

North Central 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 12th 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 **North Central London STP table discussions** are reflected in **Section 6**.

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

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01

Prevalence Data for North Central 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 31st 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.

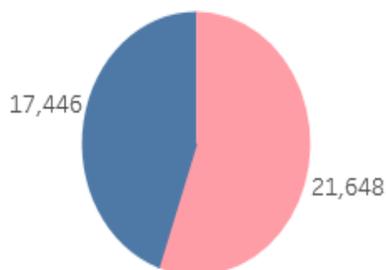
The dashboard will be updated annually.

The dashboard can be found here:

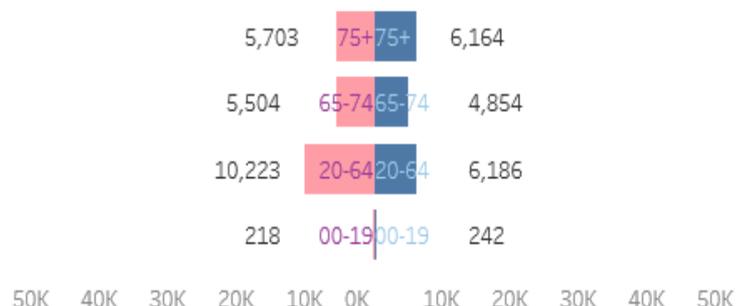
<https://www.healthylondon.org/resources/2017-cancer-prevalence-dashboard/>

People Living With or Beyond Cancer in NCL

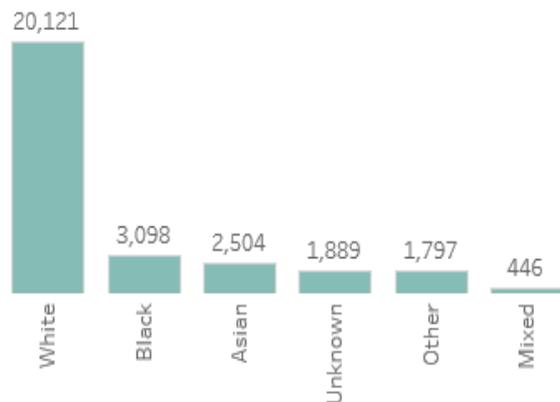
39,094 people were living with and beyond cancer in North Central London STP in 2017.
(Diagnosed between 1995-2017)



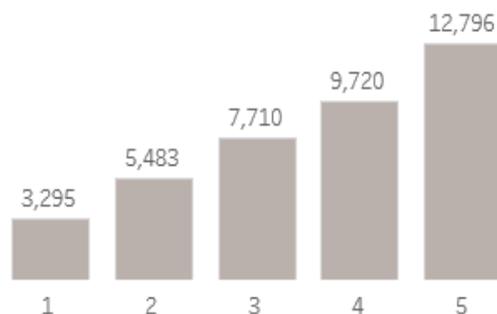
Age and Sex Distribution
(Diagnosed between 1995-2017)



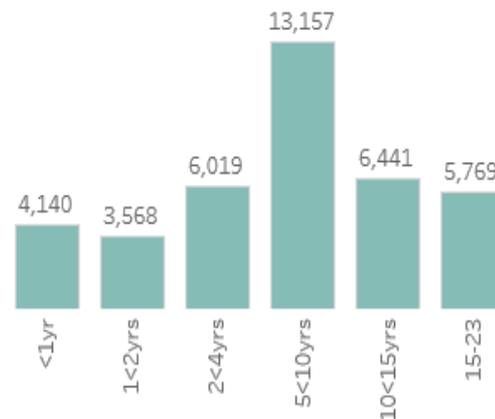
Ethnic breakdown
(2006-2017)



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

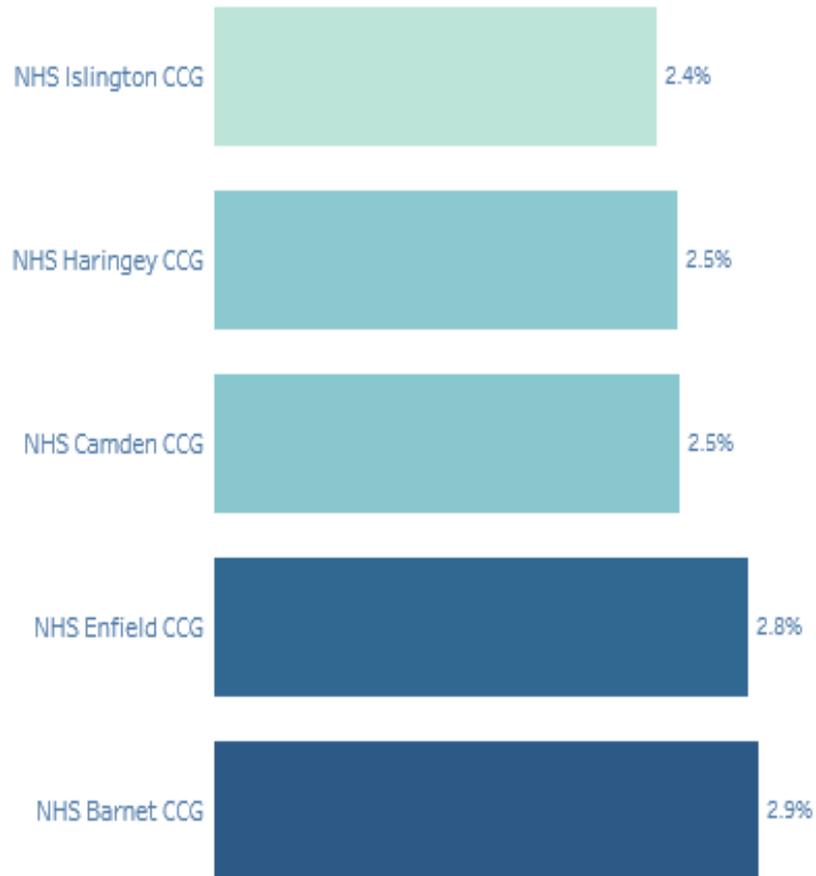


Time Since Diagnosis
(Diagnosed between 1995-2017)



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

People Living With or Beyond Cancer by CCG

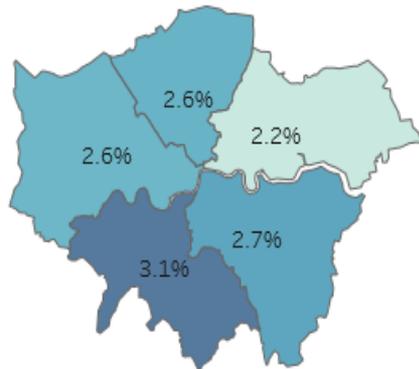


CCG	Number of people living with and beyond cancer	Projected number of people living with and beyond cancer 2030
Islington	5,520	8,400
Haringey	6,677	10,200
Camden	6,263	9,500
Enfield	9,420	14,400
Barnet	11,205	17,100
NCL STP	39,094	59,600

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

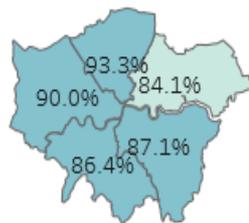
People Living With or Beyond Cancer in NCL

Cancer Prevalence
(Diagnosed 1995-2017)



