

Living With and Beyond Cancer (LWBC) Data items in COSD v9

COSD Roadshows Jan-Feb 2020

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NHS England and NHS Improvement



What this talk will cover

- **LWBC / Personalised Care - a Long Term Plan priority**
- **LWBC data items in COSD v9 from April 2020**
 1. Physical Activity Status
 2. Personalised Care and Support Plans and Holistic Needs Assessments
 3. End of Treatment Summaries
- **What else is happening around LWBC data**



Long Term Plan priorities



Deliver most comprehensive screening programme in the world



Ensure equitable and fast access to diagnostic tests and results



Provide faster, safer and more precise treatments



Offer personalised care for all patients and transform follow-up care

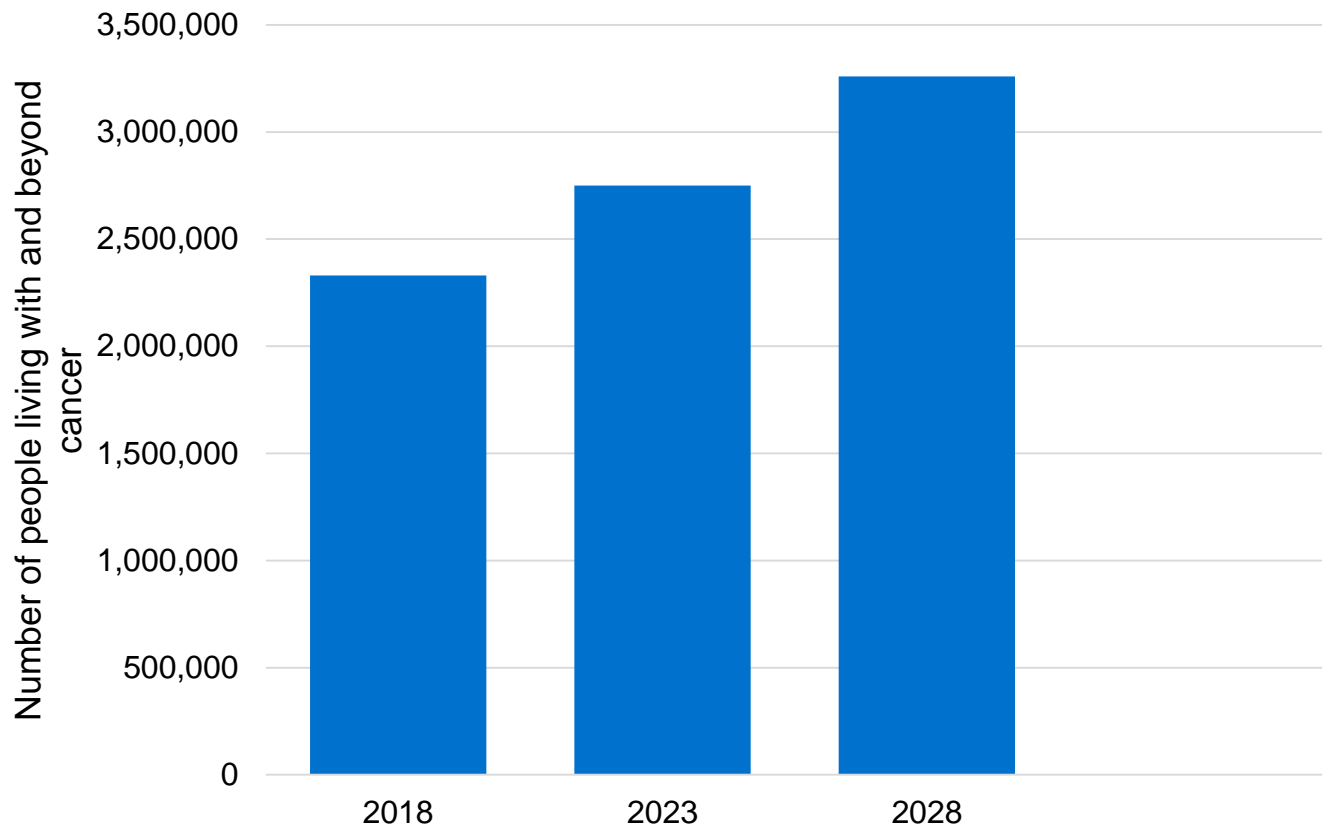


Harness the collaboration of academia, the NHS and industry

Prevalence of people living with and beyond cancer in England

Total prevalence in England is expected to rise from about 2.3 million in 2018 to 2.8 million in 2023, representing an 18% increase.

