NHS
Health Education England

MACMILLAN CANCER SUPPORT

Healthy London Partnership

Personalised Care Interventions Module 1

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Public Health England

NHS

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Introduction

Training content for managing cancer as a long term condition

Purpose

The content within these slides can be used and adapted for local use in Protected Learning Time and other training sessions on cancer as a long term condition.

This module is one of five – it can be used in isolation or as part of a wider training package. The modules are:

1. Personalised cancer care interventions
2. Holistic cancer care reviews
3. Consequences of treatment
4. Psychological support and rehabilitation
5. Social needs of people affected by cancer

Intended audience

- CCG clinical leads
- Macmillan GPs
- Primary Care Nursing Forum leads
- Training Hubs
- Social prescribing teams

Acknowledgements

The content contained within this module was co-developed with London clinicians from Transforming Cancer Services Team (part of Healthy London Partnership), Macmillan Cancer Support, Trusts and Primary Care.

When using these slides locally, please ensure branding includes Health Education England, Macmillan and Healthy London Partnership. Thank you

Aims and objectives

Aims

- Help improve understanding of the long term management of people affected by cancer

Objectives

- Introduce the changing story of cancer
- Explain the NHS Comprehensive Model of Personalised Care
- Explain the personalised care interventions for cancer
- Explain stratified follow up pathways and give examples of some models in London for breast, colorectal and prostate cancer pathways.
- Further information
    - ➢ Highlight online educational tools and resources that can enhance patient care