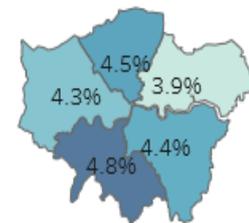
North Central London STP 2.6%

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



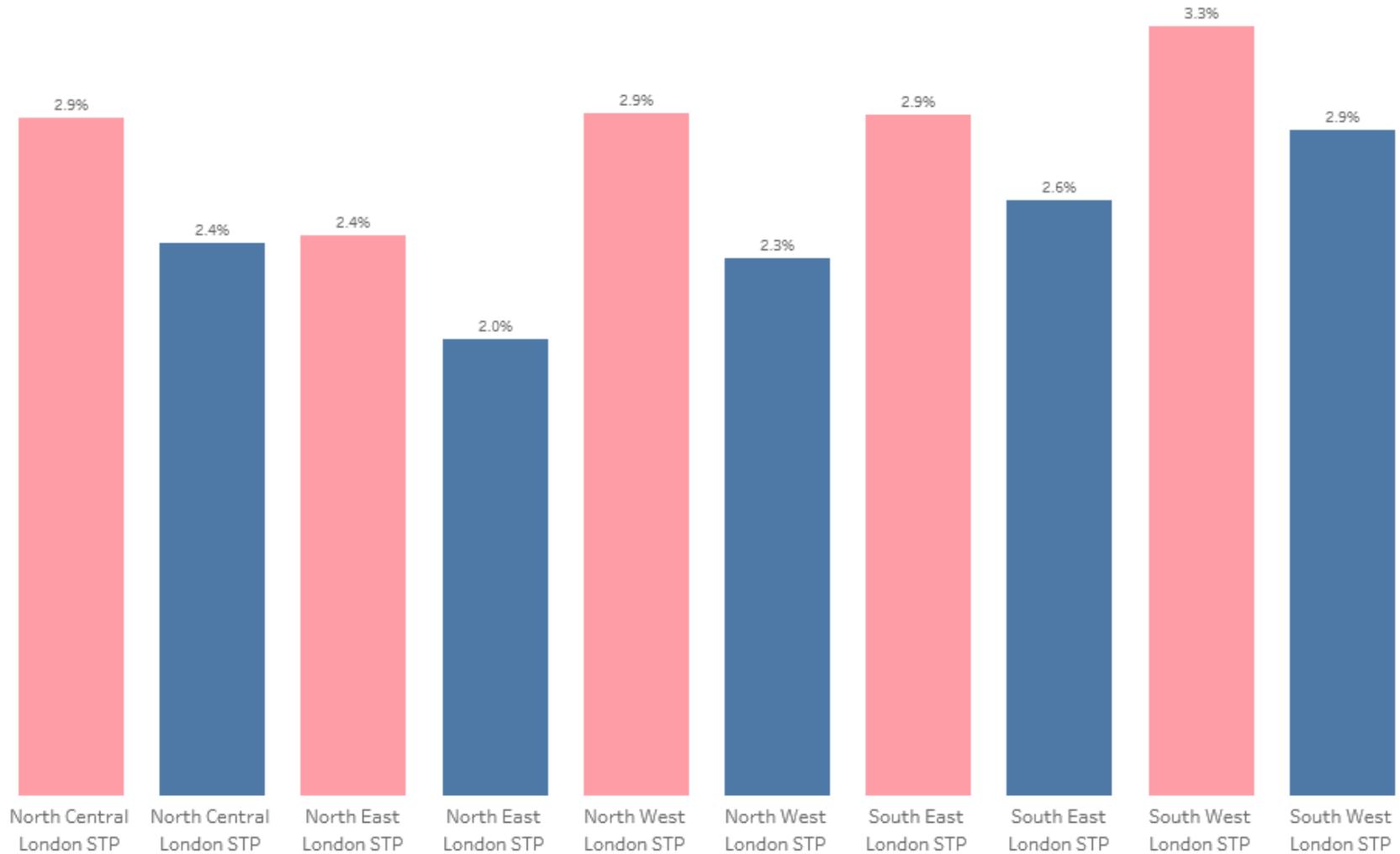
North Central London STP 93.3%

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

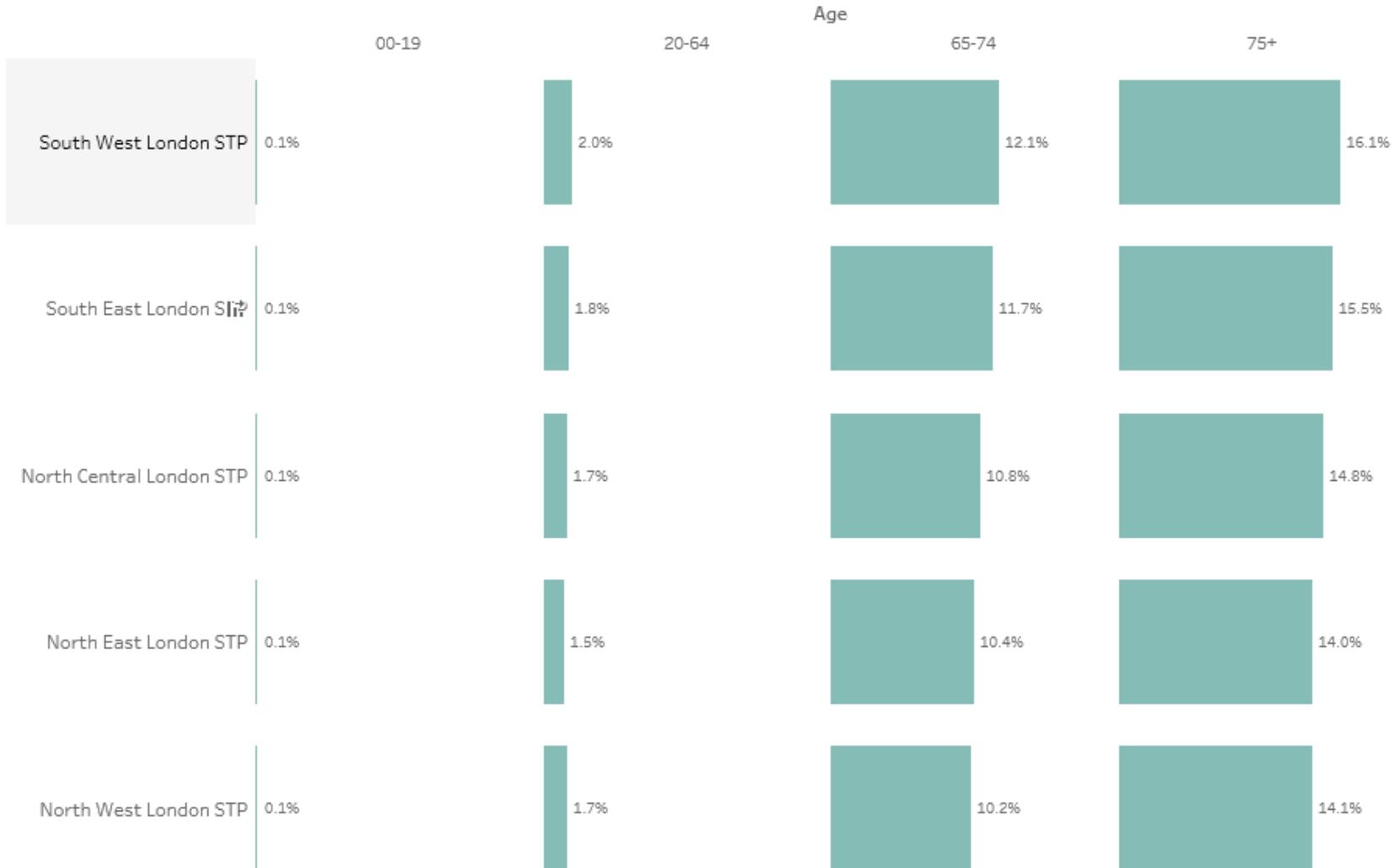


North Central London STP 4.5%

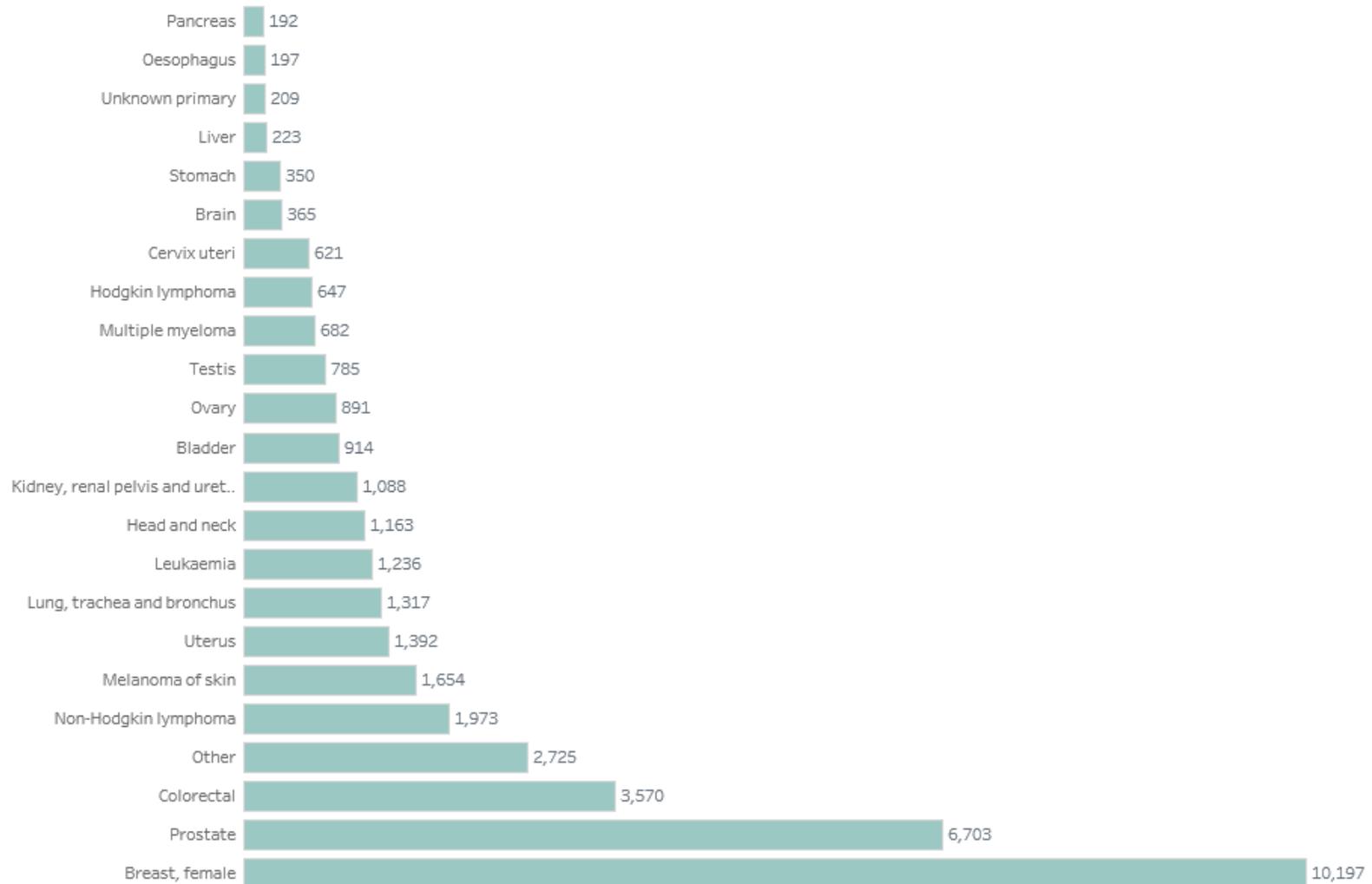
People Living With or Beyond Cancer by STP and sex



People Living With or Beyond Cancer by STP and age

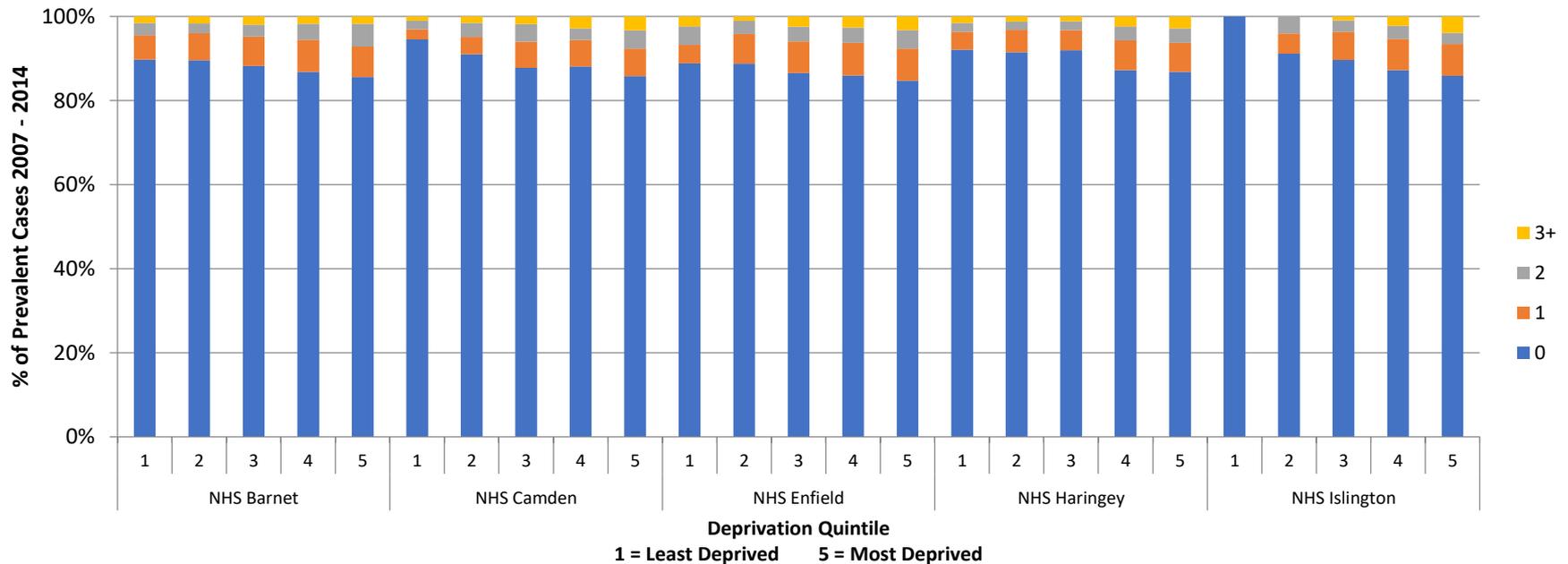


People Living With or Beyond Cancer in NCL by cancer site



Comorbidities in North Central London: Charlson Score

% of prevalent cases in London (patients) diagnosed between 2007 and 2014 and alive at the end of 2014, grouped by Charlson Comorbidity Index Score grouped into categories of 0, 1, 2, 3+



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 % of patients with comorbidities also increases with increasing deprivation. The highest % with a comorbidity score >0 occurs in the most deprived groups in Barnet and Enfield.

02

National Cancer Patient Experience Survey 2018: North Central London

National Cancer Experience Survey 2018: NCL

NCPES question	NCL STP	Barnet CCG	Camden CCG	Enfield CCG	Haringey CCG	Islington CCG	National average
Q13 Were the possible side effects of treatment(s) explained in a way you could understand?	69.18	68.91	66.81	66.95	72.51	72.04	73.11
Q14 Were you offered practical advice and support in dealing with the side effects of your treatment(s)?	62.48	62.53	64.06	58.36	64.85	64.76	67.11
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?	51.18	51.77	47.89	47.69	56.17	53.23	56.10
Q20 Did hospital staff give you information about support or self-help groups for people with cancer?	83.96	85.71	88.65	79.27	83.50	83.05	86.47
