about getting that extra support. And I think we would have probably just have to have said, 'We can't give her the support she needs and that she needed to go into a hospice'"***
> *RWS11, Community care*

> ***"Just having someone to tell me we are doing the right thing, it's what somebody wants, we can give them the support they need to stay where they want to live, helps me keep pushing for that and supporting the staff"***
> *RWS11, Community care*

RbY Outcomes

- Hostel able to manage end of life care for patient
- Primary and secondary care teams experienced greater confidence and job satisfaction knowing needs were being met by someone with a greater awareness of local support than they possess
- Relieved pressure in secondary care as less time required contacting primary care services
- Practical needs met with increased mobility on arrival of wheelchair
- Patient was able to receive treatment from the hospital without compromising methadone medication regime
- Morphine was distributed through small bottles so patient obtained pain relief with no risk of abuse within the hostel
- Financial support maintained through DS1500
- Individuals' 'wish list' was met prior to death
- Individual was able to die at the hostel surrounded by those whom she felt were the closest she had to family

Case Study II – Prisons (context)

> ***[RbY] has made a massive difference with communicating with the prison and making sure that the prisoners get the right treatment and the right care"***
> *RWS54, Secondary care*

Prior to RbY involvement there was an inequitable approach to cancer care across harder to reach groups, including prisoners.

> ***That group were very, very poorly served before"***
> *RWS54, Secondary care*

> ***"I can't state how important it is for the prisoners to have somebody like this"***
> *RWS48, Community care*

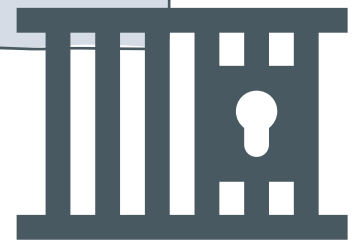
Issues affecting secondary care support for prisoners

- Difficult to organise attendance for appointments & treatment
- Individuals never seen alone as with prison guard escorts - no opportunity for confidential conversations
- Restricted time due to scheduled return to prison
- Unable to speak directly with individuals outside hospital - no opportunity for follow-up conversations

Barriers to effective cancer care in prison

- Healthcare team of primary care nurses – not experts in cancer care
- No overnight medical cover - reliance on prison staff to manage medical emergencies
- Community and voluntary services not accessible for prisoners
- Prison environment not facilitative to mobility issues

> ***The nursing staff there have really embraced it and feel that it's really valuable for the patients there"***
> *RWS6, RbY staff*



Current RbY support

- Successful engagement & embedding of RbY service in Portland-based prison
- Improved cancer care and support for prisoners
- Enhanced communication & integration between prison & secondary care
- Working with prison staff to ensure safe cancer care pathway for prisoners
- Delivery of staff training & support to:
  - Identify people living with cancer who would benefit from RbY
  - Support individuals if they become unwell during treatment
  - Increase confidence re. when appropriate to seek specialist help

Challenges to RbY delivery

- Prison healthcare team must be engaged for effective delivery
- All communications must be pre-planned (e.g. visits booked in advance) or made via prison staff
- Lack of suitable environment for confidential therapeutic conversations
- Prisoners have restricted time away from cells
- No interaction with family members
- All contacts are face to face (telephone calls require approval & timings not guaranteed)

Case Study II - Prisons

77 year old man
Rare cancer type
Palliative treatment & supportive care
Comorbidities & impaired mobility

*Mock case study based on amalgamation of individuals supported

Issues affecting patient

- Logistical difficulties attending appointments (out of county) due to rare cancer
- Miscommunication between prison & hospital around responsibility for pre-assessments leading to delay in commencing treatment
- Last minute appointment / treatment cancellations due to limited number of escorts
- Strained relationship with prison healthcare team due to treatment delays
- Long and complicated application for early release due to end of life
- Reluctance to move into prison hospital wing for specialist pain relief mattress due to isolation from his informal support group of inmates
- Not informed about treatment / appointments until last minute
- Loss of financial support (breakdown in relationship) for additional food

RbY Support

6 CNS patient visits in prison

Main patient concerns identified

- Symptoms including pain & incontinence
- Anxiety regarding cancer & symptom management
- Delays in starting treatment
- Support for family member