By 2028, this will have risen to 3.3 million, representing a 40% increase compared to 2018.



Needs of people LWBC

- **Physical**
- **Practical**
- **Emotional**
- **Family/relationships**
- **Spiritual**
- **Information and support**

A Holistic Needs Assessment will cover concerns about these, and opens a conversation on further issues such as coping mechanisms



Prevalence of needs



An estimated 25% of people have long-term poor health or disability after treatment for cancer

For example

350,000 people experiencing chronic fatigue

350,000 Sexual difficulties

240,000 Mental health problems

200,000 Moderate to severe pain after curative treatment

150,000 Urinary problems

90,000 Gastrointestinal problems

63,000 Lymphoedema

Source: Macmillan Cancer Support 2013

Policy Background



- [National Cancer Survivorship Initiative 2013](#)
- [Stratified Follow Up 'How To' Guide 2013](#)
- [National Cancer Strategy 2015](#) - People require holistic support from diagnosis onwards, encompassing their physical, financial, psychosocial, and information and support needs, throughout their entire cancer journey.
- [Long Term Plan 2019](#)

Long Term Plan ambitions



- Personalised care interventions – for everyone by March 2021
- Personalised stratified follow up
 - Breast by March 2020
 - Prostate and Colorectal by March 2021
 - Other cancers TBC by March 2024
- Quality of Life Metric

