

# South West London STP Pack: Personalised Care for Cancer- Next Steps for London, March 2020



# In this pack

This pack includes the **STP and regional data relevant to personalised care for cancer**. It also includes the findings from the **Personalised Care for Cancer-Next Steps for London** event, which was held on Wednesday 12<sup>th</sup> February 2020.

The aim of the event was to support the cancer system across London to begin their actions and succession planning for the **Macmillan funded programmes in TCST (psychosocial support, cancer rehabilitation and lymphoedema)** and **South West London's primary care nursing** workstreams. Macmillan and TCST funding for these programmes ends in March 2020.

To enable **constructive discussions**, delegates sat in STP representative tables and discussions were facilitated by TCST colleagues. We are aware that this may not include all the discussions that took place at the event, but we have tried to **summarise the key points and next steps**.

The **South West London STP table discussions** are reflected in **Section 6**.

There were two table discussions for SWL STP. **Actions and discussion points** have been combined.

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# 01

## Prevalence Data for South West London

# The Cancer Prevalence Dashboard 2017

**Prevalence data** is important for planning services. This data represents patients diagnosed from 1995 onwards and still alive on 31<sup>st</sup> December 2017.

The prevalence dashboard is to help London localities working at a population health level to use the data in their Joint Strategic Needs Assessments, and to **understand the profile of their prevalent population.**

The prevalence dashboard includes:

**Demographic breakdown** of prevalence at CCG, STP and Cancer Alliance level

**Comparison** of primary care registers (QOF) to the cancer registry (gold standard) to assess completeness.

**Prevalence of patients living with a subsequent primary cancer**

Forecasted growth of cancer prevalence to 2030.

Prevalence data will be particularly useful in **developing business cases** and identifying **inequalities in access to local services**, when compared with the patient demographics of their caseloads.

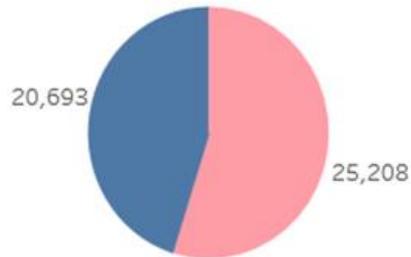
The dashboard will be updated annually.

The dashboard can be found here:

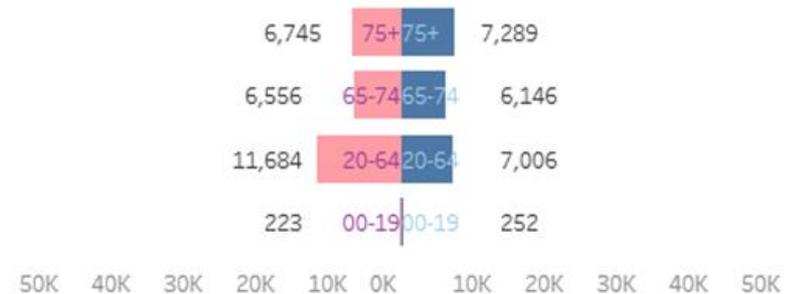
<https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

# People Living With or Beyond Cancer in SWL

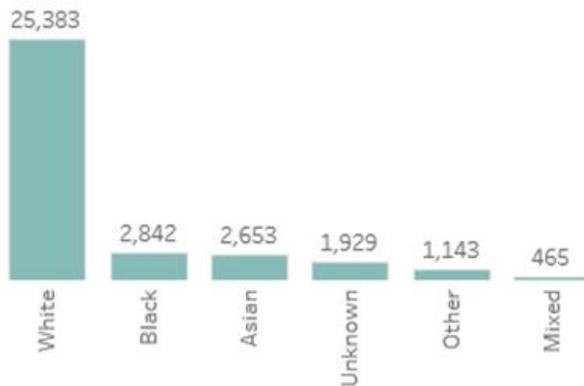
45,901 people were living with and beyond cancer in South West London STP in 2017.  
(Diagnosed between 1995-2017)



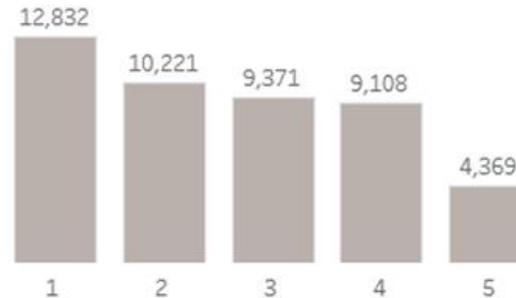
Age and Sex Distribution  
(Diagnosed between 1995-2017)



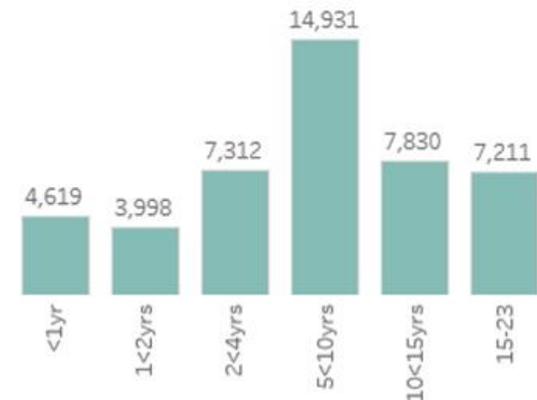
Ethnic breakdown  
(2006-2017)



Deprivation (IMD) Breakdown  
(Diagnosed between 1995-2017)  
1 - least deprived, 5 - most deprived

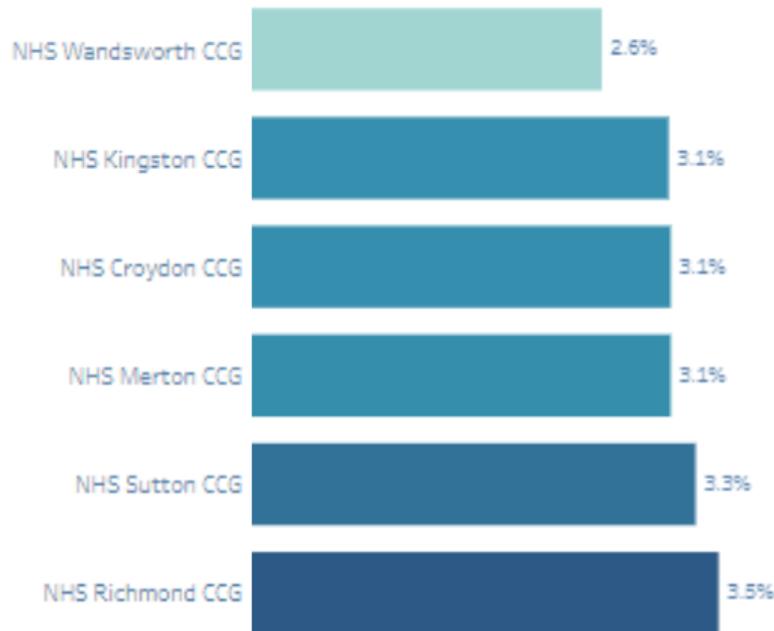


Time Since Diagnosis  
(Diagnosed between 1995-2017)



Full prevalence dashboard: <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

# People Living With or Beyond Cancer by CCG

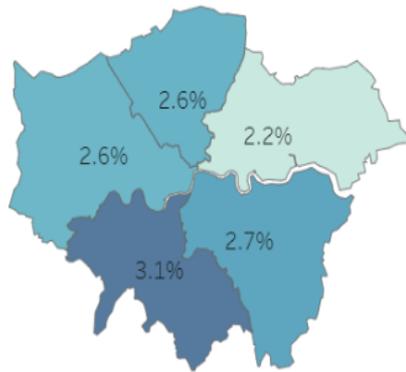


CCG	Number of people living with and beyond cancer	Projected number of people living with and beyond cancer 2030
Wandsworth CCG	<b>8467</b>	<b>12,900</b>
Kingston CCG	<b>5443</b>	<b>8,300</b>
Croydon CCG	<b>12,017</b>	<b>18,300</b>
Merton CCG	<b>6440</b>	<b>9,800</b>
Sutton CCG	<b>6725</b>	<b>10,300</b>
Richmond CCG	<b>6809</b>	<b>10,400</b>
SWL STP	<b>45,901</b>	<b>70,000</b>

**Full prevalence dashboard:** <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

# People Living With or Beyond Cancer in SWL

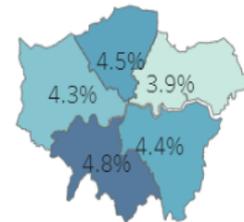
Cancer Prevalence  
(Diagnosed 1995-2017)



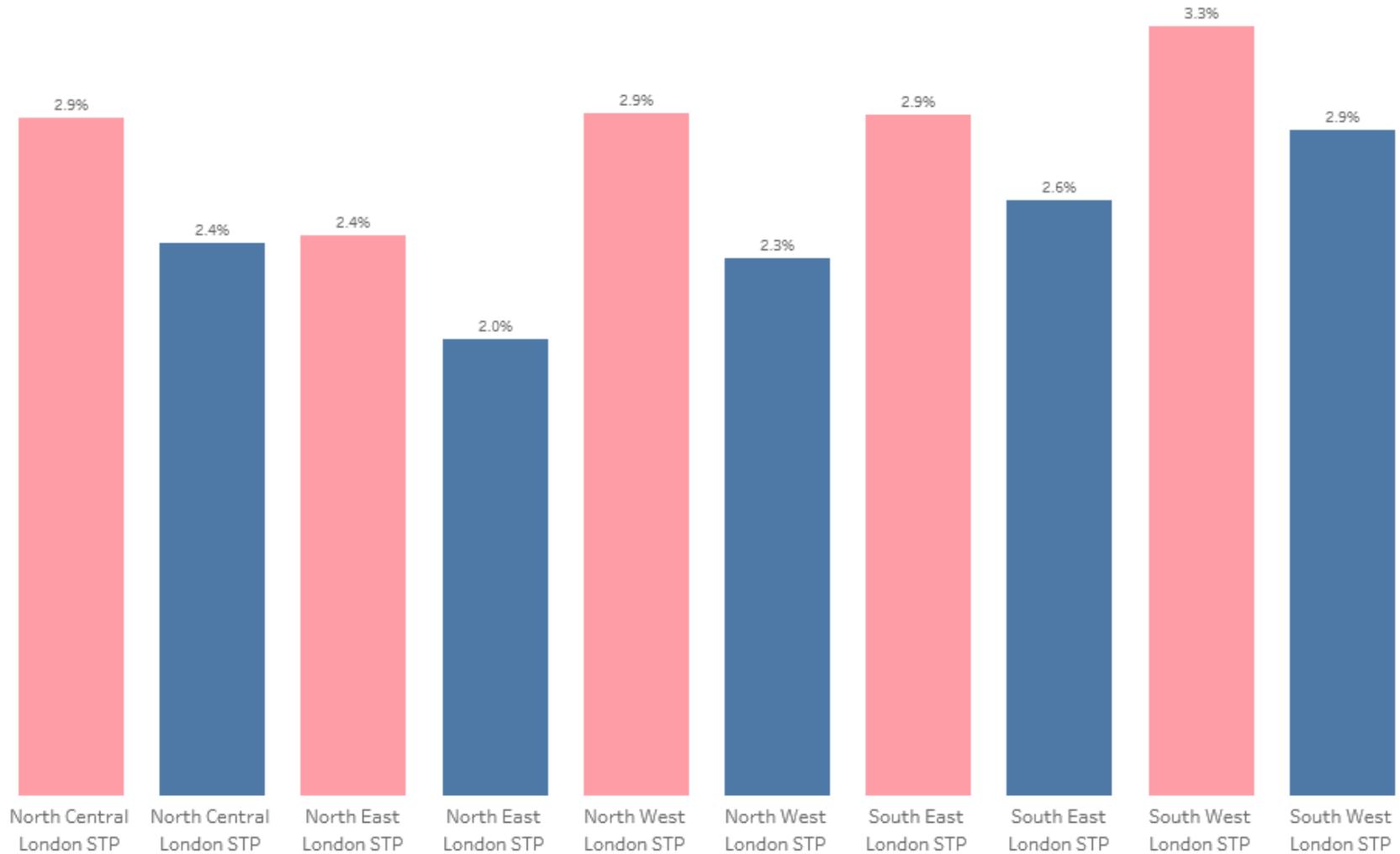
QOF Completeness Compared to Cancer Registry  
(Diagnosed 2003-31/03/2017)