> ***To have an expert to come in and take that time and talk to them about their diagnosis and what it means…. in a really compassionate way…. I think that is really valued by the prisoners"***
> *RWS48, Community care*

> ***"Using some of the CALM therapies so finding ways for him to try and live with this diagnosis and allowing him to talk through what his issues and concerns are"***
> *RWS6, RbY staff*

RbY intervention

- Physical examination
- Provision of information on cancer type
- Patient discussion regarding options for treatment and management of symptoms
- Liaison with GP and repeated advice to prison healthcare team regarding changes to pain medication
- Liaison with secondary care regarding imaging and appointments to guide prognosis and symptom management
- Patient discussion regarding early prison release application
- Opportunity to talk to someone without the presence of prison guard
- Repeated therapeutic conversations with CALM approach utilised
- Providing patient with improved confidence to manage cancer and seek support upon prison release
- Information for staff and patient regarding when appropriate to seek urgent review (for symptoms of spinal cord compression)
- Tailored information for family member to access counselling
- Discussion with CAB and Macmillan grant application

University of Southampton
Centre for Psychosocial Research in Cancer: CentRIC+
Understanding the impact of cancer on everyday lives and supporting people to live well

Translation & Conclusions

Commissioner views on RbY Wessex I

Right Model

- All commissioners agreed with the ethos and philosophy of RbY Wessex in supporting personalised care for complex needs
- They recognised RbY Wessex is a 'Gold Standard' model, with few comparators
- Commissioners acknowledged the policy relevance and timeliness of RbY Wessex with the establishment of ICBs and ICSs
- Commissioners agreed the RbY Wessex model was replicable to other health conditions
- They recommended robust referral criteria to prevent the service becoming quickly inundated
- Commissioners acknowledged the importance integrating the service with MDTs in the Trust / Acute setting, including non-cancer teams such a neurology.

Geography

- Commissioners queried how typical the locale of delivery was, e.g. Dorset's model of working with a single GP practice and Southampton's approach of working with nearly 30.
- They also queried the typicality of geographical locations in terms of equality and diversity and the age of profile Dorset.
- Such issues need to be considered when assessing the replicability of the services to other regions

Staffing

- Commissioners asked for a clear explication of why CNSs recruited from Secondary Care were required: why not staff in Primary Care / community setting (e.g. Additional Roles Reimbursement Scheme (ARRS) roles)?
- What is the appropriate staffing for a given local population level / profile if replicated?
- Commissioners asked what optimal ratio of CNS / CSW time would be?
- Commissioners underscored the importance of embedding an educational programme to build a cadre of future RbY professionals
- Commissioners stressed the importance of ensuring RbY staff recruited from secondary care have an understanding of wider health systems and community-based care

COMMISSIONER VIEWS ON RBY WESSEX II

CHALLENGES

- Commissioners noted the challenge of negotiating the 'tribal boundaries' within secondary care and between secondary, primary and community care and specialist palliative care services. It was recognised the RbY Wessex staff had done this with skill, but these tensions are likely to arise if replicated elsewhere
- There is a need to provide assurance of the quality of community services to which service users are referred via RbY Wessex
- Delivering a boundary-spanning service necessarily brings up challenges concerning the sharing of information between different care sectors
- Commissioners perceived RbY Wessex to be an expensive resource and thus, as the 'guardians of the public purse', significant cost-savings need to be identified for it to be commissionable
- There is tension between a boundary-spanning role and a risk of duplication. Commissioners felt RbY Wessex had to demonstrate whether RbY is the most economical model and how it is distinguished from, for example:
  - Specialist palliative care services
  - ARRS roles
- Relatedly, commissioners explained that almost without exception, they are starting from a point of financial deficit. They would therefore rather ensure services already contracted are delivering optimally than commission a new service. They would thus be asking what is new about RbY Wessex and whether other parts of the system should be picking up people in crisis.

RISKS

- Commissioners felt that, without referral criteria, the service could quickly reach capacity
- There is a risk that people might 'fall through the gap', should individuals self-refer and are then managed within RbY Wessex / the community. There is a need to ensure secondary and primary care are fully informed

What Evidence do Commissioners Find Compelling?