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)?	78.31	79.09	80.13	78.48	75.27	78.21	82.90
Q35 During your hospital visit, did you find someone on the hospital staff to talk to about your worries and fears?	45.83	50.00	53.33	36.26	45.54	47.13	52.66

National Cancer Experience Survey 2018: NCL

NCPES question	NCL STP	Barnet CCG	Camden CCG	Enfield CCG	Haringey CCG	Islington 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?	60.74	61.80	54.19	61.28	61.03	63.41	70.90
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?	54.40	57.11	53.80	54.23	52.82	50.92	60.29
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)?	40.27	41.15	40.37	37.13	42.50	40.54	52.54
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)?	34.54	35.71	41.79	31.93	33.75	30.26	44.69
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?	52.50	51.43	55.56	42.72	53.41	63.40	59.21
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?	50.40	51.09	51.79	47.55	49.19	53.59	61.39
Q55 Have you been given a care plan?	30.87	30.45	30.39	28.95	33.51	32.50	35.09

03

Personalised Care and Inequalities in North Central London

Inequalities in NCL

Levels of ethnic diversity vary across NCL, ranging from 32% of people in Islington from a Black and Minority Ethnic (BME) group to 42% in Enfield. The largest BME communities in NCL are Turkish, Irish, Polish and Asian (Indian and Bangladeshi) people. 'Overall, around a quarter of people in NCL do not have English as their main language.'

Areas of significant deprivation – 3/5 boroughs – Islington, Haringey and Enfield rank amongst the 20% most deprived local authority areas in the country. There is a wide spread of deprivation across NCL, but people tend to be younger and more deprived in the east and south.'