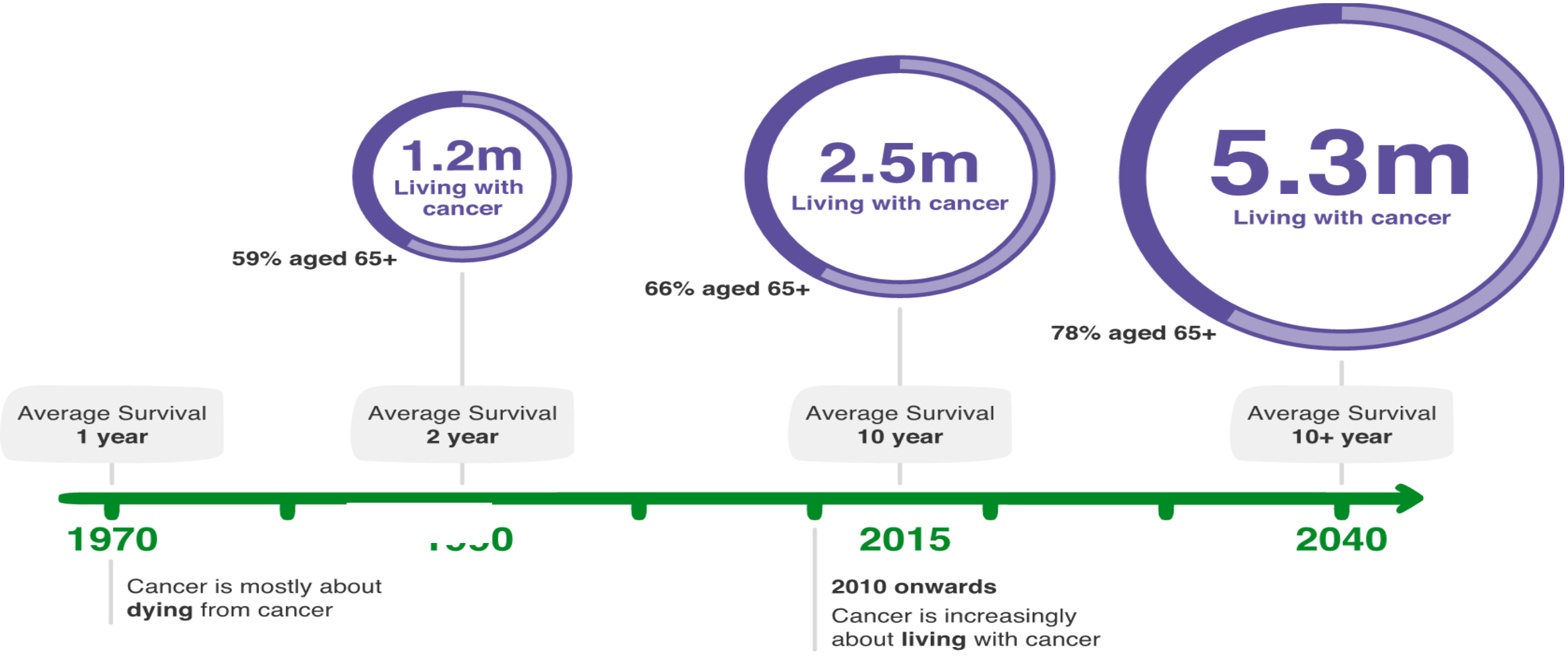
01

Background

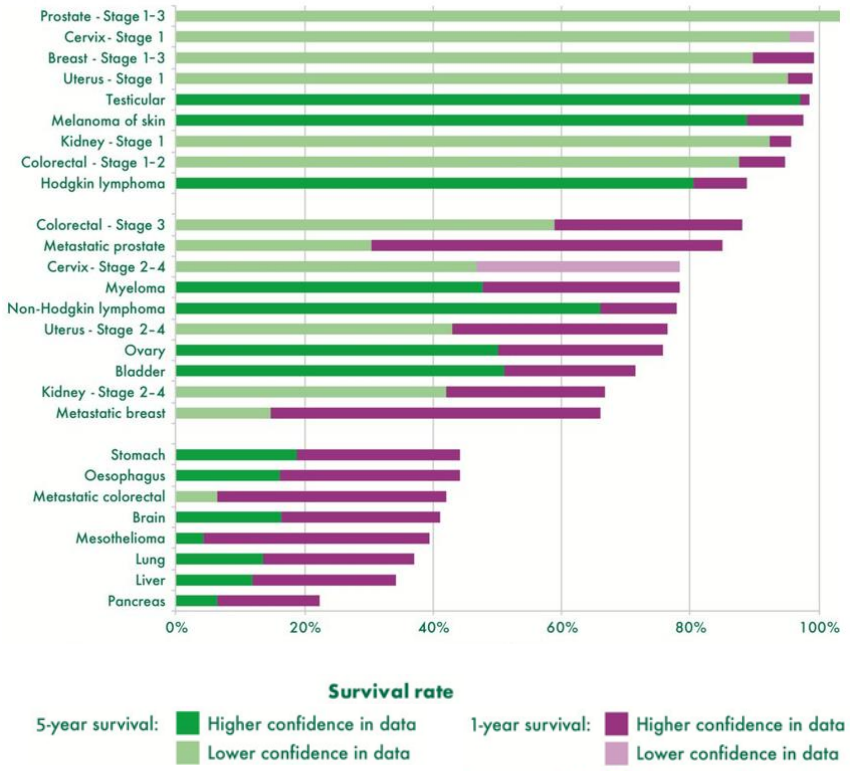
Key facts

- 1 in 2 people born after 1960 will get cancer in their lifetime (CRUK, 2015).
- In 2017, there were 231,000 people living with and beyond cancer in London (TCST/PHE, 2019).
- 53% cancer patients are living longer than 5 years and 44% more than 10 years (TCST/PHE, 2019) - improved survival results in a greater demand for services.
- 70% of people affected by cancer have at least one other long term condition (Macmillan, 2015). Living with another LTC reduces survival rates and adds complexity.
- 15 months after a cancer diagnosis (cancer treatment usually will be completed)), cancer patients are 60% more likely to attend A&E, 97% more likely have an emergency admissions and have 50% more contact with their GP (Nuffield Trust, 2014).
- The annual Cancer Patient Experience Survey shows that patients do not feel supported by primary care. Furthermore patient experience is generally worse in more derived areas. In London, people from BME groups report poorer experience than White groups (Macmillan, 2017).
- In addition to subsequent cancers, people are also at significant risk of consequences of their treatment, for example lymphoedema, heart disease, osteoporosis, depression, anxiety etc (Macmillan, 2013).

The changing story of cancer



Three cancer groups



Group 1
Many live for more than a decade

Group 2
Most similar to a long-term condition

Group 3
Survival for the majority is short term

McConnell, H. White, R. And Maher, J. *Explaining the different complexity, intensity and longevity of broad clinical needs*. 2015.

Half of people diagnosed with cancer live for longer than 10 years

Total prevalence:
2.5 million in 2015

Total prevalence:
4 million by 2030

Derived from Yip K, McConnell H, Alonzi R, Maher J; Using routinely collected data to stratify prostate cancer patients into phases of care in the UK: implications for resource allocation and cancer survivorship *Br J Cancer;* 2015; **112**: 1594–1602, doi:10.1038/bjc.2014.650 https://www.ncbi.nlm.nih.gov/pubmed/25791873 and Maddams J, Utley M, Moller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer. 2012. 107: 1195-1202.