Commissioners were asked what evidence they would find most compelling to help inform commissioning decisions. They recommended the following:

Evidence	Rationale
Is this PPI driven?	It is important any new service is grounded in patient experience and patient need. There is a concern over wasting limited resources on services that are not needed.
What's the deviation?	Given limited resources, commissioners would rather ensure services are performing optimally rather than commission anything new. Any new service must demonstrate what it adds to services already funded.
Explanation of how RbY Wessex integrates with other roles / initiatives	Related to the above, any new service must not exist in a silo, and thus must articulate how it integrates effectively with local services, recognising that these will vary from one area to another.
Quantitative data about scale and reach of service	There needs to be a clear understanding of the scale of support being provided and the range of people / communities being reached by the new initiative.
Statement of projected numbers of people who could benefit from RbY in the future	As one commissioner put it, 'Make it our problem.' Demonstrate what the projected need / demand is for the service and detail the consequences of not funding the service.
Cost analysis	Given that financial deficit is the reality for commissioning boards, there is a zero-sum consideration for funding new services. Any new service needs to demonstrate cost-neutrality and ideally cost-saving
Justification for why the grade of CNS required	Related to cost, a justification should be given for the level of expertise required. In the case of RbY Wessex, justification should be made for the funding of CNSs above Cancer Support Workers
Careful selection of rich, detailed case study / studies	Commissioners stressed that they should not be inundated by case-studies. There should be a careful selection of approximately three case-studies to give an in-depth understanding of the impact of delivery from a range of perspectives.
Qualitative data from staff, primary, acute and community care	Commissioners recommended qualitative evidence to support the effectiveness of the approach from the healthcare professional perspective and the ease with which RbY can be integrated into practice
Equality, Diversity and Inclusion	Any attempt to ensure equality of access to the service should be made explicit and examples of how typically marginalised communities are reached should be provided

Conclusions I

RbY Wessex core aims

- Evaluation findings have demonstrated that RbY Wessex has met its core aims. Specifically, the care and support provided by RbY Wessex has:
  - Enhanced patient experience and outcomes, particularly:
    - Identifying and supporting the needs of people living with and beyond cancer
    - Improving their health and wellbeing, for example by addressing needs not identified by other healthcare professionals
    - Building service user knowledge of support available and increasing self-efficacy
    - Ensuring individuals experience an integrated service across primary, secondary and community care
  - Delivered effective integrated working between primary, secondary and community care with many examples provided of:
    - Improved communication between secondary and primary care
    - Improved communication between community care providers and secondary / primary care (including hostels and specialist palliative care)
    - Healthcare professionals reporting better care for the patient as they had more information related to the individual
  - Enhanced health professional experience and outcomes, particularly
    - Increased job satisfaction (e.g. from the reassurance of patient's receiving high-quality care)
    - Improved knowledge (e.g. secondary care knowledge of management of cancer in the community, and primary care knowledge of cancer management)
    - Improved skills (e.g. through the support of Cancer Care Reviews in primary care and End of Life Care in hostels)
    - Increased confidence (e.g. discussing cancer management issues with the patient in primary care)
  - Enhanced health service delivery through examples of:
    - Management of cancer-related needs in the community
    - Fewer GP attendances
    - Fewer Emergency Department admissions

Conclusions II

RbY Wessex Scale and Reach

- 390 people were referred to RbY Wessex, resulting in a caseload that was manageable for the RbY Teams. Concern was expressed, particularly by secondary care staff and commissioners, that the service could quickly exceed capacity to deliver without clear referral criteria and as knowledge and understanding of the service continues to develop.
- The service specifically did not put in place referral criteria as it was felt that the ethos of 'Right by You' is that it should be 'Right by Everybody' and individuals should have autonomy to decide whether they need support from the service and at what level. However, in retrospect, it was acknowledged that some form of implicit referral criteria were applied, particularly from the Secondary care teams in Southampton where predominantly people with Level 4 Complex Needs were referred.
- RbY Wessex was effective in providing support to communities often marginalised in care provision, most notably prison communities (in Dorset) and homeless communities (in Dorset and Southampton). RbY Wessex thus provides important data on how needs in these often neglected communities can be optimally identified and supported.