Improved Outcomes

Quality of Life, Patient Experience, Mortality and Morbidity

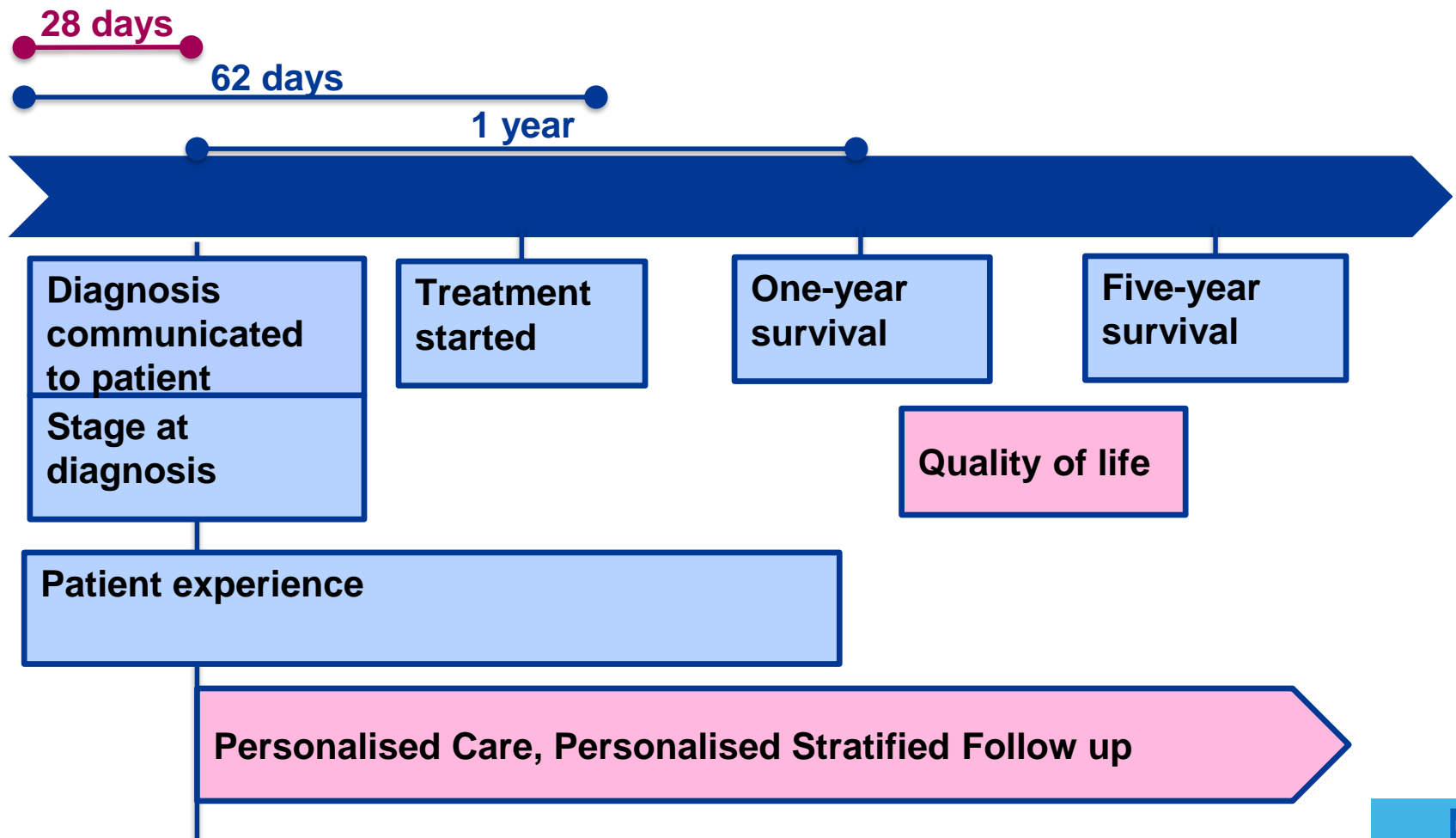
NHS Long Term Plan

www.longtermplan.nhs.uk

#NHSLongTermPlan



Where LWBC fits in cancer data collection



Personalised Care Interventions

Personalised Care and Support Plan (PCSP) based on Holistic Needs Assessment (HNA)

Ensures people's physical, practical, emotional, social needs are met and that resources are targeted to those who need them most.

End of Treatment Summary (EOTS)

Completed by secondary care and given to the patient & GP. Provides detailed summary of treatment, potential side effects, signs and symptoms of recurrence and contact details to address any concerns.

Health & Wellbeing Information & Support

Provides information and support to patients / their family before, during and after cancer treatment. This may include: how to support management of side effects, community support groups, financial support, how to get back to work, diet and lifestyle.

Cancer Care Review

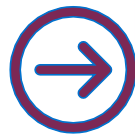
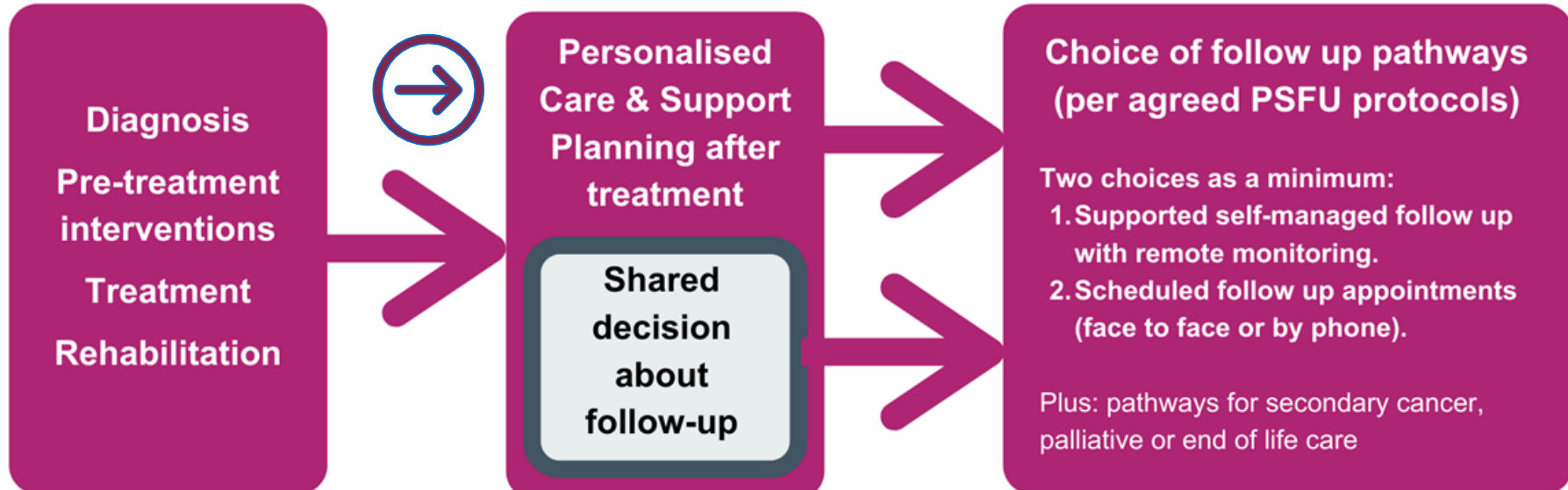
Discussion between patient & GP / Nurse about their cancer journey. Helps patient understand what information and support is available.