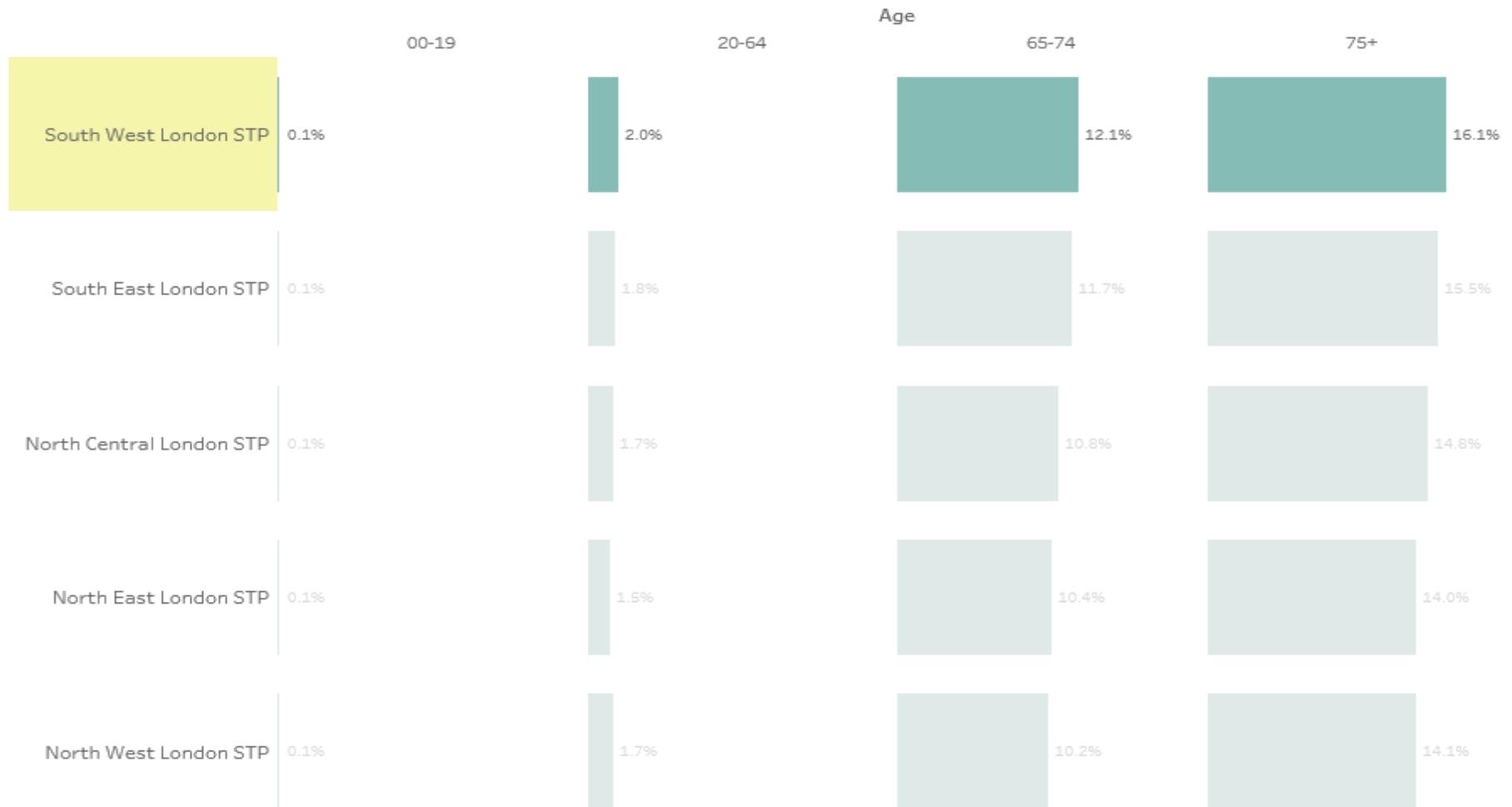
Proportion of Prevalent Population with a Subsequent Primary Cancer  
(Diagnosed 1995-2017)