There are stark **inequalities in life expectancy**; for example, men in the most deprived areas of Camden live on average 10 years fewer than those in the least deprived areas

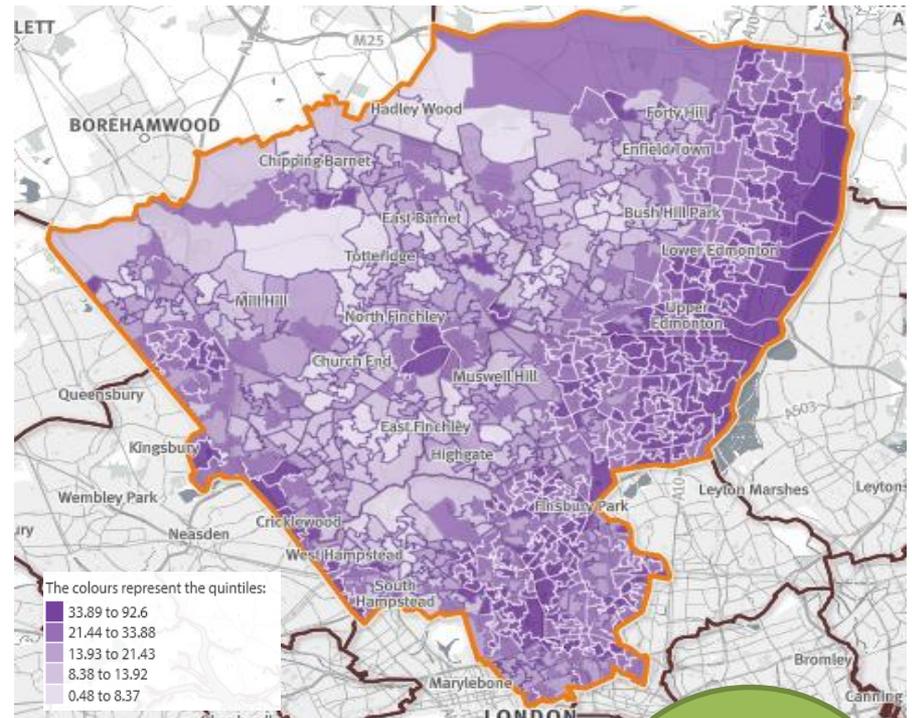
Drugs and alcohol – opiate and crack users estimated at 9798 in NCL using 2016-17 data (highest number in Islington with n= 2308 people)

People with SMI – There are an estimated 21,000 people in NCL with severe mental illness

Street homeless persons on CHAIN count n=1238 in NCL with highest number in Camden by far at n=702 (people seen living rough in boroughs, in the year).

Full inequalities toolkit:

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



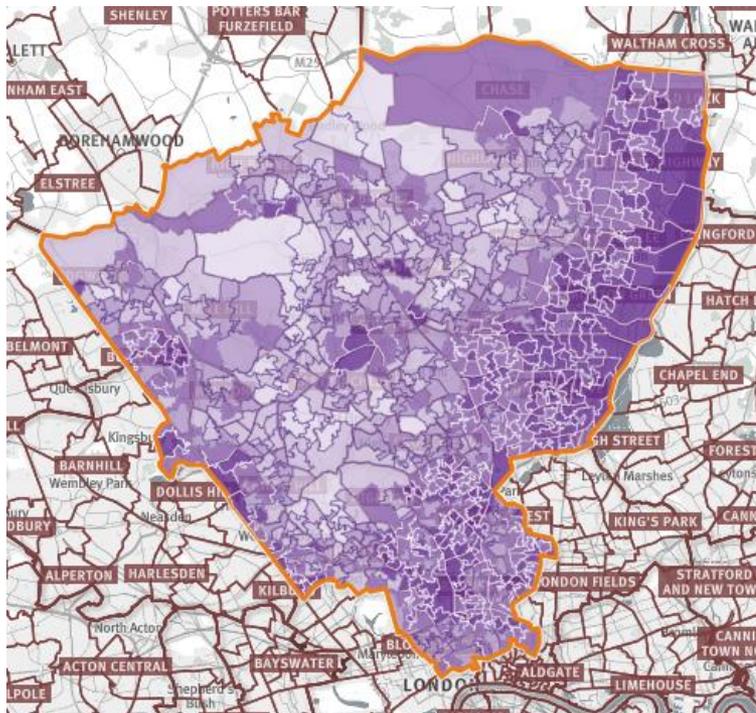
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Source: SHAPE <https://shapeatlas.net/place/>

1.4 million
people
living in
NCL

One prison – HMP Pentonville (Local prison holding 1256 men) in Islington

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



✓	GP	The Village Practice, London	56.88
✓	GPb	Broadwater Farm Community Health Centre, London	56.63
✓	GP	Tottenham Health Centre, Tottenham	55.14
✓	GP	Morris House Group Practice, Tottenham	52.50
✓	GP	Chalfont Road Surgery, Edmonton	51.72
✓	GP	Rainbow Practice, Edmonton	51.72
✓	GP	Boundary Court Surgery, Edmonton	51.72
✓	GP	Evergreen Primary Care Centre, London	51.72
✓	GP	Keats Surgery, Edmonton	50.00
✓	GP	The Rise Group Practice, London	49.45
✓	GP	The Beaumont Practice, Hornsey Rise	49.45

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.

Source: SHAPE atlas <https://shapeatlas.net/place/>

Where is the deprivation in North Central London?

Which top ten GP practices/PCNs working in most deprived areas would we focus our efforts on in NCL?

Summary of Personalised Care and Inequalities in NCL

Comorbidity in cancer patients in NCL is highest in older people, and deprived groups in Barnet and Enfield



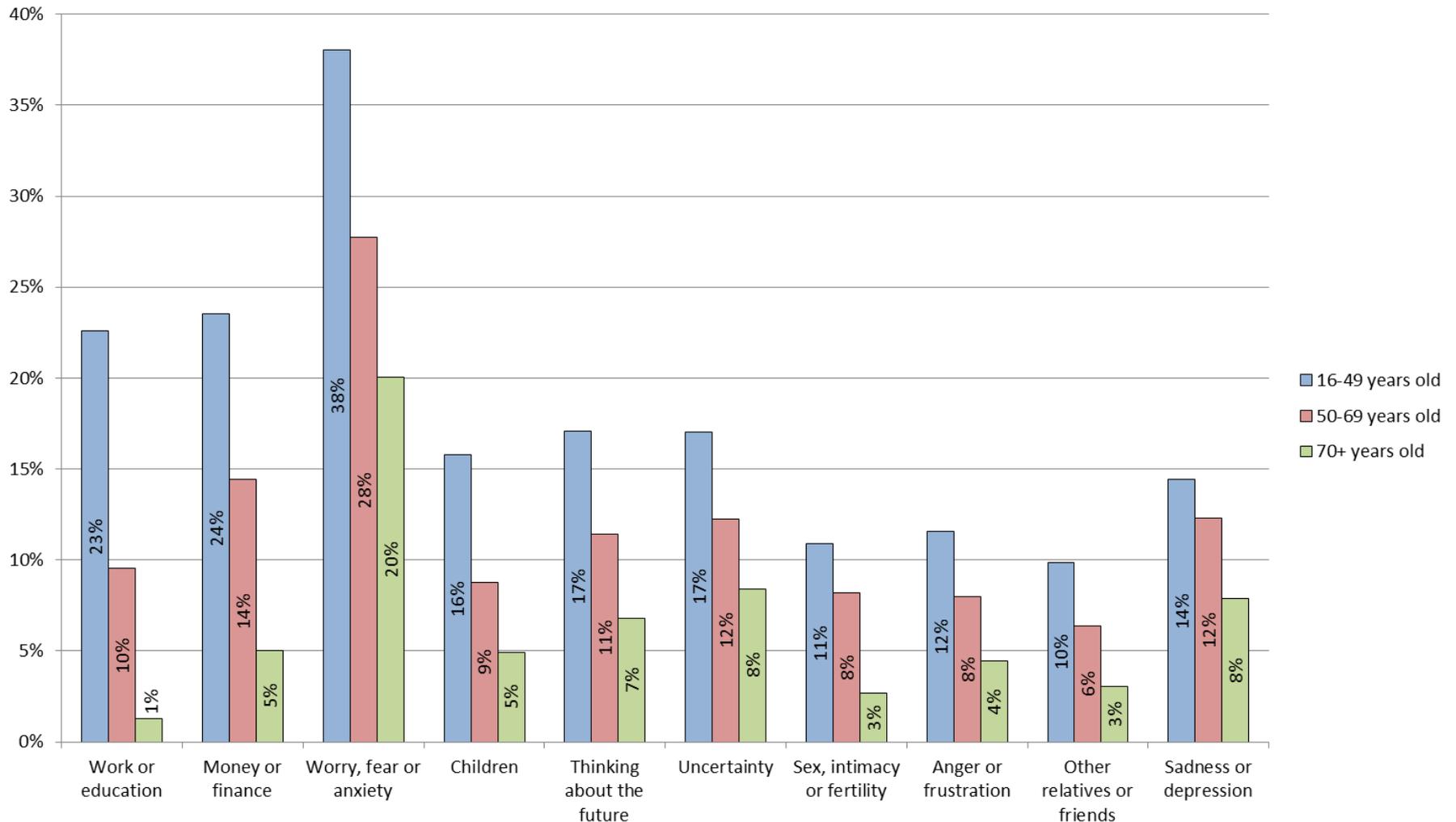
Household bills arrears are high in Enfield and Haringey