Cost and Replicability

- RbY Wessex is a resource-intensive, complex intervention. However, evidence from the 'Deep Dive' data demonstrates that substantial cost savings could accrue from avoided appointments, admissions and referrals, e.g. to Emergency Departments, GPs and psychological services. Full health economic analyses are recommended to inform commissioning decisions and replication of the service.
- Participants commented that RbY Wessex was highly replicable both to other regions and for other conditions. The adaptability of staffing and working relationships with local services enabled this replicability. However, it was recommended there be clear guidance on the optimal skill mix of the team, e.g. how many CNSs / CWSs per population.
- Should the service be commissioned and replicated, an education programme is required to build future RbY teams, including psychological support, personalised and the health care system.

Conclusions III

RbY Wessex Delivery

The elements of the RbY Wessex model that were deemed essential to its success were:

- Delivery of the service in the individuals' preferred location, typically their home (for participants who had a home). This enabled RbY Wessex to assess and identify needs and respond to non-verbal indicators of support required.
- Delivery of the service by CNSs with training in CALM and ACT techniques. This resulted in RbY Wessex providing NICE level 2+ psychological care that integrated well with limited local services and provided support where these were absent. It also helped manage and de-escalate certain psychological needs within the community, obviating the need to refer to psychological services. There are limited level 3 and no psycho-oncology level 4 practitioners in Portland. In Southampton psychological support is provided by charitable organisations (other than for haematological cancers).
- The delivery of the service demonstrated the value of CALM and ACT training. These are valuable skills that are relevant to all CNS teams and not solely those of the RbY team, enhancing the delivery of psychosocial support in services already commissioned and running.
- Longitudinal assessment of holistic needs. This ensured service users had the time they required to surface needs, recognising that needs and priorities inevitably shift across the pathway.

- The model of delivery was deployed differently between Portland and Southampton, with Portland working closely with one practice and Southampton working closely with one hospital, from which primary care practices became involved. Some RbY staff, commissioners and HCPs typically felt the Portland model was more effective in spanning the boundaries between primary and secondary care. However, Southampton was thought more typical in terms of how primary care practices operate within a particular locality. The two sites provide a helpful comparator for service delivery, e.g. with important lessons learned from working with primary care in Dorset.
- The different modes of delivery between Southampton and Portland demonstrate that the RbY Wessex approach has a high degree of adaptability and flexibility to reflect local service coordination and provision. This included different levels of CNS deployment in the two sites.
- Both teams in Portland and Southampton had worked in a sustained and effective manner in forging productive relationships with secondary, primary, specialist palliative and community care. However, a concern remains among commissioners about duplicating services, indicating a need for the service to articulate clearly its offer, the cost-effectiveness of its economic model and how it enhances and integrates with services already provided.

Conclusions IV

Limitations

- The evaluation presents findings based on a rich qualitative dataset of over 100 longitudinal interviews. Despite repeated efforts to recruit participants from practices less involved in RbY Wessex, not surprisingly many declined to participate. There is a potential for bias therefore in those consenting to participate, although this was managed through the interview process whereby challenges were elicited as well as where the service was delivering well. This was borne out in the data collected and emerging findings.
- Due to the set up the service, it was not possible to undertake a full health-economic assessment. Clarity on the design, referrals and referral criteria emerged through the delivery of the service and the natural evolution of co-design. Assessment of service costs were based on best estimates. Assessment of potential cost savings were based on RbY Wessex staff self-reporting on a sub-sample of all service users. The associated savings are thus not representative of the whole service.

RECOMMENDATIONS I

On the basis of evaluation findings, the following recommendations are made:

PROVIDE A CLEAR DEMONSTRATION OF WHAT THE SERVICE ADDS TO CURRENT CARE

There was concern by certain participants of a potential duplication of services already commissioned, e.g. specialist palliative care. It should be clear therefore what is distinct in the RbY Wessex offer. As one commissioner put it, what is the 'deviation' of RbY Wessex from other services? For example, is it appropriate for patients to be seen by Specialist Palliative Care services *and* RbY Wessex? To what extent can CNSs and CSWs already in post be upskilled to provide much of the support, e.g. with ACT and CALM training?