# People Living With or Beyond Cancer by STP and sex

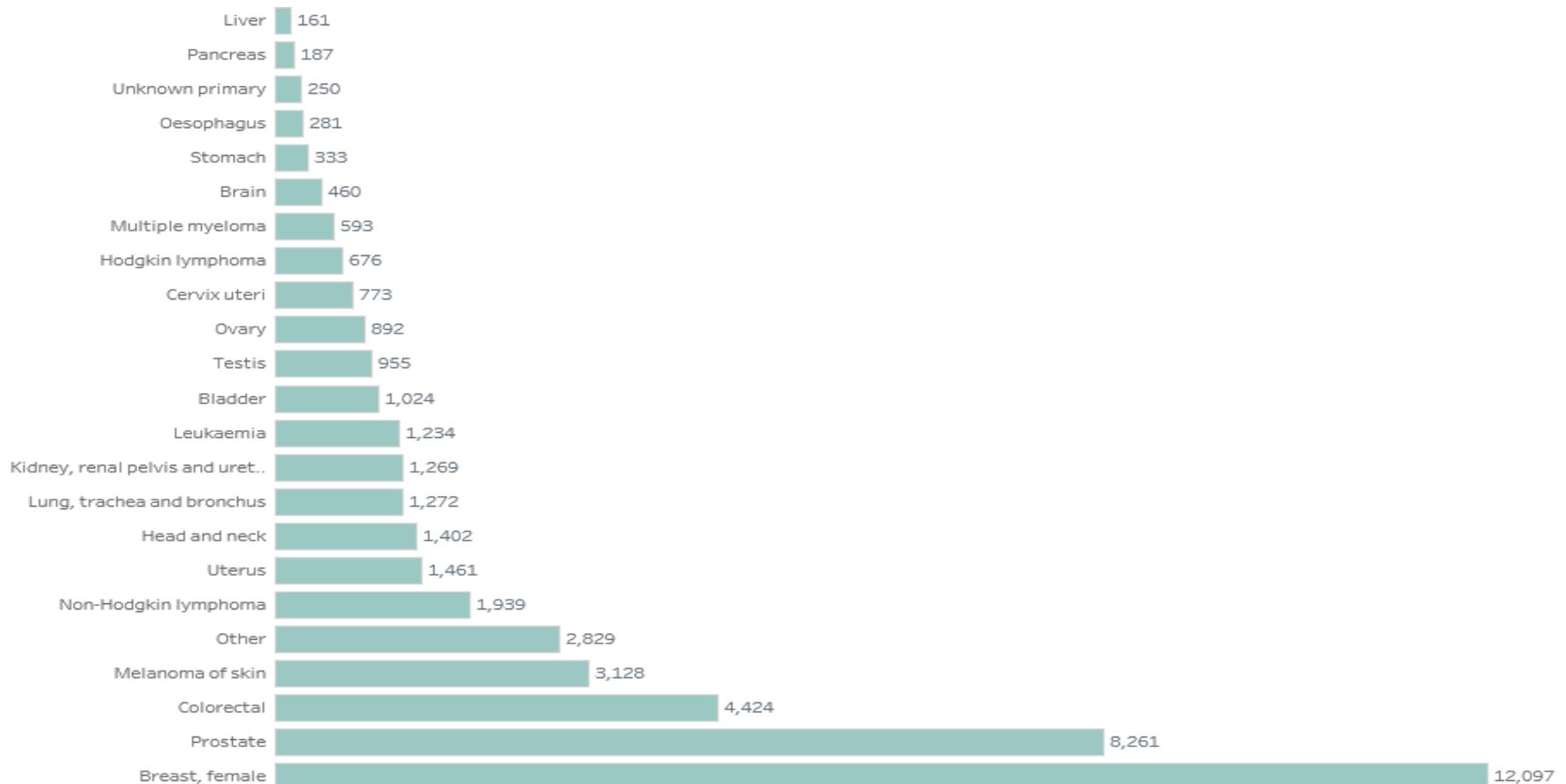


# People Living With or Beyond Cancer by STP and age



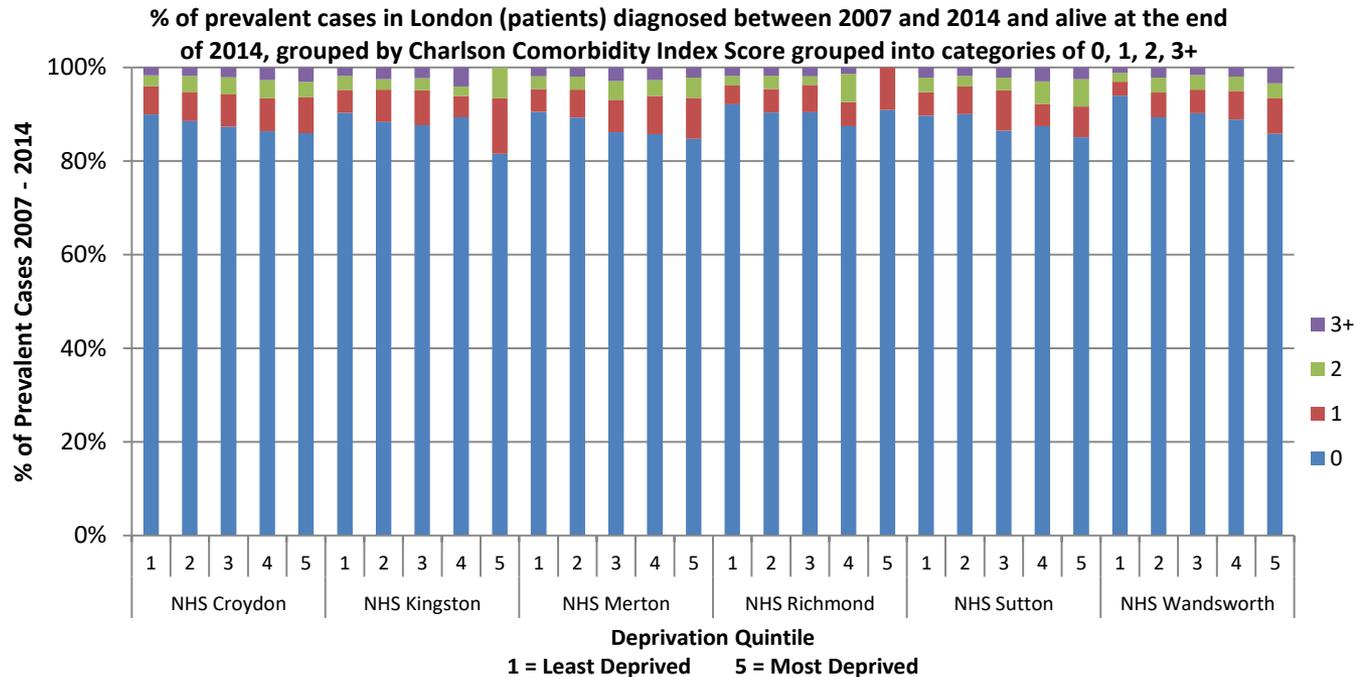
Full prevalence dashboard: <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

# People Living With or Beyond Cancer in SWL by cancer site



**Full prevalence dashboard:** <https://www.healthylondon.org/resource/2017-cancer-prevalence-dashboard/>

# Comorbidities in South West London: Charlson Score



Charlson score indicates a burden of comorbidity (combining number of conditions, risk of mortality and/or resource use) where patients with no comorbidities have a zero score and an increasing burden of comorbidity is represented by a higher score.

Across London, comorbidity increases with age, as we would expect: 12% cancer patients overall have comorbidity; 6% of under 60s to 25% of over 80s

The proportion of patients with comorbidities also increases with increasing deprivation. The most deprived groups in Kingston and Merton have the highest proportion comorbidities - this may relate to older age of the population.

# 02

## **National Cancer Patient Experience Survey 2018: South West London**

# National Cancer Patient Experience Survey 2018: SWL

NCPE question	SWL STP	Croydon CCG	Kingston CCG	Merton CCG	Richmond CCG	Sutton CCG	Wandsworth CCG	National average
Q13 Were the possible side effects of treatment(s) explained in a way you could understand?	<b>73.01</b>	72.56	76.13	70.83	73.79	73.65	71.48	<b>73.11</b>
Q14 Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	<b>65.88</b>	70.21	65.63	65.38	64.36	66.88	60.00	<b>67.11</b>
Q15 Before you started your treatment(s), were you also told about any side effects of the treatment that could affect you in the future rather than straight away?	<b>55.09</b>	57.74	57.87	53.57	52.03	55.05	53.36	<b>56.10</b>
Q20 Did hospital staff give you information about support or self-help groups for people with cancer?	<b>86.97</b>	87.85	87.36	88.42	85.53	84.74	88.02	<b>86.47</b>
Q21 Did hospital staff discuss with you or give you information about the impact cancer could have on your day to day activities (for example, your work life or education)?	<b>82.27</b>	83.44	82.78	85.44	80.20	82.86	79.02	<b>82.90</b>
Q35 During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	<b>51.05</b>	54.65	50.55	50.00	45.83	56.90	46.49	<b>52.66</b>

# National Cancer Patient Experience Survey 2018: SWL

NCPES question	SWL STP	Croydon CCG	Kingston CCG	Merton CCG	Richmond CCG	Sutton CCG	Wandsworth CCG	National average
Q41 While you were being treated as an outpatient or day case, did you find someone on the hospital staff to talk to about your worries and fears?	<b>68.87</b>	70.92	65.70	64.29	69.70	71.18	68.75	<b>70.90</b>
Q49 Did the doctors or nurses give your family or someone close to you all the information they needed to help care for you at home?	<b>61.02</b>	65.56	63.95	58.64	59.73	58.80	56.86	<b>60.29</b>
Q50 During your cancer treatment, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	<b>44.57</b>	47.55	48.48	46.09	46.22	42.45	35.34	<b>52.54</b>
Q51 Once your cancer treatment finished, were you given enough care and support from health or social services (for example, district nurses, home helps or physiotherapists)?	<b>40.82</b>	39.31	49.28	40.51	49.33	32.53	37.35	<b>44.69</b>
Q53 Do you think the GPs and nurses at your general practice did everything they could to support you while you were having cancer treatment?	<b>57.93</b>	56.63	58.33	55.15	54.59	62.56	60.10	<b>59.21</b>
Q54 Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care?	<b>57.82</b>	60.46	58.74	56.90	50.52	64.10	53.99	<b>61.39</b>
Q55 Have you been given a care plan?	<b>35.64</b>	42.86	33.53	39.13	28.51	31.58	34.95	<b>35.09</b>

# 03

## **Personalised Care and Inequalities in South West London**

# Inequalities in SWL

## Levels of ethnic diversity vary across SWL:

21% BME in Sutton, 39% in Merton and highest at 45% in Croydon

**Areas of significant deprivation:** Croydon most deprived CCG in SWL (rank 91 out of 326 England LA), next is Wandsworth (rank 147<sup>th</sup>). There are pockets of deprivation across SWL in every borough. Croydon one of London's fastest growing boroughs (second only to Barnet in NCL)<sup>1</sup>

**Prisons and IRC:** HMP Wandsworth holds 1700 men; Lunar House Immigration asylum screening centre, Croydon, where people go to register for asylum<sup>2</sup>. Non-residential short term holding facility – approx. 1200 detentions per year, average 5 hours before transfer to another facility

## Drugs and alcohol:

Opiate and crack users estimated at 6285 in SWL using 2016-17 data (highest number in Croydon n=1933 people)

## People with severe and enduring mental illness (SMI):

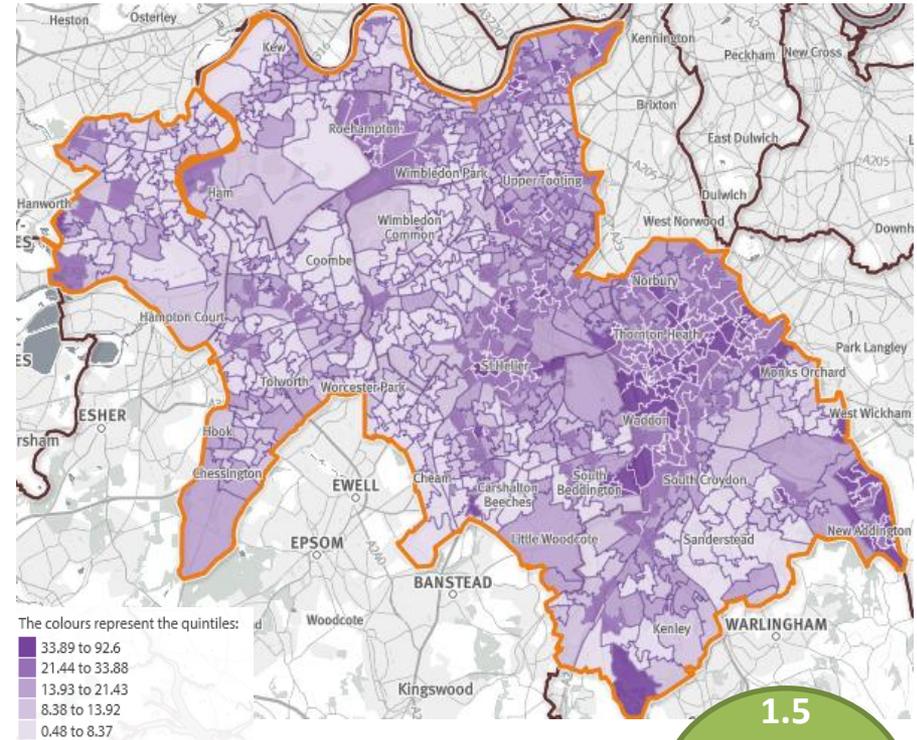
Estimated 14,000 people with SMI amongst GP registered population (1%)

## Street homeless persons on CHAIN:

n=494 in SWL with highest number in Croydon (n=105)

## Full inequalities toolkit:

<https://www.healthylondon.org/resource/cancer-inequalities-toolkit/>

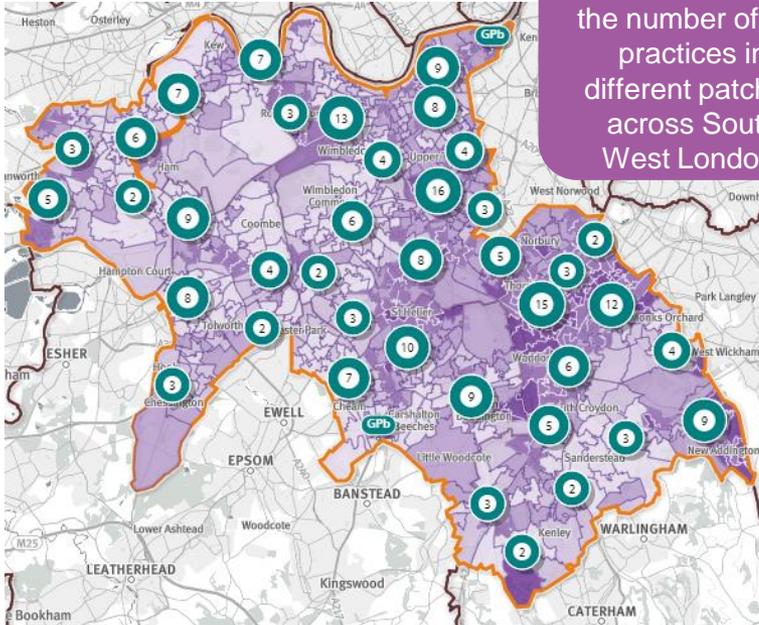


© Crown copyright and database rights 201 Ordnance Survey 100016969  
Source: SHAPE <https://shapeatlas.net/place/>

1.5 million people living in SWL

# Where would we focus primary and community care efforts for cancer in SWL?

The map shows the number of GP practices in different patches across South West London.