04

E-HNA data: London

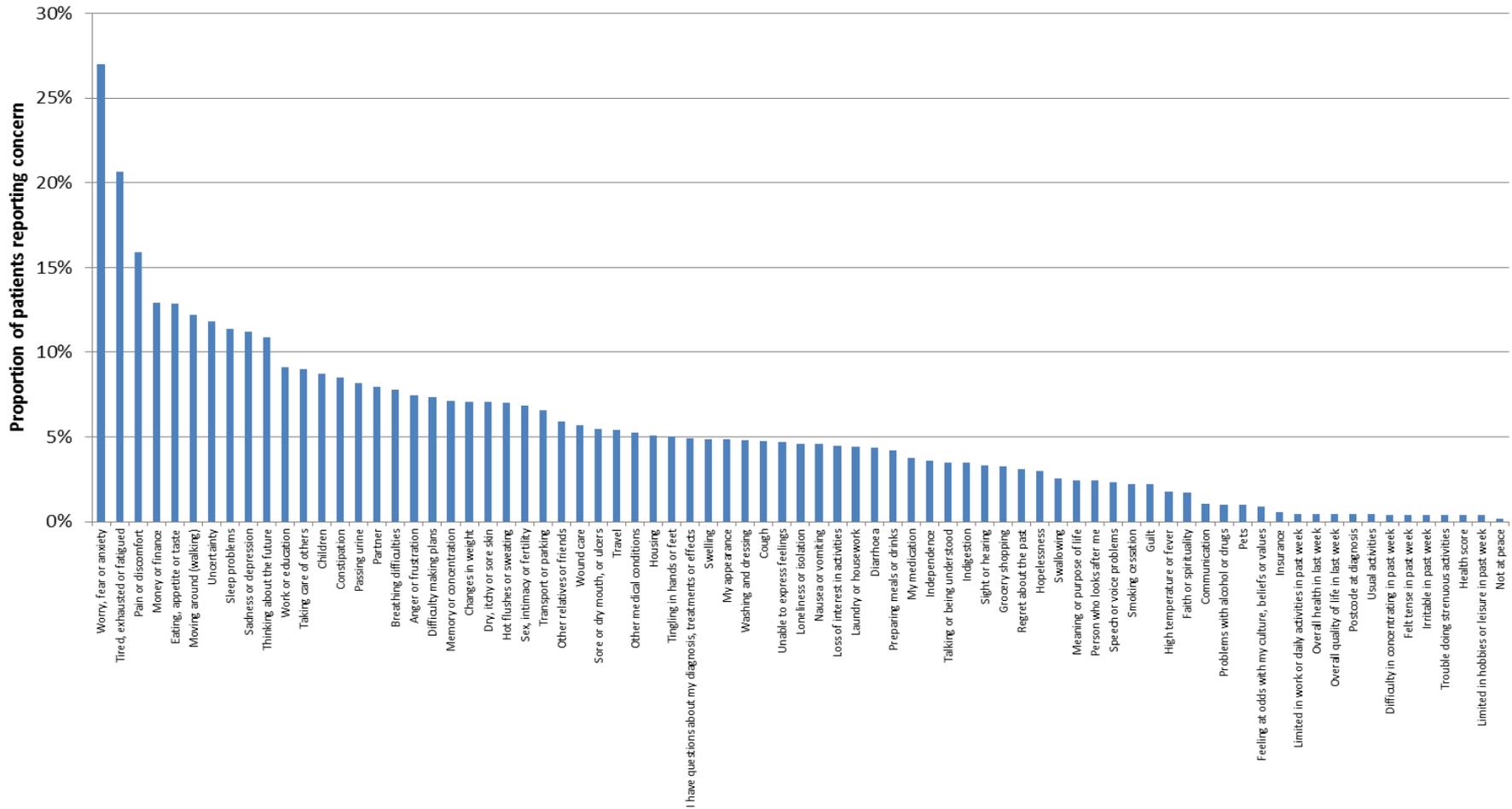
E-HNA Data for London: Top Ten Concerns

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 North Central 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**

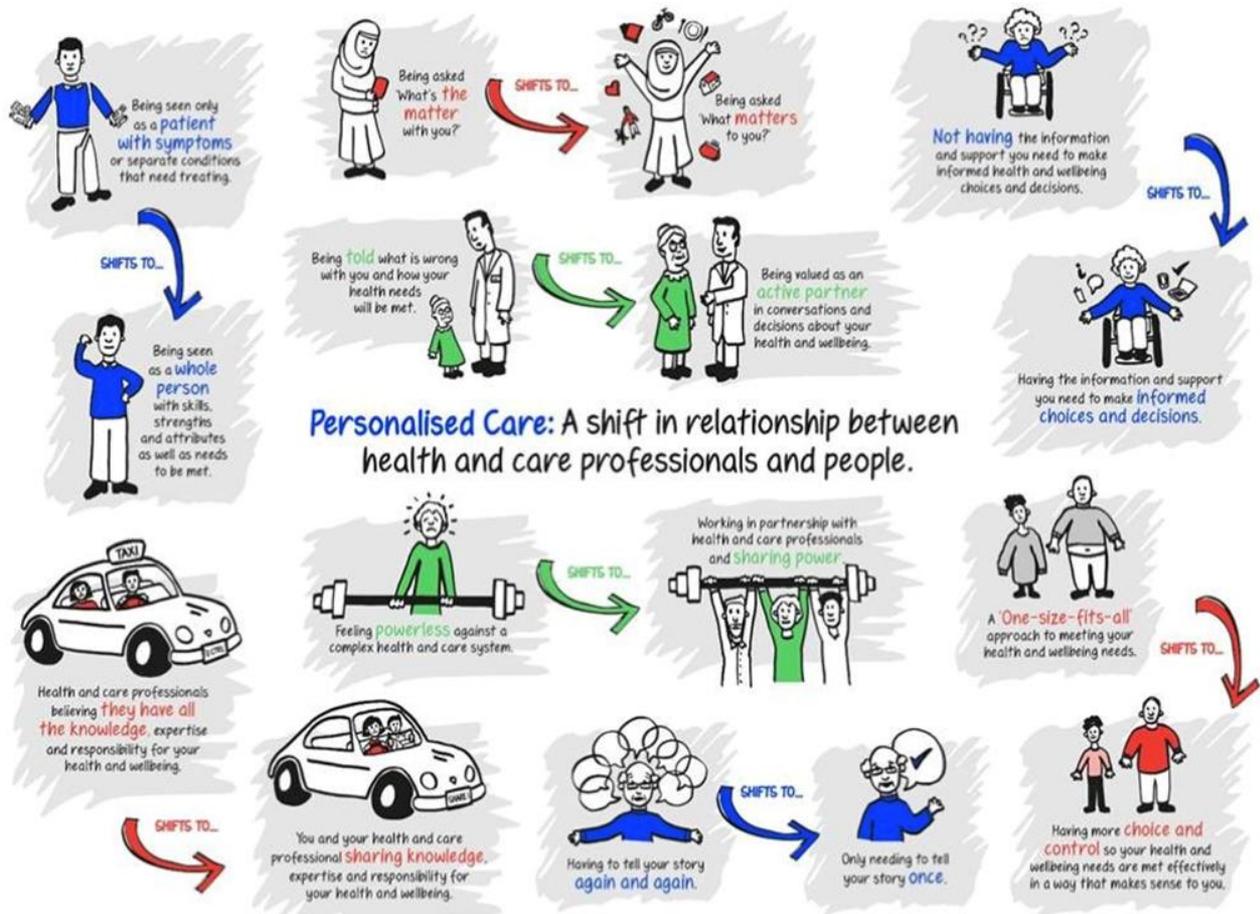
- All patients will have access to personalised care interventions – needs assessment, care plan, health and wellbeing information, and access to the right care and support – by 2021.
- Follow up based on patient needs (stratified follow-up) for all breast cancer patients by March 2020 and all prostate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

From 2021, the new **Quality of Life (QoL) Metric** will be in use locally and nationally. The NCEL Cancer alliance is one of five cancer alliances participating in the national evaluation.