Living beyond cancer does not mean living well

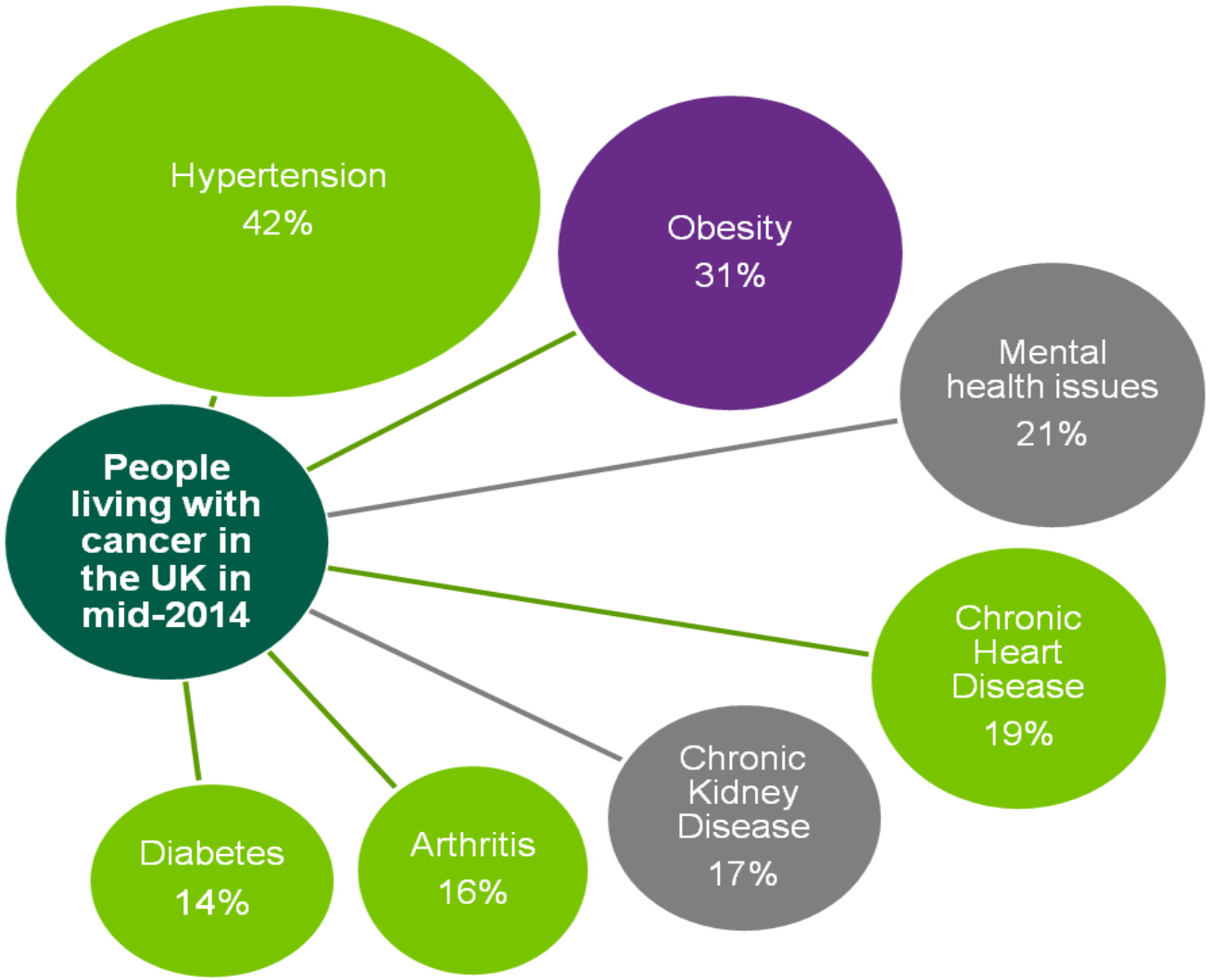
At least **1 in 4** of those living with cancer – around **625,000 people** in the UK – face poor health or disability after treatment[1]

Over 70% need emotional support[2] – research shows that 2 in 5 people living with cancer are affected by depression, and 1 in 10 experience anxiety[3]

4 in 5 people living with cancer experience a financial impact. The average is £570 a month.

[1]Macmillan Cancer Support. *Throwing light on the consequences of cancer and its treatment*. 2013 (1 in 4 people using estimated prevalence of 2.5 million)
[2]Macmillan Cancer Support. *Hidden at Home – The Social Care Need of People Living with Cancer*. 2015.
[3]Pitman A, et al. *Depression and anxiety in patients with cancer.* BMJ 2018; 361:1415.
[4]Macmillan Cancer Support. *No Small Change: Time to act on the financial impact of cancer.* 2012.

Cancer increasingly co-exists with other conditions



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Macmillan Cancer Support. *Cancer in the context of other long-term conditions. Scoping evidence review and secondary data analysis*. 2015.

At least 500,000 people in the UK experience long term health conditions caused by their cancer or its treatment

- 90,000 affected by gastrointestinal problems, such as faecal incontinence, diarrhoea and bleeding
- 350,000 experiencing sexual difficulties
- 150,000 with urinary problems
- 63,000 affected by lymphoedema
- 350,000 with chronic fatigue
- 240,000 living with mental health problems
- 80,000 living with hormonal symptoms

Macmillan Cancer Support. *Throwing light on the consequences of cancer and its treatment.* 2013. London