Index of Multiple Deprivation

✓	GP	London Road Medical Practice, Thornton Heath	57.63
✓	GP	Thornton Heath Health Centre, Thornton Heath	48.98
✓	GPb	Greenside Group Practice, Croydon	43.64
✓	GPb	Fieldway, Croydon	42.97
✓	GP	Fieldway Medical Centre, Croydon	42.97
✓	GPb	Ravi-Shankar, Croydon	42.73
✓	GP	Headley Drive Surgery, Croydon	41.40
✓	GP	Eversley Medical Centre, Thornton Heath	41.35
✓	GP	North Croydon Medical Centre, Thornton Heath	41.35
✓	GP	South Norwood Medical Practice, South Norwood	41.28

The **Index of Multiple Deprivation** is a UK government qualitative study of deprived areas in English local councils.

The score in the table covers seven aspects of deprivation; which are income, employment, health deprivation and disability, education skills and training, barriers to housing and services, crime and living environment.

Where is the deprivation in South West London?

What are the top GP practices working in most deprived areas in South West London?

Where would we focus our efforts on in South West London?

The GP practices with the populations with the highest deprivation are all in Croydon.

# Summary of Personalised Care and Inequalities in SWL

**Co-morbidity in cancer patients in SWL is highest in deprived groups in Kingston and Merton**



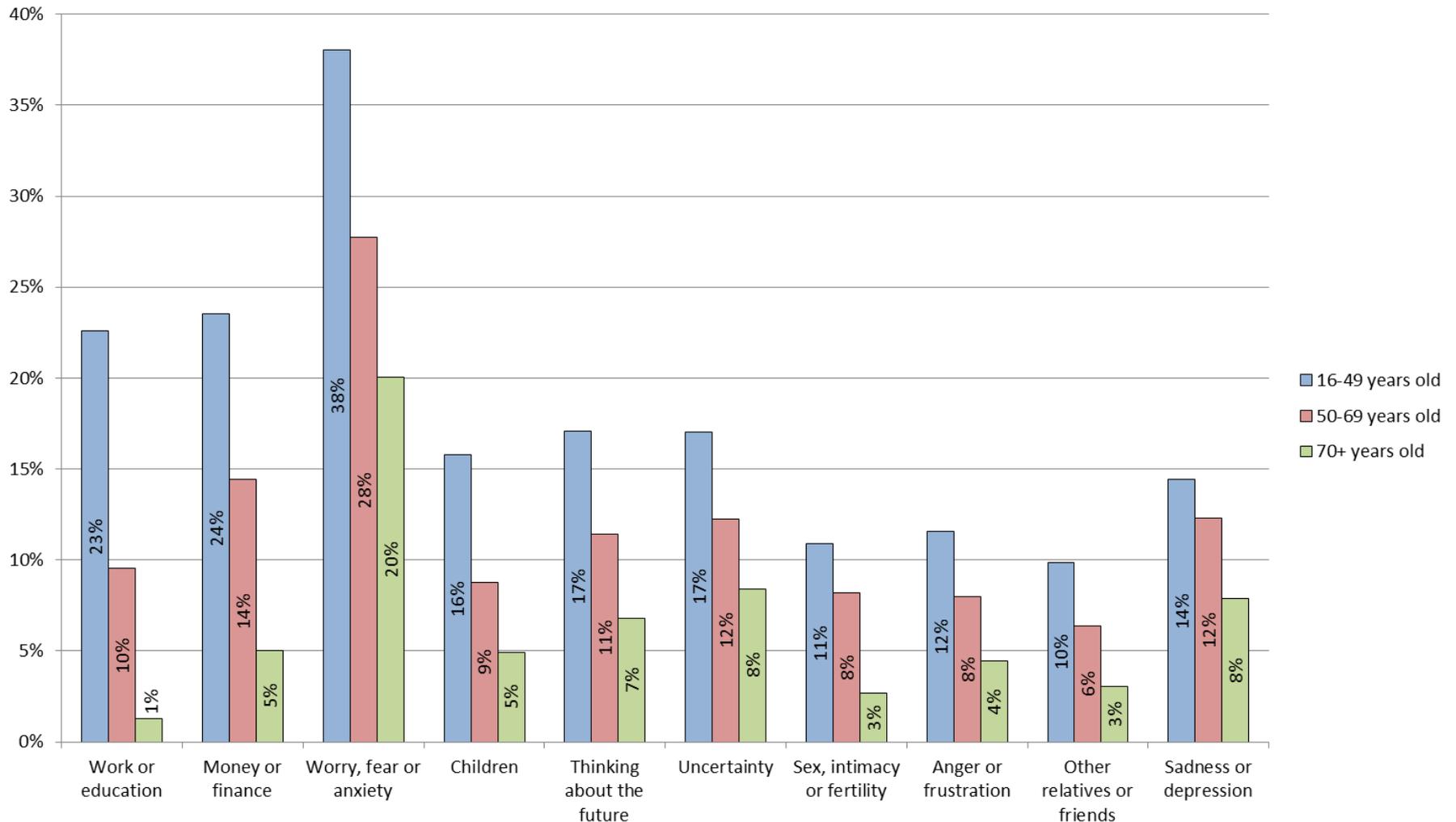
**There are high levels of household debt in Croydon and Sutton**

# 04

## E-HNA data: London

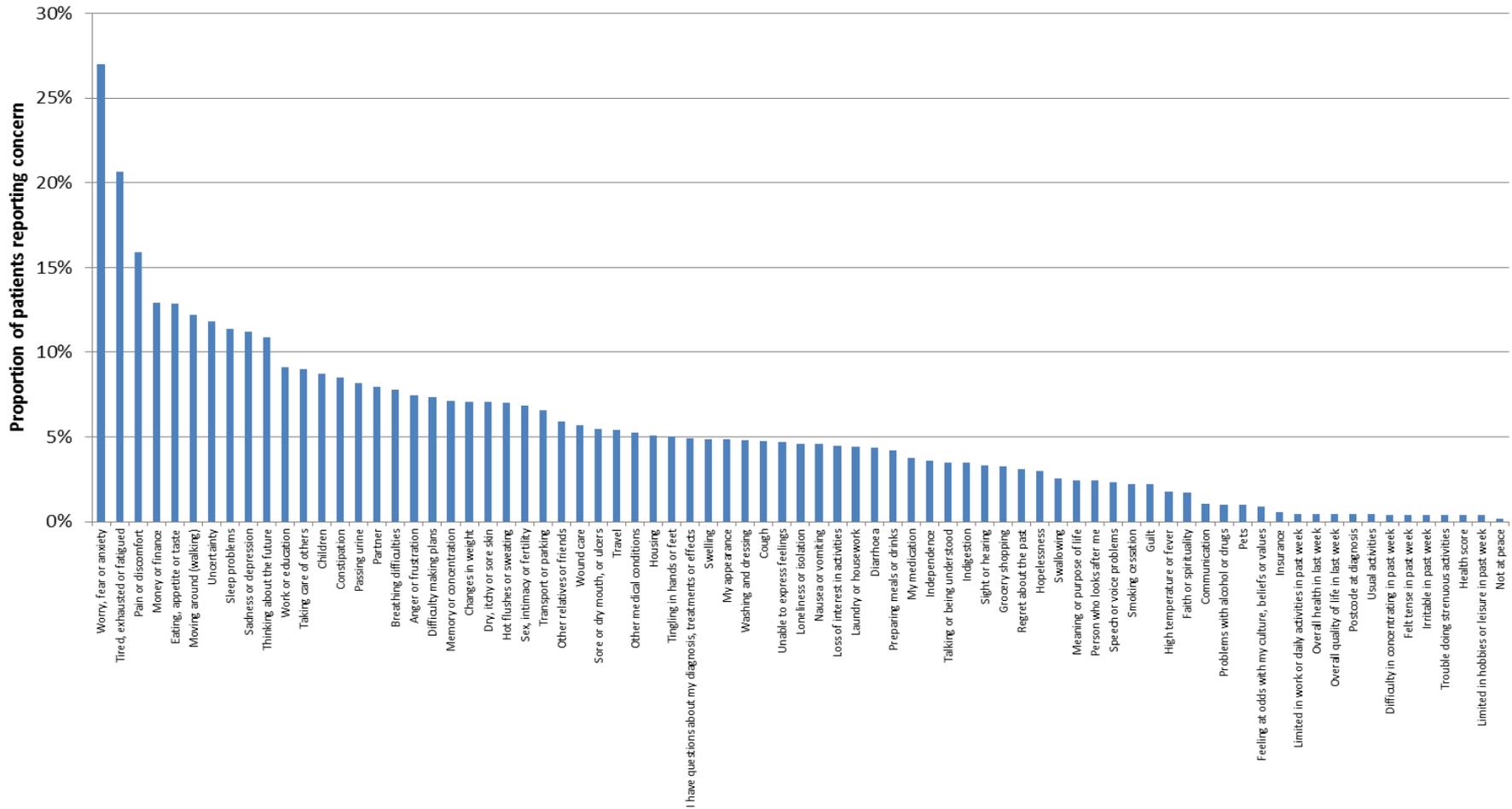
# E-HNA Data for London: Top Ten Concerns

Graph showing the proportion of patients by age-band across London who reported concerns in e-HNA in 2018 (Ten concerns with biggest variation by age band)



# E-HNA Data for London: Proportion of patients reporting each concern

Graph showing the proportion of patients completing an e-HNA in London reporting each concern in 2018, for all tumour types



# 05

## **STP Priorities in South West London**

# Personalised care and support



- **Quality of life metric**

- Measuring how well people are living after cancer treatment – no other health system in the world is doing this at this scale.