Use local QoL data to inform service improvements .

2020 onwards -Develop access (primary and/or secondary) to Lymphoedema services across the NCL footprint.

Cancer rehab pathways in place to manage the consequences of treatment

Ensure appropriate psychological support is commissioned and develop business case

Ensure appropriate AHP/rehab support and develop case to invest in rehab services pending findings of rehab mapping project

Recommendations for Personalised Care in NCL: 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) Increasing demands on services and insufficient capacity have been identified as challenges across NCL.

2) For example: Royal Free Hospitals NHS Foundation Trust provides the Oncology Psychological Support Service with limited staffing to cover 3 sites at Barnet Hospital, Chase Farm Hospital and Royal Free Hospital.

Recommendations for Personalised Care in NCL: 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/>

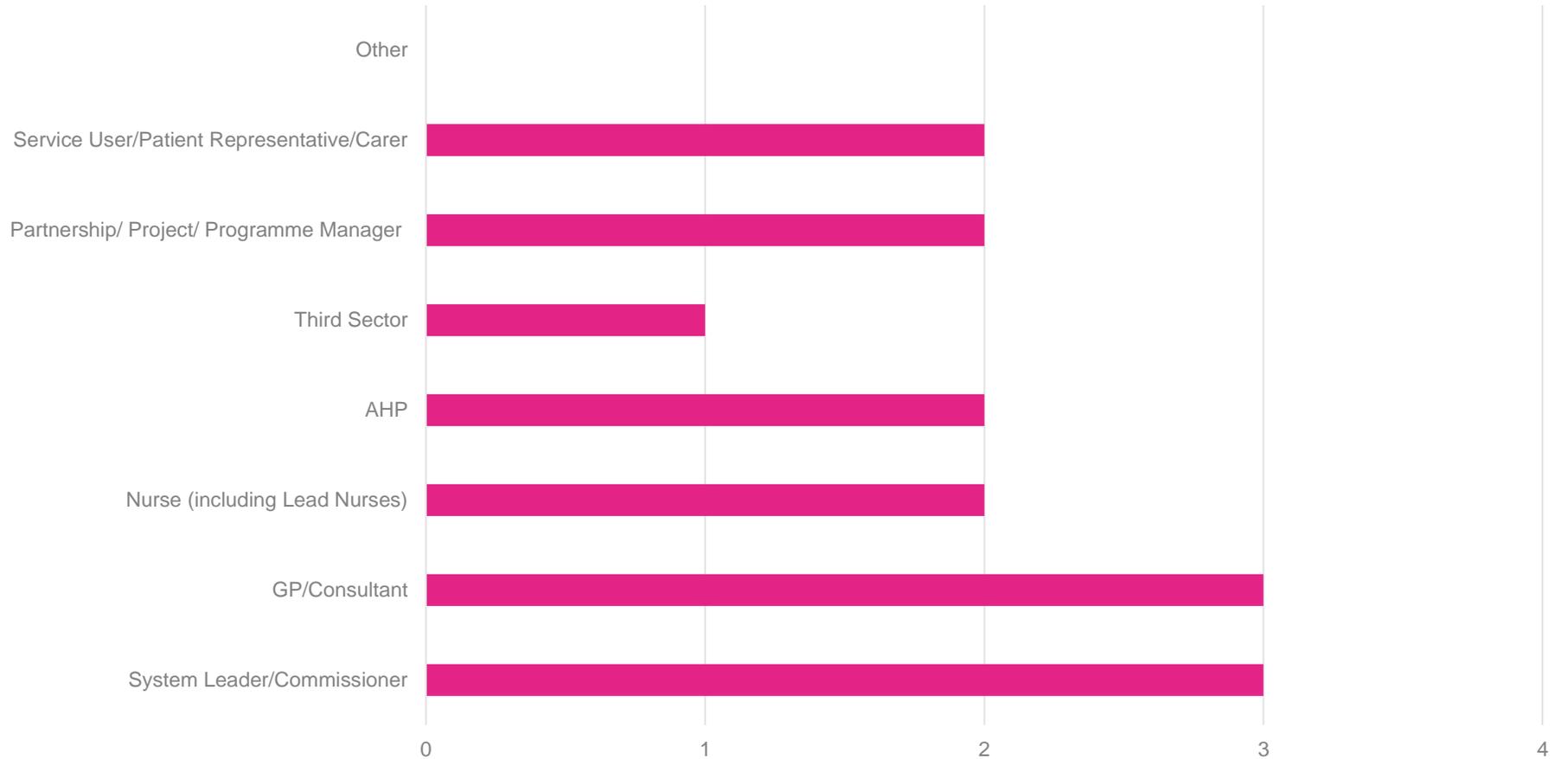
06

Personalised Care for Cancer

Next Steps Update: Actions and Succession Planning -North Central London

North Central London STP Table Discussion: Who attended?

STP Representation from North Central London



North Central London STP Table

Discussion: Personalised Care for Cancer

	Strategic	Operational
Strengths	<ol style="list-style-type: none"> 1. The presence of the Community Link worker network 2. Clinical leadership and Support from TCST: In January 2020, Dr Philippa Hyman and Dr Karen Robb from TCST presented at NCL Cancer Commissioning Board. Explained the psychosocial support and cancer rehabilitation workstreams work to date and gave strategic direction on how apply and implement the projects in NCL. 3. Strong evidence base for integration of the four workstreams into cancer pathways. 4. Pockets of excellent services which enables shared learning. 5. Considerations of if the resources work at the same level across the patch. 	<ol style="list-style-type: none"> 1. In-house Macmillan psychologists for patients with established cancer diagnosis. 2. Governance being set up with Personalised Care Board: inaugural meeting held on 5 Feb 2020. 3. To set up T&F group – what does it mean for NCL and development of 1-5-year strategy in personalised care 4. Onco-physio programme in talks to be cascaded across NCL 5. Prehab – doing motivational interviewing and Macmillan pre-rehabilitation document produced 6. Approved Business Case and strong senior management buy-in for lymphoedema services: Setting up lymphoedema T&F group to develop, plan how to commission lymphoedema services across the patch with a deep dive on the new Barnet service
Gaps	<ol style="list-style-type: none"> 1. In terms of cancer rehab: health care professionals do not have specialist cancer expertise or support time. <p><u>The role of social prescribers</u></p> <ol style="list-style-type: none"> 1. Do we have social prescribers across the patch? Have social prescribers got capacity, skills, knowledge and experience to be involved in carrying these projects forward in the future? 2. Have we approached the third sector to become social prescribers? 	<ol style="list-style-type: none"> 1. 'Move for you' patients and groups – how can they access cancer rehabilitation <p><u>Huge gaps in Lymphoedema services</u></p> <ol style="list-style-type: none"> 1. No consistent services across NCL, which has led to an inequality of service provision and funding. Some of large trusts don't have lymphoedema provision e.g. Barts, Royal Free London. 2. Need a community service in place to pick up both from secondary care. 3. One practitioner service/lone working: heavy pressures on workforce capacity and management capacity to deliver quality care due to every changing political and operational environment. 4. Lack of education/awareness for patients and health care professionals. Patients are unaware of how to access services

North Central London STP Table

Discussion: Personalised Care for Cancer

	STP focussed	Pan London
Opportunities	<ol style="list-style-type: none"> 1. Setting up Task & Finishing group to determine where the need and willingness to support and fund personalised care for people affected by cancer in the patch; spotlighting on primary care nursing, psychosocial support, cancer rehabilitation and lymphoedema. 2. Finding partners to work with on STP initiatives and projects to support workstreams in NCL 	<ol style="list-style-type: none"> 1. Culture change to enable staff to have protected time to attend training. 2. Upskilling nurses- Education for Primary Care Nurses and GPs to be equipped to deal with issues including supporting people with disabilities 3. Provision of transportation for people affected by cancer. 4. 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. 5. Supporting primary care to understand the barriers in cancer care.
Concerns	<ol style="list-style-type: none"> 1. Practice nurses with population 2. Larger practice will have more staff and can release staff for education – will be harder for smaller practices. Not all practices have cancer patients – issues with access 3. Difficulty re time/cost for staff to travel for training/education 4. Services available in most of NCL, although services not robust enough to manage capacity 	<ol style="list-style-type: none"> 1. Inconsistent approach: Reactive rather than pro-active approach to planning, strategising and implementing programmes 2. Less funding from the third sector. 3. Lack of integrated IT systems. 4. Access issues into primary care especially getting an appointment with the GP. 5. Lack of holistic view of patients and considering unique family situations and circumstances. Patients don't always feel part of the decision-making process. 6. Workforce issues: general practice can have one nurse each which reduces the opportunity for training and can lead to retention issues. 7. Communications barrier between primary care and secondary providers and community teams.