02

National Cancer Patient Experience Survey

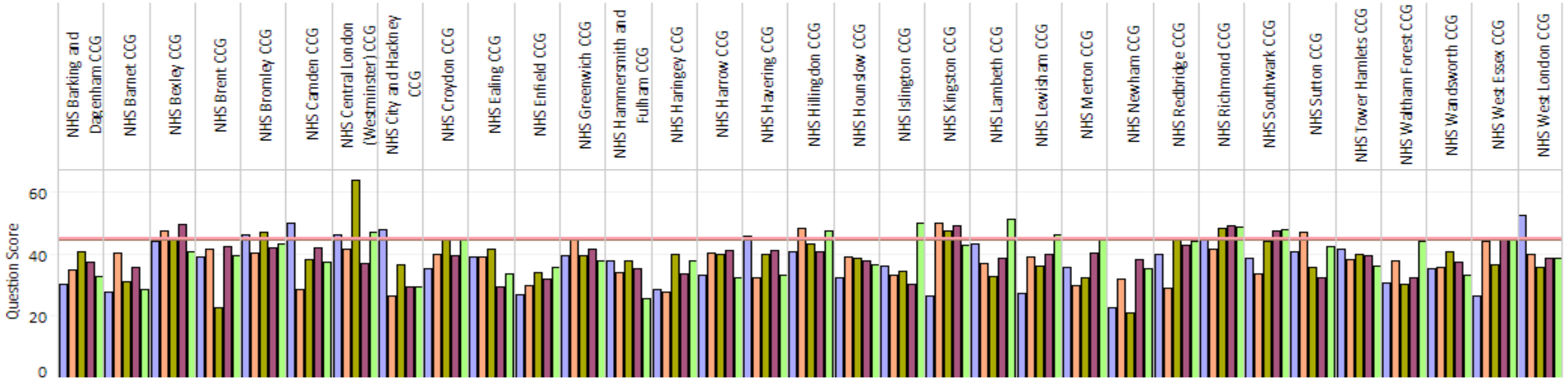
National Cancer Patient Experience Survey

includes questions on:
* Did primary care do everything they could to support you during treatment?
* Did health and social care do everything they could to support you after treatment ended?

National Cancer Patient Experience Survey 2015-2019

NCPES tells us that there is a difference between patient satisfaction of their stay in hospital compared to that of the support provided by primary and community care. Patient satisfaction with support following discharge is even worse. London continues to fall below the national average

Q53. 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)?



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National Cancer Patient Experience Survey 2015-2019

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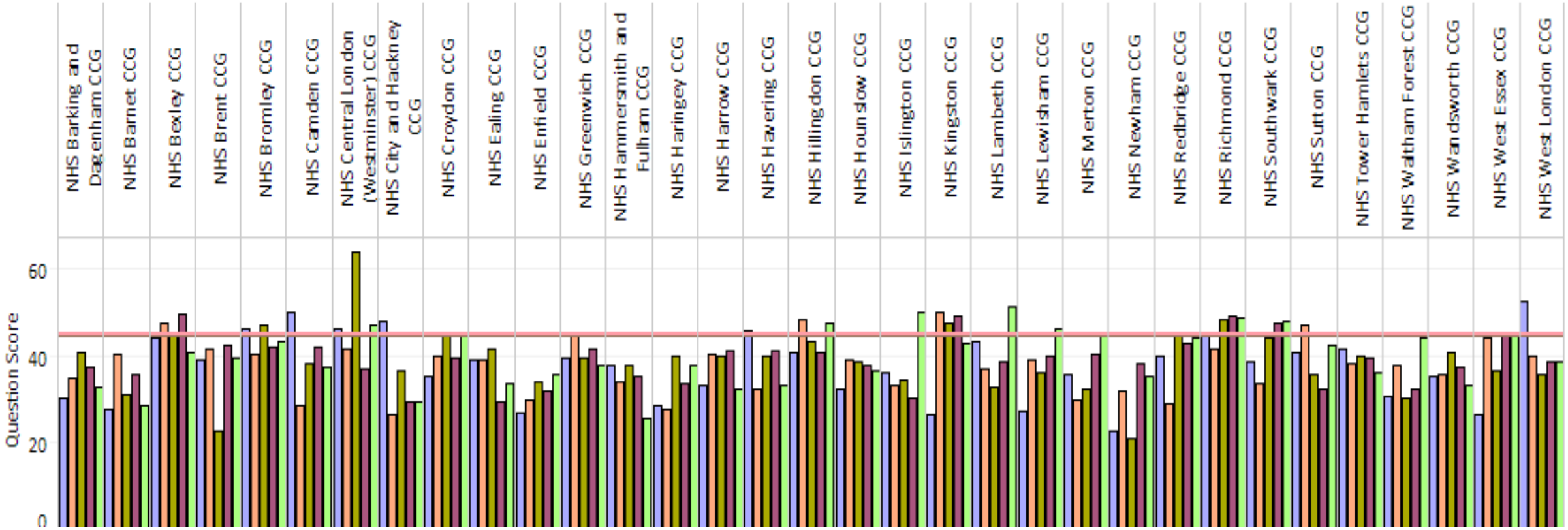


Credit: National Patient Experience Survey Time Series. Transforming Cancer Services Team for London 2015-2019. Source
https://public.tableau.com/profile/transforming.cancer.services.for.london#!/vizhome/NationalCancerPatientExperienceSurveyResults2015-2019London/Story1?publish=yes