- **Personalised care**

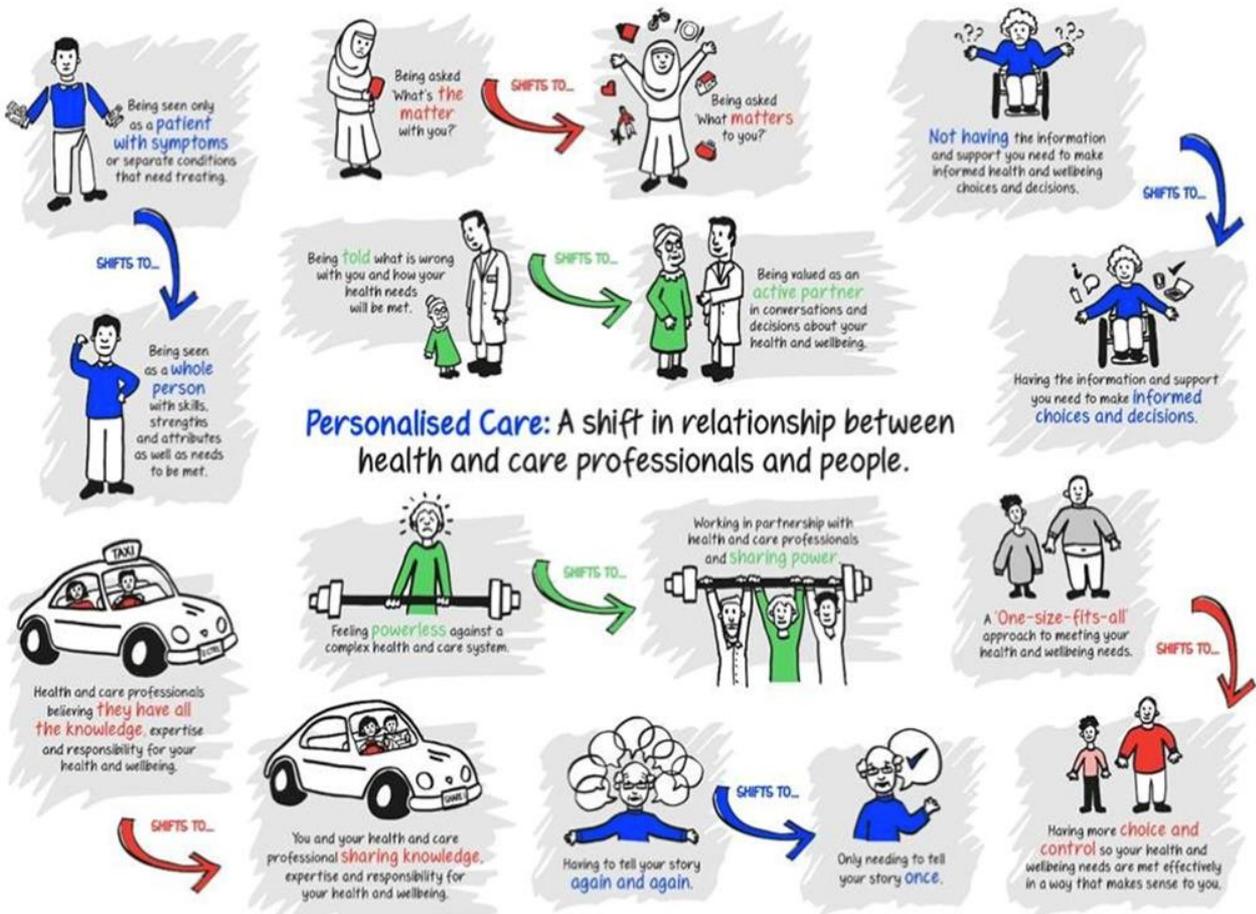
- All patients will have access to personalised care interventions – needs assessment, care plan, health and wellbeing information, and access to the right care and support – by 2021.
- Follow up based on patient needs (stratified follow-up) for all breast cancer patients by March 2020 and all prostate and colorectal cancers by March 2021.



- **Patient experience**

- Continue to deliver National Cancer Patient Experience Survey (NCPES).
- Group of trusts to use results to tackle variation in patient experience.





This visual is a best practice example by the National Personalised Care team.

Image: Personalised Care Strategic Coproduction Group, 2019

# Draft SWL Priorities: Personalised Care

2019-2021 - support Trusts to continue to roll out and improve the quality of personalised care interventions including **needs assessment, a care plan and health and wellbeing information and support.**

2019/20 - support Trusts to continue to roll out and improve the quality of personalised care interventions including needs assessment, a care plan and health and wellbeing information and support.

2021 onwards - support Trusts to continue to roll out and improve the quality of personalised care interventions including needs assessment, a care plan and health and wellbeing information and support.

2019/20 - continue to roll-out the **Cancer Psychological Support service.**

2019/20 - complete and evaluate the **Macmillan Primary Care Nursing Leadership** project to upskill primary care nurses to provide more personalised care to cancer patients.

**2020 onwards** - continue to work with partners to **implement comprehensive model** of personalised care for cancer patients. This could include:

**Cancer rehabilitation and prehabilitation;**

**Cancer psychosocial support;**

Ensuring that there social prescribing models support patients with cancer;

Using expert patients and peer support to enable patients to better self-manage and take a more active role in decisions around their treatment care.

Using digital tools to enable greater personalisation for example, patients having access to their health records and developing a patient/carer helpline.

# Recommendations for Personalised Care in SWL: Psychosocial support

**System  
leaders/commissioners  
are asked to:**

**1. Adopt the proposed  
London Integrated  
Cancer Psychosocial  
Care Pathway**

**2. Localise the  
pathway by mapping  
current resources,  
supporting  
partnership working  
and identifying gaps at  
STP/ICS level.**

**3. Where there are no or very  
limited Psycho-oncology teams,  
allocate sufficient resource to  
ensure a Psycho-oncology service  
is available to deliver the  
outcomes indicated in the  
pathway (including closer  
working partnerships across  
Primary Care and Improving  
Access to Psychological Therapies  
(IAPT) services).**

## **Key challenges:**

It is acknowledged that the below does not include all of the challenges in this area. We encourage each STP to review the Pan-London Mapping of Psycho-oncology services for further details: <https://www.healthylondon.org/resource/psychosocial-support/>

1) Staff capacity across the STP still needs to be addressed and especially expectations on St Georges to fill gaps in the region which has resource and capacity implications for the team.

2) Epsom and St Helier University NHS Trust have a newly funded Clinical Psychologist (Band 8a) funded for a two year period by Macmillan Cancer Support. The post ends in October 2021 unless an alternative funding source is agreed.

# Recommendations for Personalised Care in SWL: Cancer Rehabilitation and Lymphoedema

System  
leaders/commissioners  
are asked to:

1. Examine local  
provision of cancer  
rehab (inc physical  
activity) and develop an  
action plan for where to  
enhance provision

2. Embed the  
service  
improvement  
tools across all  
services

3. Use the TCST  
Minimum Data  
Set to  
benchmark local  
data collection

4. Establish  
strong links with  
name rehab  
champion and  
lymphoedema  
champion

## Examples of good practice:

*Prehabilitation:* Get Set 4 Surgery, St George's NHS FT

*Rehabilitation:* The South East London Head and Neck Cancer Rehabilitation Team

*Palliative rehabilitation:* Marie Curie Hospice Hampstead Therapy Team

*Physical Activity services:* Macmillan Move More Wandsworth

All of these are showcased in the TCST Integrated Care System Guidance for Cancer Rehabilitation, available here:

<https://www.healthy london.org/resource/guidance-for-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation/>

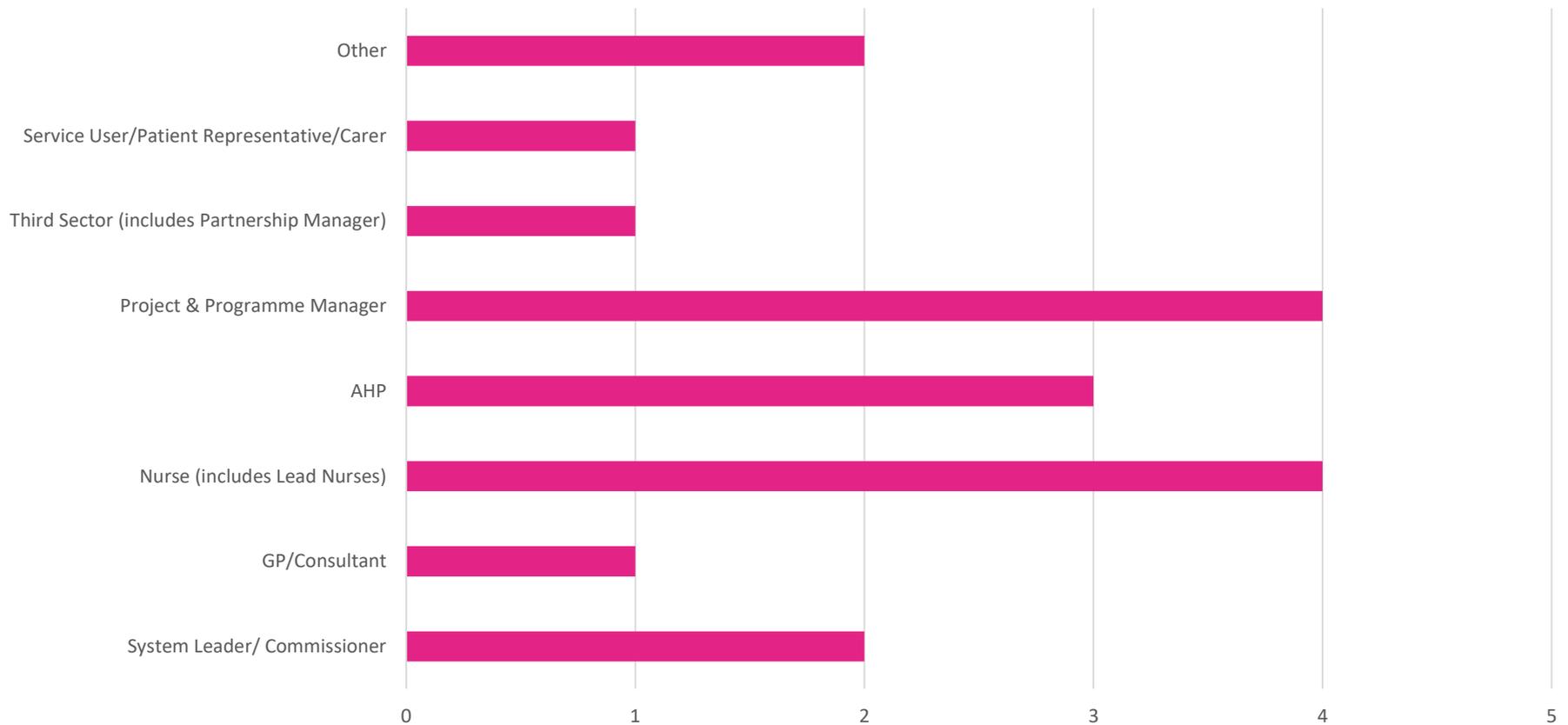
# 06

## **Personalised Care for Cancer**

### **Next Steps Update: Actions and Succession Planning -South West London**

# South West London STP Table Discussion: Who attended?

## STP Representation from South West London



# South West London STP Table Discussion: Personalised Care for Cancer

	Strategic	Operational
Strengths	<ol style="list-style-type: none"> <li>1. Pan London Community of Practice in Primary Care Nursing</li> </ol>	<ol style="list-style-type: none"> <li>1. Good intelligence on gaps, knowledge and barriers to access education</li> <li>2. Primary care navigator pilot.</li> <li>3. Commissioned psychosocial support service at St. George's Hospital and expanding to Croydon University Hospital.</li> <li>4. Variety of services at Royal Marsden's Hospital working in conjunction with the Maggie's centres in psychosocial support for people affected by cancer</li> <li>5. Macmillan Cancer Support's 'Get Fit for Surgery' programme has been successful.</li> <li>6. Health and Wellbeing events have been effective in hospitals and these could potentially be expanded into the community.</li> <li>7. Lymphoedema services at St George's and Royal Marsden's Hospital. Croydon also has a local service provision.</li> </ol>
Gaps	<ol style="list-style-type: none"> <li>1. Variable levels of knowledge and engagement across CCGs.</li> </ol>	<ol style="list-style-type: none"> <li>1. Knowledge of how to refer and where services are available.</li> <li>2. IAPT – it is not always known when to refer to which service.</li> <li>3. Advanced communications training in acute and primary care settings as well as training in psychosocial oncology is not widely available in the patch.</li> <li>4. Bereavement support given to families and the people around the patient</li> <li>5. Community services in cancer rehabilitation are not available in the STP – patients need to go to hospital</li> </ol>