PROVIDE A CLEAR DEMONSTRATION OF HOW RBY WESSEX INTEGRATES WITH CURRENT PRACTICE

With the clear statement of the 'deviation' of RbY Wessex, there is a need to demonstrate precisely how the service works with other services to deliver optimal care for people living with cancer. This is particularly important with specialist palliative care services where there is a potential for overlap. There should be a clear explication of how RbY Wessex integrates with multidisciplinary teams within and beyond cancer services, e.g. neurology. In addition, it is important for the service to articulate how RbY Wessex can integrate with new roles and opportunities, particularly in primary care with the creation of Additional Roles Reimbursement Scheme (ARRS) roles in primary care to provide seamless, coordinated care. Consideration should be given to the extent RbY Wessex can address some of the gaps in psychological service provision identified in the Alliance's recent mapping exercise.

DEVELOP A CLEAR COMMUNICATION PLAN OF THE RBY WESSEX SERVICE

It was evident during the evaluation that those working in secondary, primary and community gained greater clarity of the service through their involvement with RbY Wessex. For others, there is a lack of awareness or understanding of what support RbY Wessex can provide. It is recommended that a communications plan is developed and delivered to increase awareness among healthcare teams where appropriate.

CREATE REFERRAL CRITERIA

Setting referral criteria was essential if the demand for the service does not exceed capacity to deliver. It was evident that implicit application of criteria for assessment was being applied in Southampton, resulting in more complex, high level needs being referred. It is recommended therefore that the RbY Wessex team review the referrals to date and generate criteria to be applied in the future.

CONTINUED COLLECTION OF SERVICE DATA

The data collection tool developed for the evaluation should be adapted and implemented for the long term. It is important core data are collected to demonstrate reach and impact to inform future commissioning decisions and to inform continuous service improvement.

Recommendations II

Undertake a rigorous economic analysis to inform commissioning decisions and replication of service

The evaluation makes use of the best-available data on costs and savings using recent tariff information. It is recognised that the information in this report is based on 'Deep Dive' collected over a short time frame. To aid future commissioning decisions, further cost / health economic data should be collected to demonstrate impact. Robust evidence for cost neutrality / saving should be presented, e.g. reductions in GP attendance or emergency admissions elsewhere in the system.

Provide clear rationale for staffing levels

To aid replication of RbY Wessex, information should be provided on appropriate staffing levels for RbY, recognising that any replication of service needs to adapt to local circumstances. It would be helpful nonetheless to articulate what core costs would be expected in terms of staffing (e.g. CNS / CSW / Admin time) and associated costs (e.g. premises, IT, travel) for any given population.

Develop and implement a training, recruitment and retention strategy

The educational support of RbY Wessex staff was an important factor in ensuring the effectiveness of support provided. Training in ACT techniques and CALM was supplied for CNSs, learning from which was frequently deployed in the therapeutic dynamic provided to service users. In addition, End of Life care training was provided to RbY Wessex staff who required it. Consideration should thus be given to the educational needs of RbY Staff. A review of the learning and development activities of the RbY Wessex team should be undertaken with a training needs analysis. This can be used to inform an educational programme which can be rolled out regionally or beyond and evaluated, should the intervention be replicated. In addition, consideration should be given to whether CNSs, CSWs and other staff beyond RbY Wessex should receive training, e.g. in ACT or CALM, to improve the provision of psychosocial support to enhance current service provision. Should the RbY Wessex approach be replicated elsewhere, attention needs to be given to a recruitment and retention strategy to build and sustain a cadre of professionals to deliver boundary-spanning, community outreach personalised care.

Improved information sharing

The challenge of information exchange between sectors of healthcare is well known and documented. However, they become particularly problematic for boundary spanning roles. It was evident that RbY Wessex staff were often the conduit for health information exchange between specialist palliative care, primary and secondary care. It should be considered whether this is sustainable in the long term, or whether systems of information exchange between sectors can be enhanced.

Showcase the significant work of RbY Wessex for diversity and inclusion

RbY Wessex makes a significant contribution to understanding of delivering personalised care for often marginalised sections of society, most notably prison and homeless communities. This should be promoted in any description of services or business cases relating to RbY Wessex. Consideration should be given to a communications plan specifically for these communities, e.g. presentations at notable events and conferences such as UKONS.

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