03

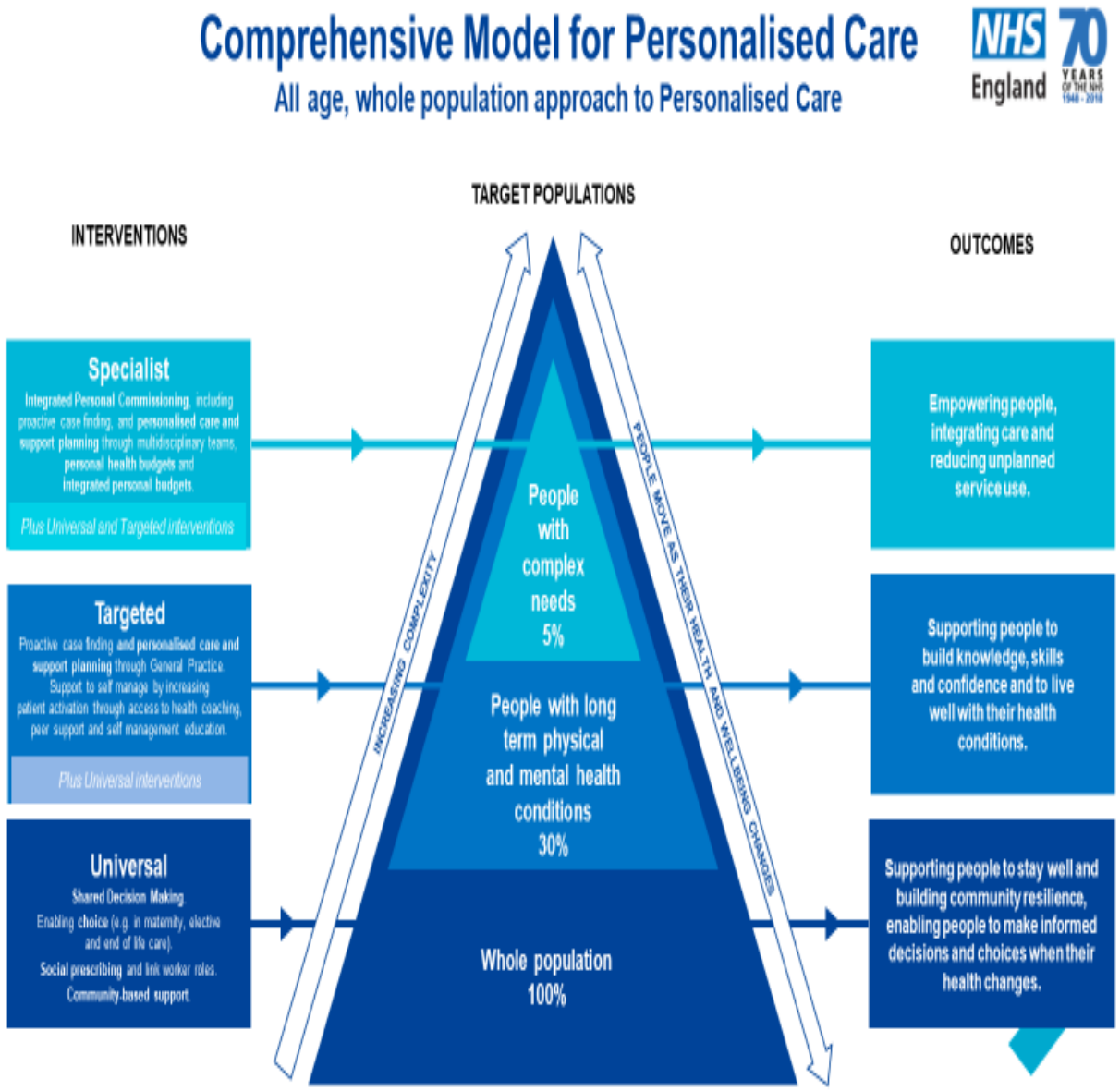
Cancer Personalised Care and its interventions

Comprehensive model for personalised care

Routine use of the personalised care tools

A combination of different interventions, which when delivered together, greatly improves the outcomes and coordination of care for people living with and beyond cancer. Interventions support people to self manage to the best of their ability.

Primary care should receive copies of the **Holistic Needs Assessments with an up to date care plan** (subject to patient consent) **and Treatment Summary** so that they can conduct holistic **cancer care reviews** and **personalised care reviews** to support patients to self manage.



Personalised care interventions in cancer (1)

Holistic Needs Assessments and Care Plans: ensures that people's physical, practical, emotional, spiritual and social needs are met in a timely and appropriate way, and that resources are targeted to those who need them most. An HNA is a simple questionnaire that is completed by a person affected by cancer

Personalised care interventions in cancer (2)

A Treatment Summary is a document (or record) completed by secondary care professionals, usually the multi-disciplinary team (MDT) after a significant phase of a patients cancer treatment. It describes the treatment, potential side effects, and signs and symptoms of recurrence. It is designed to be shared with the person living with cancer and their Primary Care Team .