# South West London STP Table Discussion: Personalised Care for Cancer

	STP focussed	Pan London
Opportunities	<ol style="list-style-type: none"> <li>1. Teleconsulting e.g. using Skype or similar could be used to improve accessibility.</li> <li>2. There is a 6-week online Macmillan Cancer Support course called 'Hope' which supports patients to move on after treatment – this could be promoted for better use across the patch.</li> <li>3. Raising awareness of services.</li> <li>4. Secure long-term funding for Macmillan move more programme. Short term funding exists, the opportunity is to secure long-term funding and embed across SWL as the CCGs merge (currently in Merton and Wandsworth). SWL grant has been obtained for Move More to link up with Get Fit for Surgery to bring a more sustainable, longer term community element; but this is small and short term</li> <li>5. Lymphoedema Hospital and hospice-based services to be improved.</li> <li>6. Opportunities to improve community services knowing where services are and how to refer.</li> <li>7. Social Prescribers and Primary Care Navigators could be better utilised.</li> <li>8. Prehab, this is not funded for all people affected by cancer. However, it is widely believed to reduce recovery time.</li> </ol>	<ol style="list-style-type: none"> <li>1. The lead primary care nursing role could be strengthened.</li> <li>2. Cancer nurses are managing long term conditions but are not routinely managing cancer.</li> <li>3. Interoperability between systems – if this was optimised it would be great.</li> <li>4. HNAs should ask the question: Do you know about the Information Centre? This would alert patients and initiate signposting because many don't know they exist.</li> <li>5. Primary Care Nurse or network?</li> </ol>
Concerns	<ol style="list-style-type: none"> <li>1. Prehab is variable across South West London; the current provision is hospital based and just for surgical patients.</li> </ol>	<ol style="list-style-type: none"> <li>1. Quality of Cancer Care Reviews carried out by GPs are variable.</li> <li>2. Lack of resources to support colleagues at grass roots level.</li> <li>3. Communication and relationships between primary and secondary care teams.</li> <li>4. Rehab mapping falls out of date.</li> <li>5. There are gaps still to be identified in Lymphoedema services, but concerns arise around <ul style="list-style-type: none"> <li>• Small services which are run by one overwhelmed practitioner</li> <li>• Loss of current infrastructure going forward is a concern.</li> <li>• Prevalence of lymphoedema is increasing.</li> <li>• Variable provision and complex referral routines.</li> </ul> </li> <li>6. Prescribing issues especially with treatment garments</li> </ol>

# South West London STP Table Discussion: Personalised Care for Cancer

## Agreed Actions: Primary Care Nursing Project

1. Developing the knowledge across London about cancer as long-term condition and working with long term conditions teams.
2. Consider the opportunities of the PCNs and the role of social prescribing in the context of nursing and cancer as a long-term condition. Locate and link in with the work of navigators in primary care.
3. Data held in different sectors should be accessible where appropriate e.g. secondary care and primary care interoperability between systems.
4. Prioritise support and training for Primary Care and Community Nurses with funding for Protected Learning Time.
5. Cancer Care Reviews: There should be a LES in the STP for Cancer Care Reviews to be offered after treatment has finished. This could be used to promote more consistency across the patch in terms of the support offer given.

# South West London STP Table Discussion: Personalised Care for Cancer

## Agreed Actions: Psychosocial Support

1. Psychosocial support is already a named priority in the STP area for acute settings. This should be scaled up across the whole patch to reach community services by developing a model for the whole STP.
2. Information centres should be promoted and signposted along the whole cancer pathway.
3. Stronger links to services should be included in Cancer Care Reviews in Primary Care which should be carried out again at the end of treatment.
4. Link into the work with the prehab, primary care networks and upskilling workforce.
5. Exploring how the primary care navigator and nursing can align together with psychosocial support.

## Agreed Actions: Cancer Rehabilitation

1. There should be clarity around the benefits of acute services provisions over community settings or vice versa.
2. Macmillan's 'Get Fit for Surgery' should be rolled out . There should be case studies to support clinical and cost effectiveness.
3. Education should be improved around rehab, physical activity and exercise. This should be discussed at the early stages within the pathway and consistent health and wellbeing information should be given to patients and their families. This could be provided via PCN social prescribing service. Social resources should be identified and used to improve access to rehabilitation, for example, through Community Activator Roles.
4. Mapping should actively be kept up to date. Demand and need mapping using the service tool should be conducted.
5. Not sure this is quite right, is it more about looking at the patients who currently don't receive any prehab and looking to standardise provision of services. (Get Fit for Surgery is just at SG at the moment with interest from Kingston) but RMH for example provide prehab for a different cohort of patients – do we need a better understanding of who offers what.

## Agreed Actions: Lymphoedema

1. A lead should be identified for lymphoedema for the STP.
2. Gaps will be identified when the new guidance is published in April 2020 and someone should have overall responsibility for picking up the work once the gaps have been identified in the STP.
3. Understand the workforce challenges by reviewing the pan London mapping and link into the primary care nursing project on how to mitigate against this.

## South West London STP: Peer Feedback

- ❖ A comment from a SEL representative agreed that: The story is similar in SEL.
- ❖ Similar comments across STPs – the discussion at the NCL table reflected largely that of SWL.

## General Peer Feedback for all STPs across London

- ❖ Rehab, prehab and lymphoedema needs a **voice** on **cancer boards** across London.
- ❖ The **Cancer Care Map** should be used to demonstrate where improvement is needed.
- ❖ Health Education England should give accreditation to achieve **CPD learning** which is already available.
- ❖ Each STP should develop **SMART goals** and actions to achieve the proposals outlined in the discussions for the next steps for London in Personalised Care for Cancer.

## Personalised Care for London: Pan London Opportunities identified in STP discussions across London

- ❖ Universal Personalised Care -opportunity to shift some of the discussion from cancer specific treatment and care to Long Term Condition agenda which may be more sustainable in primary care.
- ❖ Supporting primary care to understand the barriers in cancer care. Cancer nurses are managing long term conditions but are not routinely managing cancer.
- ❖ Culture change to enable staff to have protected time to attend training. Education for Primary Care Nurses and GPs to be equipped to deal with issues including supporting people with disabilities
- ❖ Building on SWL project in Primary Care Nursing: Macmillan are funding a senior lead in each STP; upskilling Primary Care Nurses to better support patients who have been affected by cancer. The Lead Primary Care Nursing role could also be strengthened.
- ❖ Interoperability between systems – if this was optimised it would be great.
- ❖ HNAs should ask the question: Do you know about the Information Centre? This would alert patients and initiate signposting because many don't know they exist.
- ❖ Creating better links with community mental health nurses and form links with IAPT
- ❖ Provision of transportation for people affected by cancer.

# Personalised Care for London: Pan London Concerns identified in STP discussions across London

## Primary Care

- ❖ Primary Care Nursing workforce is stretched, and General Practice Nursing and education is often get forgotten.
- ❖ Workforce issues: general practice can have one nurse each which reduces the opportunity for training and can lead to retention issues.
- ❖ Awareness of the role primary care nurses play in cancer and their impact on people affected by cancer.
- ❖ Access issues into primary care especially getting an appointment with the GP.
- ❖ Quality of Cancer Care Reviews carried out by GPs are variable.

## Pathways and referrals

- ❖ The introduction of the Faster diagnosis standards can put pressure and create a threat to cancer prehab
- ❖ Patients need a clear picture of what to expect along treatment pathway
- ❖ Allied Health Professionals have a fear of cancer progression and there are unclear routes into psychosocial support services
- ❖ Challenges in reading and extracting important information in LCR
- ❖ Ensuring people affected by cancer are well prepared for stratified follow up pathways.
- ❖ Lymphoedema: Variable provision and complex referral routines.
- ❖ Limited awareness of lymphoedema pathway

# Personalised Care for London: Pan London Concerns identified in STP discussions across London

## Management and Strategy

- Inconsistent approach: Reactive rather than proactive approach to planning, strategising and implementing programmes
- There is no dedicated strategic role to take this work forward
- Lack of integrated IT systems.
- Communications barrier and relationships between primary care and secondary providers and community teams.
- Lack of resources to support colleagues at grass roots level.
- Rehab mapping falls out of date.
- Lymphoedema: Small services which are run by one overwhelmed practitioner. Loss of current infrastructure going forward is a concern.
- No national strategy for lymphoedema
- Holistic Needs Assessment after treatment – difficult to get timing right. Helpful to have examples of where HNAs working well in London

## Patient's view

- Lack of holistic view of patients and considering unique family situations and circumstances. Patients don't always feel part of the decision-making process
- The need for a holistic approach to a patient's care is not appreciated across the board and disjointed services with leave patients in a more vulnerable position.
- Motivation is required for patients to deliver exercise programme – need to create supportive and competitive environment

## Lymphoedema

- Prescribing issues especially with treatment garments

# Personalised Care for Cancer: General Themes across STPs in London

Education and training of the workforce

Commissioning and Funding

Clarity of referral pathways

Keeping personalised care on the agenda at STP level (having the right people sitting at the right tables in terms of governance and clinical leadership).

Comments from an attendee:

Integrated Care- Don't forget about social housing providers and the support they can offer.