Agreed Actions: Primary Care Nursing Project

1. Develop and deliver a communications and inequalities strategy to target primary care nurses and its population.
2. Develop a plan to continue influencing cancer as a long-term condition and how services can deliver a more holistic approach to maximise resources across the STP footprint; which includes rolling out Cancer Care Review and developing standard operating procedures to ensure patients are aware they are having a Cancer Care Review.
3. An education strategy to deliver an education course through Primary Care Networks and use different forms of technology to deliver training e.g. webinars and e-learning (desk based) modules.
4. Engaging patients through co-design and co-production: Winning hearts and minds and the Patient and Public Group. This will lead to culture change and help the dissemination of information.
5. Maximise the role of Primary Care Networks; which should include evaluating the role of Health Care Assistants and Social prescribers in primary care networks and develop a cancer lead clinical nurse practitioners for each Primary Care Network.

North Central London STP Table Discussion: Personalised Care for Cancer

Agreed Actions: Psychosocial Support

- ❖ Explore gaps in community services in psychosocial support in the area.

TCST Response: To achieve the above action the STP will need to clearly identify when a person affected by cancer requires a generalised service such as IAPT or a cancer psychological specialist (psycho-oncology teams). Localising the integrated pathway for cancer psychosocial support will be the first step in achieving this.

- ❖ Demand and capacity planning for access to psychosocial support services for people living with and beyond cancer.
- ❖ Create a shift in philosophy to build and facilitate links between mental health clinicians and acute medical clinicians.
- ❖ The co-production of the patient support networks with people living with and beyond cancer and their families. This could include working with families to promote and implement more holistic care in psychosocial from the beginning of the pathway.

Agreed Actions: Cancer Rehabilitation

1. Locally commissioned services for patients affected by cancer with increased and continued dialogue between patient and health care professional.
2. Develop a provider-based model to have a dedicated rehab team for 1:1 service with open referral routes and develop services to reduce barriers to access e.g. financial, access to transportation etc. For example, engage local authorities to make gym available to patients affected by cancer.
3. Training and education for GPs, HCP and patients- all professionals need to check in regarding provision of rehab and take responsibility. At diagnosis, a letter should be sent to both GP and patient to talk about benefit of exercise.
4. Deliver pre-rehab services in the community setting and maximise different ways to engage and prepare patients for treatment. These could be done through patient's Holistic Needs Assessment. Health and wellbeing events could address these issues.

Agreed Actions: Lymphoedema

1. Focus on Barnet's service and launch the service in 2020/21.
2. Pathway analysis- develop a system where there will be a direct flag for referrals. To ensure secondary care and community services are working together on patient flow; where secondary care diagnose lymphoedema and pass over to community service for further treatment.
3. Develop a system where there will be joint working between CCGs to take work forward on lymphoedema for both cancer and non-cancer patients.
4. Develop a patient education/support programme-this should empower patients and promote self-management. This will depend where patient is on their journey and pathway. It could happen at prehab and health and wellbeing events.
5. Raising awareness of lymphoedema with GPs and primary care health professionals.

North Central London STP: Peer Feedback

- ❖ The STP should develop SMART goals and actions to achieve these proposals.
- ❖ Raising Lymphoedema awareness could be extended to Allied Health Professionals and a cost impact analysis could also be conducted.

TCST Response: A template business case from 2017 has been produced for Lymphoedema services and the new Lymphoedema commissioning guidance has case studies which show the cost benefits.

- ❖ Focus groups and peer support networks should be set up to achieve the above proposals.

Some comments from attendees:

Chance to plan together as NCL and hear from patients

Getting everyone up to speed on how we got to where we are and developing NCL commitments to take forward

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

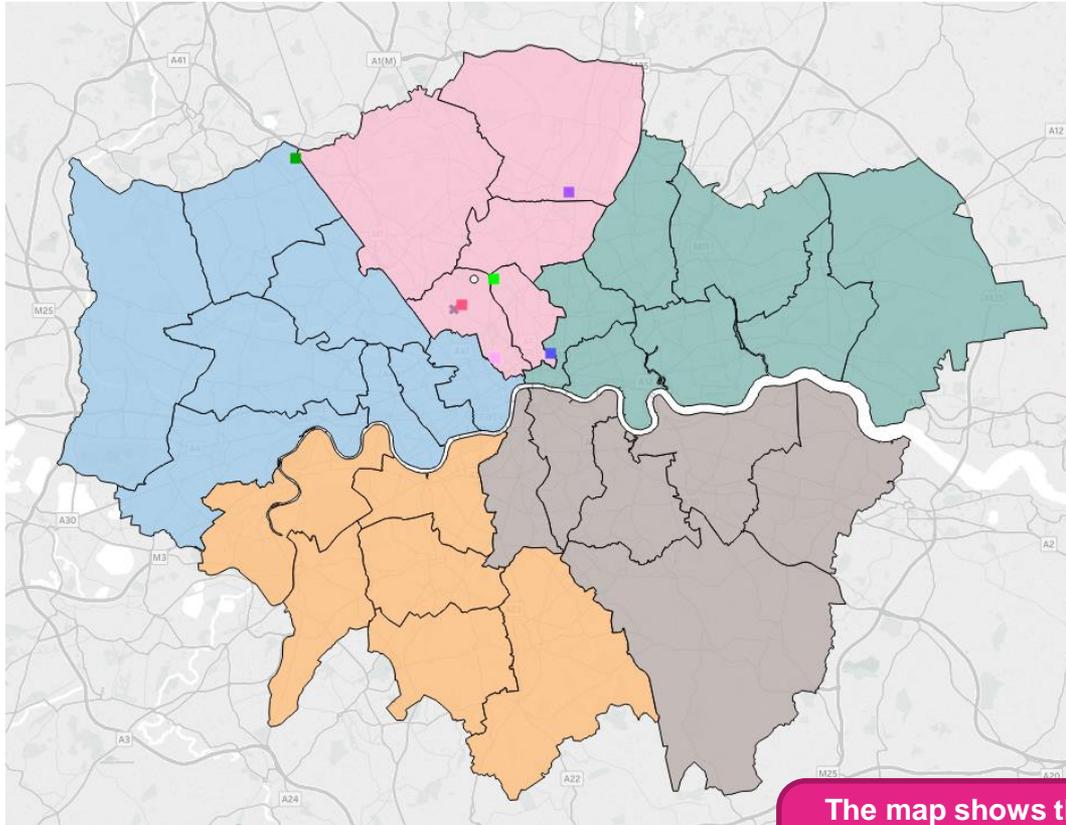


Cancer Rehab and Psychosocial support

07

Key Contacts and Resources in North Central London: Personalised Care for Cancer

Cancer Rehabilitation: Key Resources



The map shows the cancer rehabilitation services in North Central London.

Service Provider

- Marie Curie Hospice Hampstead
- Moorfields Eye Hospital NHS Foundation Trust
- North Middlesex Univeristy Hospital NHS Trust
- Royal Free London NHS Foundation Trust
- Royal National Orthopaedic Hospital NHS Trust
- University College London Hospitals
- Whittington Health

Type of provider

- Acute Trust
- Hospice

- **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.