Treatment Summary template

Treatment Summary
Insert GP Contact Details

Insert Trust Logo and Address

Dear Dr X,
Re: Add in patient name, address, date of birth and record number
Your patient has now completed their initial treatment for cancer and a summary of their diagnosis, treatment and ongoing management plan is outlined below. The patient has a copy of this summary.

Diagnosis:	Date of diagnosis:	Organ/Staging Local/Distant
Summary of Treatment and relevant dates:		Treatment aim:
Possible treatment toxicities and / or late effects:		Advise entry on to primary care palliative or supportive care register Yes / No DS1500 application completed Yes/No Prescription Charge exemption arranged Yes/No
Alert Symptoms that require referral back to specialist team:		Contacts for referrals or queries: In Hours: Out of hours:
Secondary Care Ongoing Management Plan: (tests, appointments etc)		Other service referrals made: (delete as necessary) District Nurse AHP Social Worker Dietician Clinical Nurse Specialist Psychologist Benefits/Advice Service Other
Required GP actions in addition to GP Cancer Care Review (eg ongoing medication, osteoporosis and cardiac screening)		
Summary of information given to the patient about their cancer and future progress:		
Additional information including issues relating to lifestyle and support needs:		

Completing Doctor: Signature: Date:

For more information, please see our *Treatment summmary and user guide* which can be ordered at http://be.macmillan.org.uk/be/s-689-recovery-package.aspx

Personalised care interventions in cancer (3)

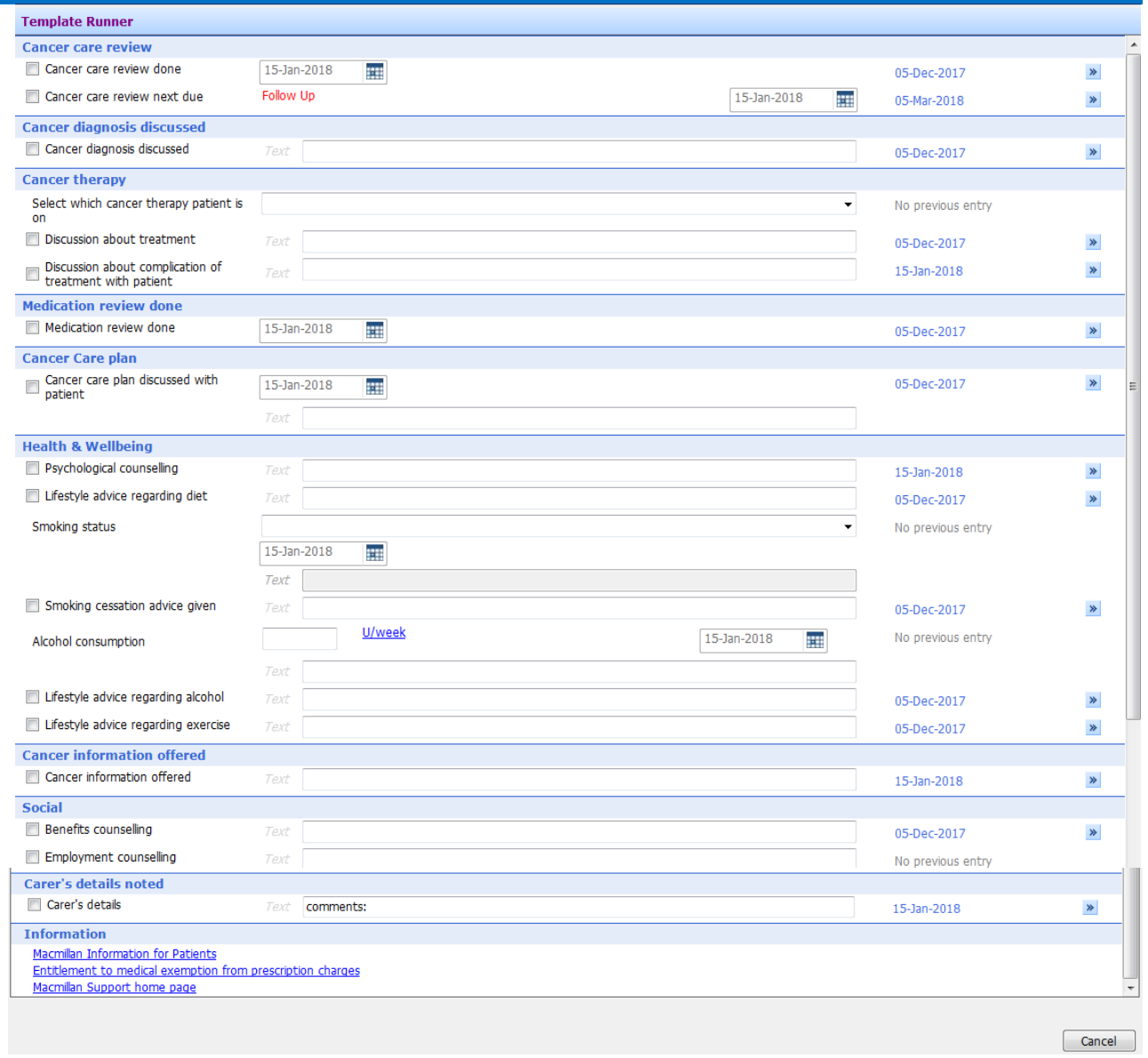
Health and wellbeing information & support: Education and information interventions to support and enable people living with cancer and their families to take control and participate in their recovery, giving them necessary information, and promoting positive lifestyle change such as nutritional advice and encouragement to increase physical exercise.