Social inclusion teams



Community Development

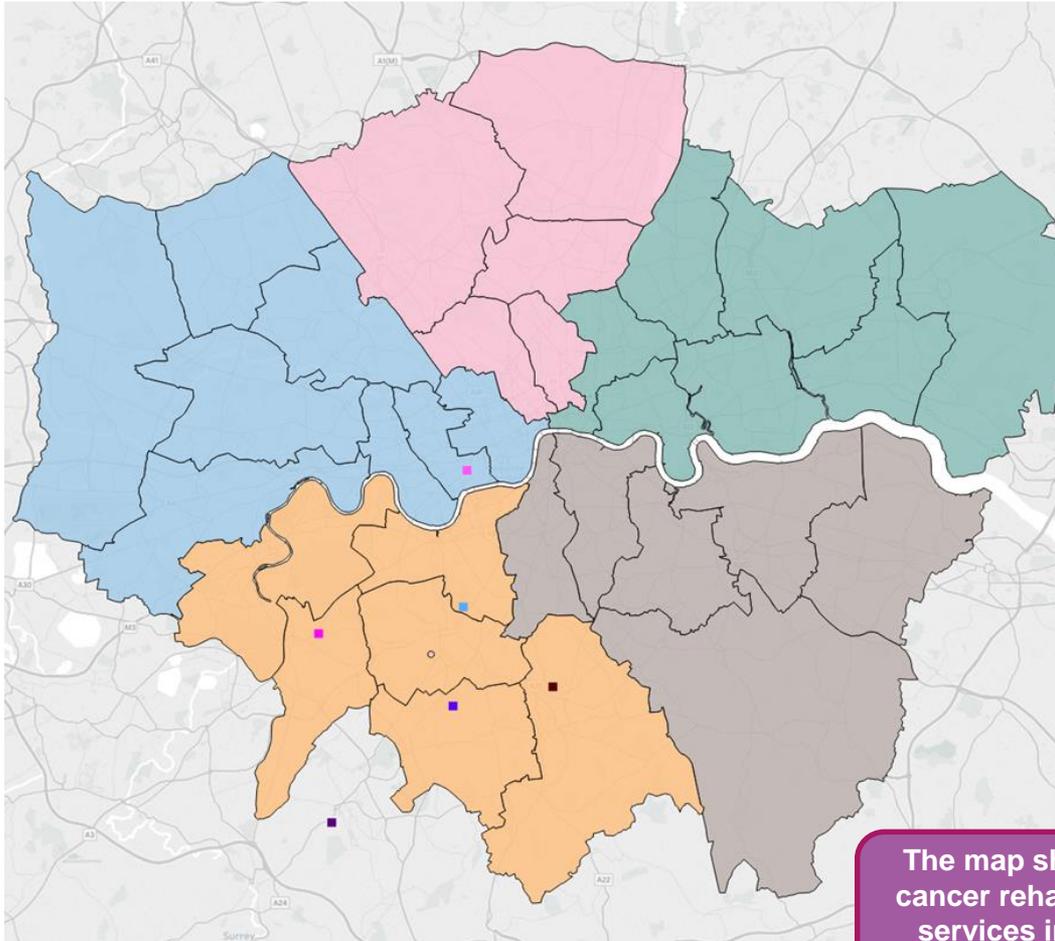


Cancer Rehab and Psychosocial support

# 07

## **Key Contacts and Resources in South West London: Personalised Care for Cancer**

# Cancer Rehabilitation: Key Resources



## Service Provider

- Croydon Health Services NHS Trust
- Epsom and St Helier NHS Trust (Epsom)
- Epsom and St Helier NHS Trust (Sutton)
- Kingston Hospital NHS Foundation Trust
- Royal Marsden NHS Foundation Trust
- St George's University Hospitals NHS Foundation Trust

## Type of provider

- Acute Trust

The map shows the cancer rehabilitation services in South West London.

- **Scoping report (2017):**  
<https://www.healthylondon.org/resource/cancer-rehabilitation-scoping-report-london/>
- **Data recommendations (2017)**  
<https://www.healthylondon.org/resource/cancer-rehabilitation-services-data-recommendation-report/>
- **Service improvement tools (2018)**  
<https://www.healthylondon.org/resource/cancer-rehabilitation-pathways-service-improvement-tools/>
- **Commissioning guidance (2019):**  
<https://www.healthylondon.org/resource/guidance-for-reducing-variation-and-improving-outcomes-in-cancer-rehabilitation/>
- **Service mapping (2019):**  
<https://www.healthylondon.org/resource/mapping-of-pan-london-cancer-rehabilitation-services/>

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# Cancer Rehabilitation: Additional Resources



Community rehabilitation services deliver tailored assessment, treatment and support to improve physical and mental health, reduce hospital admissions and help people manage long-term conditions.

But in too many cases, people access them too late – or not at all:

- ▶ Only 40% of the 1.3m people living with traumatic brain injury receive rehabilitation.
- ▶ After a hip fracture, only 1 in 5 services provide people with immediate rehabilitation on discharge from hospital.

<https://www.csp.org.uk/publications/manifesto-community-rehabilitation>

## Rehab Matters

The CSP's #RehabMatters campaign highlights the importance of community rehabilitation.

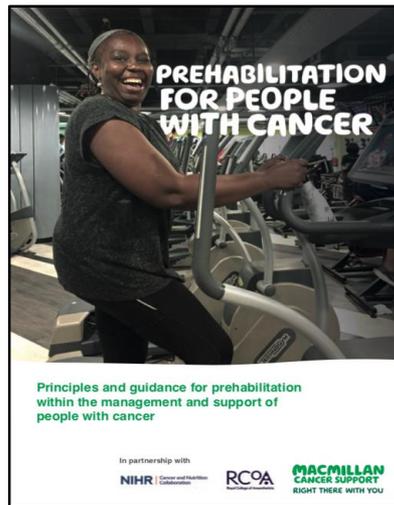


<https://www.csp.org.uk/campaigns-influencing/campaigns/rehab-matters>



[https://www.acsm.org/docs/default-source/files-for-resource-library/exercise-for-cancer-prevention-and-treatment-infographic.pdf?sfvrsn=ad47b1e1\\_2](https://www.acsm.org/docs/default-source/files-for-resource-library/exercise-for-cancer-prevention-and-treatment-infographic.pdf?sfvrsn=ad47b1e1_2)

<https://www.macmillan.org.uk/about-us/health-professionals/resources/practical-tools-for-professionals/prehabilitation.html>



RCGP Consequences of treatment toolkit:  
<https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/consequences-of-cancer-toolkit.aspx>

## NHS 'prehab' fitness plan aims to cut recovery time for cancer patients

Exercise can help reduce side-effects of chemotherapy and amount of time spent in hospital, say doctors

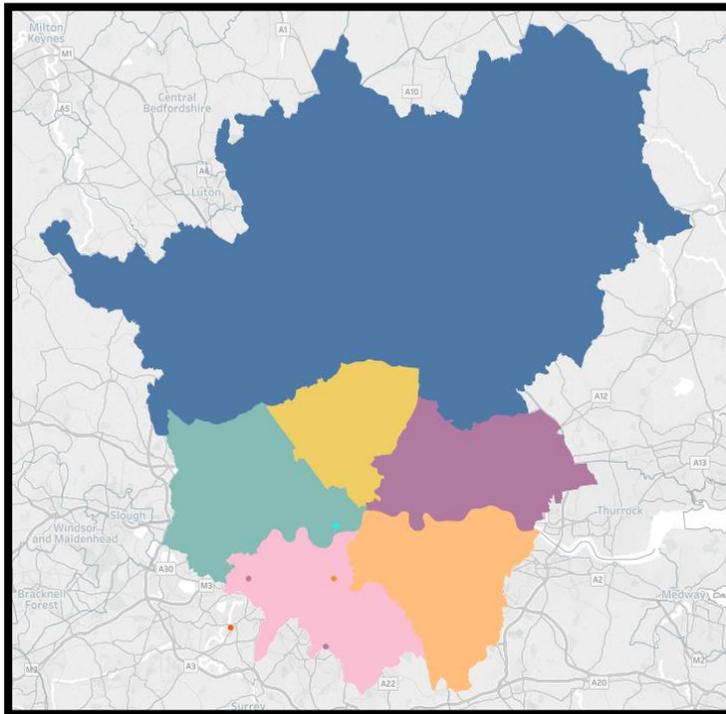


▲ The 'habilitation' can support people to prepare both physically and mentally for cancer treatment. © NHS/Alamy/Getty

<https://www.theguardian.com/society/2019/dec/26/nhs-prehab-fitness-plan-aims-to-cut-recovery-time-for-cancer-patients>

Macmillan tools for healthcare professionals:  
<https://www.macmillan.org.uk/about-us/health-professionals/resources/practical-tools-for-professionals>

# Lymphoedema: Key Resources



Details of Service	
	St George's University Hospitals
	Princess Alice Hospice service
	Richmond Service
	Royal Marsden service - Chelsea site
	Royal Marsden service - Sutton site

## Commissioning guidance:

<https://www.healthylondon.org/resource/commissioning-guidance-lymphoedema/>

Lymphoedema service specification and Minimum Data Set spreadsheet can be accessed using the above link

## Business case

<https://www.healthylondon.org/resource/template-business-case-lymphoedema-services/>

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# Psychosocial Support for adults affected by cancer: Key Resources



## Service location

- Kingston Hospital NHS Foundation Trust
- Croydon Health Services NHS Trust
- St George's University Hospitals NHS Foundation Trust
- Epsom and St Helier University Hospitals NHS Trust

- **Commissioning guidance**
- **Business case**
- **Service specification**
- **Service mapping**

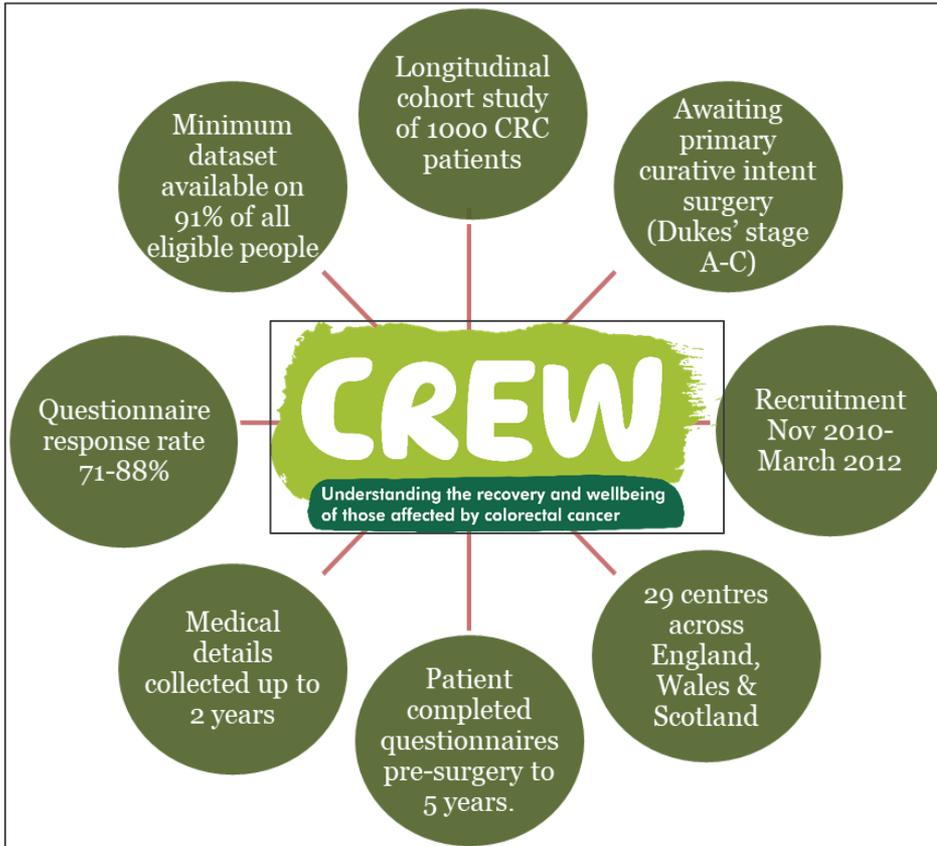
**All available here:**

<https://www.healthylondon.org/resource/psychosocial-support/>

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# Psychosocial Support for adults affected by cancer: Additional Resources