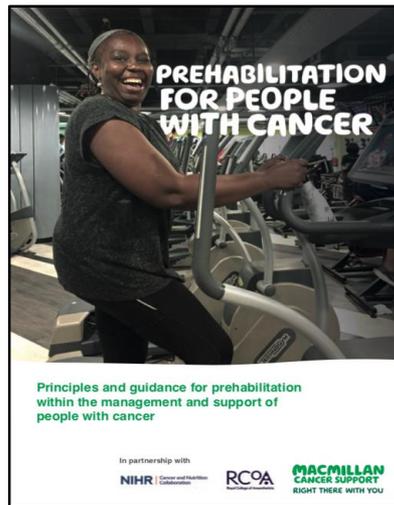


<https://www.csp.org.uk/campaigns-influencing/campaigns/rehab-matters>



https://www.acsm.org/docs/default-source/files-for-resource-library/exercise-for-cancer-prevention-and-treatment-infographic.pdf?sfvrsn=ad47b1e1_2

<https://www.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

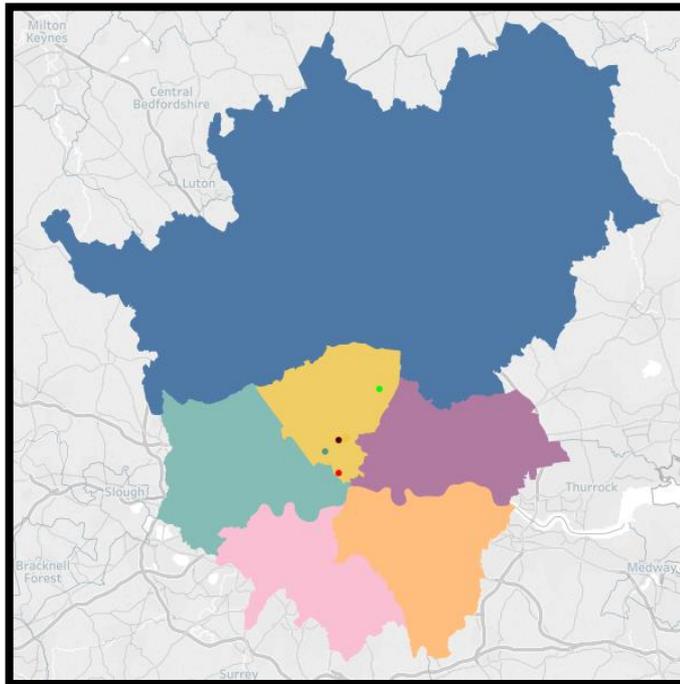
Exercise can help reduce side-effects of chemotherapy and amount of time spent in hospital, say doctors



<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	
	Enfield Macmillan Lymphoedema service
	Maggie's Centre Royal Free Hospital
	UCLH London NHS Foundation Trust
	Whittington Health NHS Trust

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

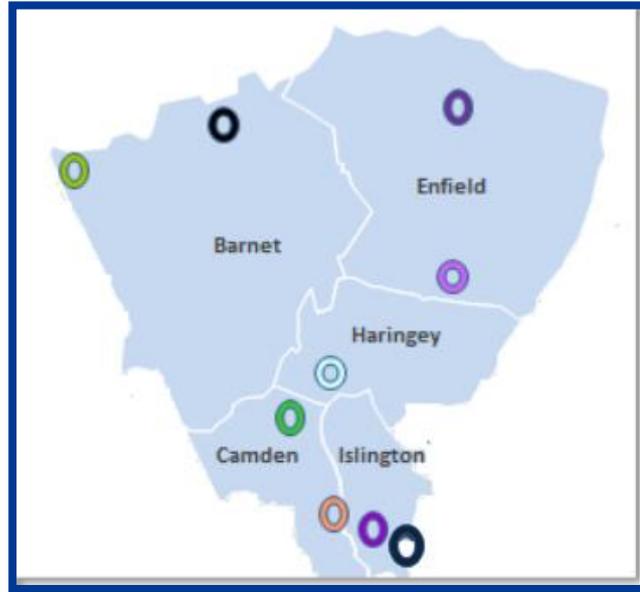
Business case

<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

- Royal Free Hospitals NHS Foundation Trust – Barnet Hospital
- Royal Free Hospitals NHS Foundation Trust – Chase Farm Hospital
- Moorfields Eye Hospital NHS Foundation Trust
- Royal Free Hospitals NHS Foundation Trust – Royal Free Hospital
- Royal National Orthopaedic Hospital
- University College London Hospitals NHS Foundation Trust
- North Middlesex University Hospital NHS Trust
- The Whittington Health NHS Trust

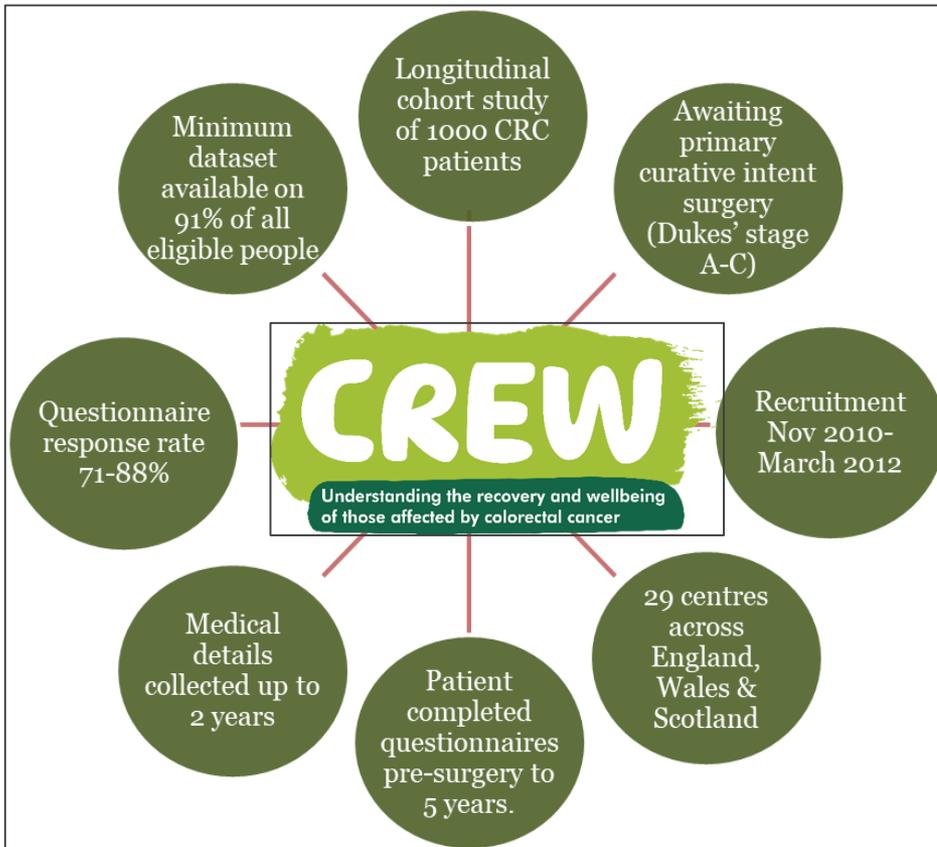
- Commissioning guidance
- Business case
- Service specification
- Service mapping

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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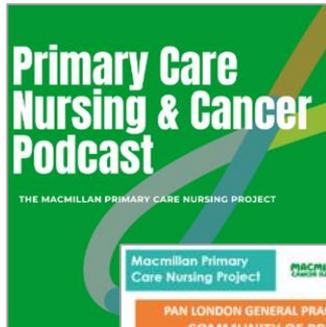
Primary Care Nursing: Key Resources

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



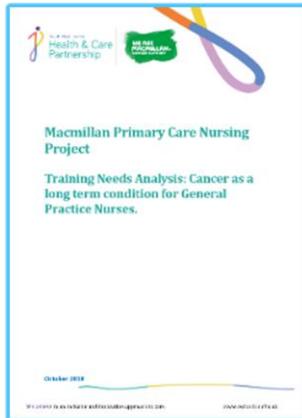
Primary Care Nursing: Key Resources

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 North Central London

Name, Job Title and Organisation	Email address
General	
Sharon Cavanagh, Personalised Care Programme Lead, NCEL Cancer Alliance	sharon.cavanagh@nhs.net
Cancer Rehabilitation	
To be confirmed	
Lymphoedema	
Kay Eaton, Consultant Nurse, Cancer and Supportive Care Clinical Lead for the Lymphoedema Service, University College London Hospitals NHS Foundation Trust	kay.eaton@uclh.nhs.uk
Psycho-social support	
(Mark Barrington, Consultant Clinical Psychologist, Barts Health NHS Trust)	markbarrington@nhs.net
Primary Care Nursing	
Macmillan is in discussion with colleagues in your STP to create a Primary Care/Cancer workforce lead (2 years fixed term), building on the work funded in South West London. The ambition is for one lead in each STP.	
Macmillan Cancer Support	
Jo Van Tijn, Macmillan Partnership Manager	jvantijn@macmillan.org.uk