These might be 121 or group based interventions, such as holistic needs assessment clinics, end of treatment clinics, HWB events, Information & Support Centres (e.g. Macmillan, Maggies etc).

Personalised care interventions in cancer (4)

Cancer care reviews (CCRs) are undertaken in primary care the aim being to identify unmet needs and offer support. These can be carried out by a Practice Nurse or GP.

As part of this training resource, there is a separate module dedicated to CCRs.



What is stratified follow-up ?

- Self-management in safe & supported manner (patients with lower risk of recurrence and late physical and psychosocial effects)
- Improved patient experience by eliminating anxiety and stress
- Rapid re-entry into the specialist cancer service when needed
- Removal of routine follow-up appointments from pathway

Why is there a need to change?

Traditional follow up model of ‘one size fits all’ is no longer feasible

There is no evidence that it is the best model

Demand for follow up care continues to increase

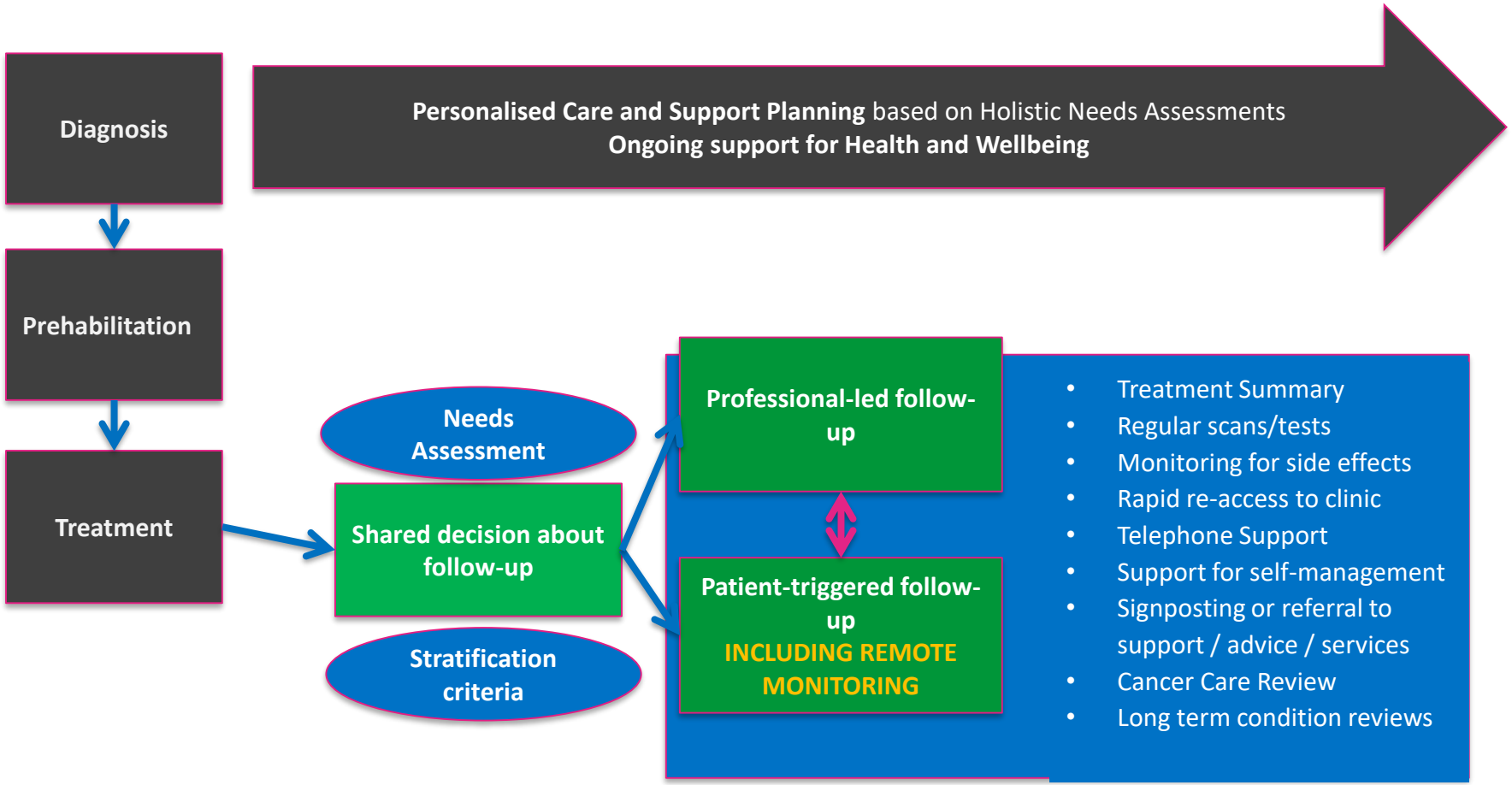
Waiting lists are under pressure

Cost effectiveness is a challenge

Traditional model doesn’t necessarily provide best patient experience

Traditional model isn’t supportive of self management

Personalised (Stratified) follow-up model



04

New ways of working in the NHS

Primary Care Networks (PCNs)

- How might PCNs enhance support for people living with cancer in Primary and Community Care?
- New roles – Social Prescribers, Pharmacists, ACPs etc
- Sharing of resources?
- Practice Nurses working across Networks?
- Primary Care Cancer ‘champions’ across Networks?
- Improved use of Community Assets

Social Prescribing

- An important element of supporting people living with cancer in the community from time of diagnosis through to EOLC
- Should be considered an integral part of the Primary Care Team
- Many of the needs of people living with cancer aren't medical
- 25% of people after a cancer diagnosis suffer from loneliness – SPs ideally placed to help
- 70% people living with cancer need emotional support – SPs can help identify and signpost
- 4 in 5 people living with cancer have a negative financial impact – SPs can help get people the right help

SOCIAL PRESCRIBING FOR CANCER PATIENTS

A guide for networks

PRIMARY CARE 10 TOP TIPS

For Social prescribing

This edition: August 2019
Next planned review: Month/Year
Any extra info (more information, edtion details, references etc.)

1 Social prescribing can be an essential way to support people living with cancer (PLWC) in the community, from the time of their diagnosis right through their cancer experience.

2 Social prescribers should be considered a vital member of the Primary and Community care teams, linking regularly with the GPs, Nurses and admin staff.

3 PLWC have described feeling like they have 'fallen off a cliff' when they're discharged from regular follow up. Having the opportunity to be seen by such a key role working in Primary Care can provide the support they need.