<https://www.southampton.ac.uk/msrg/ourresearch/macmillan-crew-cohort/macmillan-crew-cohort.page>

## Prevalence, associations, and adequacy of treatment of major depression in patients with cancer: a cross-sectional analysis of routinely collected clinical data



Jane Walker\*, Christian Holm Hansen\*, Paul Martin, Stefan Symeonides, Ravi Ramessur, Gordon Murray, Michael Sharpe

### Summary

**Background** Major depression is an important complication of cancer. However, reliable data are lacking for the prevalence of depression in patients with cancer in different primary sites, the association of depression with demographic and clinical variables within cancer groupings, and the proportion of depressed patients with cancer receiving potentially effective treatment for depression. We investigated these questions with data from a large representative clinical sample.

**Methods** We analysed data from patients with breast, lung, colorectal, genitourinary, or gynaecological cancer who had participated in routine screening for depression in cancer clinics in Scotland, UK between May 12, 2008, and Aug 24, 2011. Depression screening was done in two stages (first, Hospital Anxiety and Depression Scale; then, major depression section of the Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition). Data for depression status were linked with demographic and clinical data obtained from the Scottish National Cancer Registry.

**Findings** We analysed data for 21151 patients. The prevalence of major depression was highest in patients with lung cancer (13.1%, 95% CI 11.9–14.2%), followed by gynaecological cancer (10.9%, 9.8–12.1), breast cancer (9.3%, 8.7–10.0), colorectal cancer (7.0%, 6.1–8.0), and genitourinary cancer (5.6%, 4.5–6.7). Within these cancer groupings, a diagnosis of major depression was more likely in patients who were younger, had worse social deprivation scores, and, for lung cancer and colorectal cancer, female patients. 1130 (73%) of 1538 patients with depression and complete patient-reported treatment data were not receiving potentially effective treatment.

**Interpretation** Major depression is common in patients attending cancer clinics and most goes untreated. A pressing need exists to improve the management of major depression for patients attending specialist cancer services.

**Funding** Cancer Research UK and Chief Scientist Office of the Scottish Government.

Lancet Psychiatry 2014;

1:343-50

Published Online

August 28, 2014

[http://dx.doi.org/10.1016/S2215-0366\(14\)70313-X](http://dx.doi.org/10.1016/S2215-0366(14)70313-X)

See Comment page 320

See Articles Lancet 2014;

published online Aug 28.

[http://dx.doi.org/10.1016/S0140-6736\(14\)61231-9](http://dx.doi.org/10.1016/S0140-6736(14)61231-9)

See Articles Lancet Oncol 2014;

published online Aug 28.

[http://dx.doi.org/10.1016/S1470-2045\(14\)70243-2](http://dx.doi.org/10.1016/S1470-2045(14)70243-2)

See Online for podcast

interview with Michael Sharpe

and Jane Walker

\*Contributed equally

Psychological Medicine

Research, University of Oxford

Department of Psychiatry,

Warneford Hospital, Oxford,

UK (J Walker PhD, R Ramessur

BMBCh, Prof M Sharpe MD);

Psychological Medicine

[https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366\(14\)70313-X/fulltext](https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(14)70313-X/fulltext)

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# Primary Care Nursing: Key Resources

## Educational Videos



### 'The Value of good Cancer Care Reviews and the role that nurses play in delivering them'

This video explains the importance of delivering effective cancer care reviews, the role of nurses in delivering them and the positive impact that this can have for patients living with and beyond cancer.

<https://www.youtube.com/watch?v=wh4E-4Rcdul&feature=youtu.be>



### 'How to carry out a Cancer Care Review'

This video demonstrates how to carry out an effective cancer care review, and where you can get guidance on how to complete one. It also demonstrates the role of nurses in delivering them and the positive impact that this can have for patients living with and beyond cancer.

<https://www.youtube.com/watch?v=ul2020fr6Do&feature=youtu.be>



### Webinar – Managing Cancer as a Long-Term Condition

An online taster session for General Practice Nurses on 'Managing Cancer as a Long-Term Condition'. This webinar will provide an overview of cancer as a long-term condition and support General Practice Nurses deliver truly personalised care for their patients.

<https://www.youtube.com/watch?v=ZURLZDcSKw4&feature=youtu.be>



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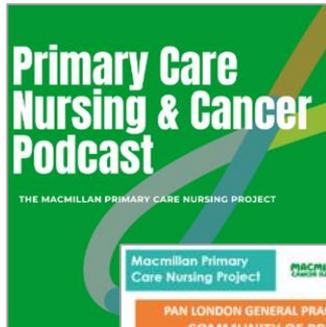
# Primary Care Nursing: Key Resources

## Sharing Learning & Good Practice



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### Primary Care Nursing and Cancer Podcast Channel

The 'Primary Care Nursing and Cancer Podcast' explores the work that has been happening in SWL on topics such as what does good practice look like in primary care, the value of working collaboratively, the importance of patients partners and more...

<https://anchor.fm/macmillan-primary-care-nursing-project>

### Macmillan Pan London GPNs Community of Practice

This group is for GPNs who are interested in leading on the development of primary care nurses' roles in relation to cancer as a long-term condition. It is open to all nurses across London with an interest in being part of this work and especially those who have completed the Macmillan Practice Nurse Course.

<https://drive.google.com/file/d/1nO7kyHgigJxbxe69i6R1HUdoD8flqJS/view>

### Cancer in the community – an introduction to cancer as a long-term condition for Community Nurses

Evaluation of a short course for Community Nurse that was developed by the project team in collaboration with Central London Community Healthcare (CLCH).

[https://drive.google.com/file/d/1r1lvRFb2zwLvMb3NCu\\_mw-9dWYm8Hs1F/view](https://drive.google.com/file/d/1r1lvRFb2zwLvMb3NCu_mw-9dWYm8Hs1F/view)



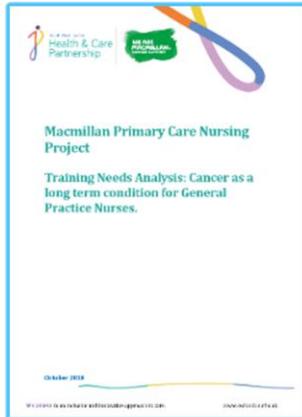
# Primary Care Nursing: Key Resources

## Sharing Learning & Good Practice cont...



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### Training Needs Analysis: Cancer as a long-term condition for General Practice Nurses 2018

This report provides an account of the methodology, results and recommendations of a training needs analysis conducted with general practice nurses across SW London in August 2018. The project team are in the process of a follow up analysis with GPNs in 2019/20 which will be available shortly.

<https://drive.google.com/file/d/1UMpXKI3P5XSy2Lyus0WMmXhiMm5sRS4j/view>



### Macmillan Primary Care Nursing Facebook Page

The project team have a Facebook Page. Like and follow our page to receive our latest updates and to link with other General Practice Nurses working in SWL.

<https://www.facebook.com/SWLMacNursingProject>

The project team are in the process of designing a web page that will host current and future outputs, including the evaluation from the project. This content will be hosted on the SWL Health & Care Partnership website and will be available very soon.

# Key Contacts in South West London

Name, Job Title and Organisation	Email address
<b>General</b>	
Maggie Lam, Deputy Director Cancer and UEC, South West London Health & Care Partnership	<a href="mailto:maggie.lam@swlondon.nhs.uk">maggie.lam@swlondon.nhs.uk</a>
Andre Chagwedera, Programme Manager – Cancer, South West London Health & Care Partnership	<a href="mailto:andre.chagwedera@swlondon.nhs.uk">andre.chagwedera@swlondon.nhs.uk</a>
	<a href="mailto:vanessa.brown5@nhs.net">vanessa.brown5@nhs.net</a>
Vanessa Brown, Senior Project Manager, RMP Cancer Alliance- Personalised Care Lead	<a href="mailto:ekta.patel@swlondon.nhs.uk">ekta.patel@swlondon.nhs.uk</a>
Ekta Patel, Project Manager Cancer, South West London Health & Care Partnership	
<b>Cancer Rehabilitation</b>	
Kate Ashforth, Joint Head of Speech and Language Therapy, The Royal Marsden NHS Foundation Trust	<a href="mailto:kate.ashforth@rmh.nhs.uk">kate.ashforth@rmh.nhs.uk</a>
Siobhan Cowan-Dickie, Clinical Specialist Physiotherapist, The Royal Marsden NHS Foundation Trust	<a href="mailto:siobhan.cowan-dickie@rmh.nhs.uk">siobhan.cowan-dickie@rmh.nhs.uk</a>
Carolyn Johnston, Consultant Anaesthetist, St. George's University Hospitals NHS Foundation Trust	<a href="mailto:carolyn.johnston1@nhs.net">carolyn.johnston1@nhs.net</a>
<b>Lymphoedema</b>	
Mary Woods, Nurse Consultant Lymphoedema, The Royal Marsden NHS Foundation Trust	<a href="mailto:mary.woods@rmh.nhs.uk">mary.woods@rmh.nhs.uk</a>
<b>Psycho-social support</b>	
Sahil Suleman, Macmillan Consultant Clinical Psychologist, Lead for Macmillan Cancer Psychological Support (CaPS) Team, St George's University Hospitals NHS Foundation Trust	<a href="mailto:sahil.suleman@stgeorges.nhs.uk">sahil.suleman@stgeorges.nhs.uk</a>
<b>Primary Care Nursing</b>	
Sandra Dyer, Macmillan Primary Care Lead Nurse	<a href="mailto:sandra.dyer@swlondon.nhs.uk">sandra.dyer@swlondon.nhs.uk</a>

# Macmillan Cancer Support in South West London

Name and Title	Email address
Robyn Jenkins, Partnership Manager, South West London	<a href="mailto:RJenkins@macmillan.org.uk">RJenkins@macmillan.org.uk</a>

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