4 We know that almost a quarter of PLWC are suffering from loneliness as a result of their cancer. Social prescribers can help people identify community groups, activities or support that may alleviate this. The Macmillan Online community can also be a way for people to connect with others who've had the same experience.

5 Over 70% of PLWC need emotional support, with 2 in 5 people suffering from depression and 1 in 10 troubled by anxiety. Social prescribers can contribute to identifying these needs, asking what matters to the person and signposting/referring to appropriate support, such as identifying sources of support in the community or referring the individual back to their GP/CNS where appropriate.

6 4 in 5 PLWC experience a negative financial impact as a result of their cancer with the average person living with cancer being £570 a month worse off. Social prescribers can identify sources of benefits advice and ensure PLWC are getting the financial support they are entitled to. It is also possible for PLWC to speak to a Macmillan welfare rights adviser by

7 Getting back to work after a cancer diagnosis can be difficult, but we know that 87% of PLWC who were employed at the time of diagnosis would like to return to work. Over half of PLWC don't know where to go to get help with this; a social prescriber could provide vital support. Get Macmillan's 'Work Support Route' guide and Top Ten Tips for Primary Care Professionals to help with these discussions.

8 Appropriate advice and support regarding physical activity can be essential for PLWC from the time of being diagnosed, through treatment and recovery, and to prevent effects of treatment or recurrence of cancer. Social prescribers can signpost PLWC to services that are available locally. Further information can be found here.

9 PLWC can have multiple physical consequences of their cancer and its treatment that may need medical intervention. Having a close relationship with the Primary Care Team and understanding and developing links back into and from secondary care can ensure these problems are identified early, and that people are offered appropriate support.

10 Over 70% of PLWC will be living with at least one other co-morbidity. We are already seeing how social prescribers can help Primary Care teams provide individual personalised care to meet people's physical, social and practical needs.

MACMILLAN CANCER SUPPORT

Glossary of terms

AHP	Allied Health Professional
CCG	Clinical Commissioning Group
CCR	Cancer Care Review
CNS	Clinical Nurse Specialist (cancer)
NCPES	National Cancer patient experience survey
EHNA	Electronic Holistic Needs Assessment
HLP	Healthy London Partnership
HNA	Holistic Needs Assessment
HWBE	Health and Wellbeing Event (or clinic)
IAPT	Improving Access to Psychological Therapies
LTC	Long term condition
LWBC	Living with and beyond cancer
MDT	Multidisciplinary Team
NCIN	National Cancer Intelligence Network
NCSI	National Cancer Survivorship Initiative
NICE	National Institute for Health and Care Excellence
QoL	Quality of Life
RP	Recovery Package
STP	Strategy & Transformation Partnership
T&F	Task and Finish group
TCST	Transforming Cancer Services Team for London
TS	Treatment Summary