Personalised Care and follow-up



From diagnosis and repeated at relevant time points:

- Personalised Care and Support Planning based on Holistic Needs Assessments (HNA)
- Ongoing support and information for Health and Wellbeing



In general, everyone, including those in scheduled follow up, should have:

- Personalised Care and Support Planning based on HNAs
- Information on signs/symptoms of recurrence
- Health and Wellbeing Information and Support
- Support for self-management
- End of Treatment Summary
- Surveillance scans/tests
- Rapid access to clinic
- Telephone support
- Signposting or referral to services e.g. consequences of treatments
- Monitoring for side effects
- Cancer Care Review

Support from Cancer Programme and Cancer Alliances

National Cancer Programme offer:

- LWBC webinars and events
- Cancer Alliances Workspace (sharing good practice etc) on future.nhs.uk
- Guidance documents

Email england.cancerpolicy@nhs.net

Cancer Alliances

- <https://www.england.nhs.uk/cancer/cancer-alliances-improving-care-locally/cancer-alliance-contacts/>
- Alliance websites re LWBC / Personalised Care implementation

Why measure Personalised Care activity in cancer?



- Personalised Care and Support Plans, Holistic Needs Assessments and End of Treatment Summaries must be offered to everyone by 2021 – **need to measure if this is on track or not**
- Personalised Care and Support Plans (PCSP) are a **headline Long Term Plan indicator**
- **Gain greater insight** , for example:
 - What proportion of people take up offer of PCSP/HNA?
 - Do PCSP/HNA/EOTS improve outcomes?
 - What staff are involved?
 - Are there cancer type differences?
 - Physical activity status in relation to survival

What data exists already?

- Holistic Needs Assessment date and pathway timepoint are already in COSD v8 (required from April 2018)
- National Cancer Patient Experience Survey
- National quarterly monitoring of Cancer Alliances' achievement against LWBC targets
- Local LWBC data collection e.g. London Cancer Alliances

No national data collection currently on:

- Personalised Care and Support Plans
- End of Treatment Summary
- Health and Wellbeing Information and Support
- Personalised Stratified follow up
- Physical activity status

COSD v9 LWBC data items

CR7840	Risk Factor Assessment	Physical Activity (Current)	New	Required
CR7900	Holistic Needs Assessment	Assessment Offered	New	Required
CR3140		Assessment Completed Date	Existing	Required
CR3150		Assessment Point	Existing	Required
CR7910		Staff Role Carrying Out The Assessment	New	Required
CR8000		Care Planning Offered	New	Required
CR8010	Personalised Care and Support Planning	Care Planning Completed Date	New	Required
CR8020		Point Of Pathway	New	Required
CR8030		Staff Role Carrying Out The Planning	New	Required
CR8420	Treatment	End Of Treatment Summary Date	New	Optional

Physical Activity status

CR7840	Risk Factor Assessment	Physical Activity (Current)	New	Required
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Data item No.	Data Item Section	Data Item Name	Format	Schema specification (M/R/O/X)
CR2050	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	CLINICAL NURSE SPECIALIST INDICATION CODE	an2	R
CR7800	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	TOBACCO SMOKING STATUS <i>[SMOKING STATUS (CANCER)]</i>	an1	R
CR7810	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	TOBACCO SMOKING CESSATION <i>[TOBACCO SMOKING CESSATION TREATMENT INDICATION CODE]</i>	an1	R
CR6760	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	HISTORY OF ALCOHOL (CURRENT) <i>[ALCOHOL HISTORY (CANCER IN LAST 3 MONTHS)]</i>	an1	R
CR6770	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	HISTORY OF ALCOHOL (PAST) <i>[ALCOHOL HISTORY (CANCER BEFORE LAST 3 MONTHS)]</i>	an1	R
CR7820	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	DIABETES MELLITUS INDICATOR <i>[PATIENT DIAGNOSIS INDICATOR (DIABETES)]</i>	an1	R
CR7830	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	MENOPAUSAL STATUS <i>[MENOPAUSAL STATUS (AT DIAGNOSIS)]</i>	an1	R
CR7840	CORE - CLINICAL NURSE SPECIALIST + RISK FACTOR ASSESSMENT	PHYSICAL ACTIVITY (CURRENT) <i>[PHYSICAL ACTIVITY VITAL SIGN LEVEL (CURRENT)]</i>	an1	R

Physical Activity status

CR7840	Risk Factor Assessment	Physical Activity (Current)	New	Required
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1	Achieves guidance level* of Physical Activity
2	Does not achieve guidance level* of Physical Activity
Z	Not Stated (Person asked but declined to provide response)
9	Not Known (not recorded)

*The 'guidance level' of physical activity is
150 mins moderate intensity physical activity per week
 or
75 mins of vigorous intensity physical activity per week



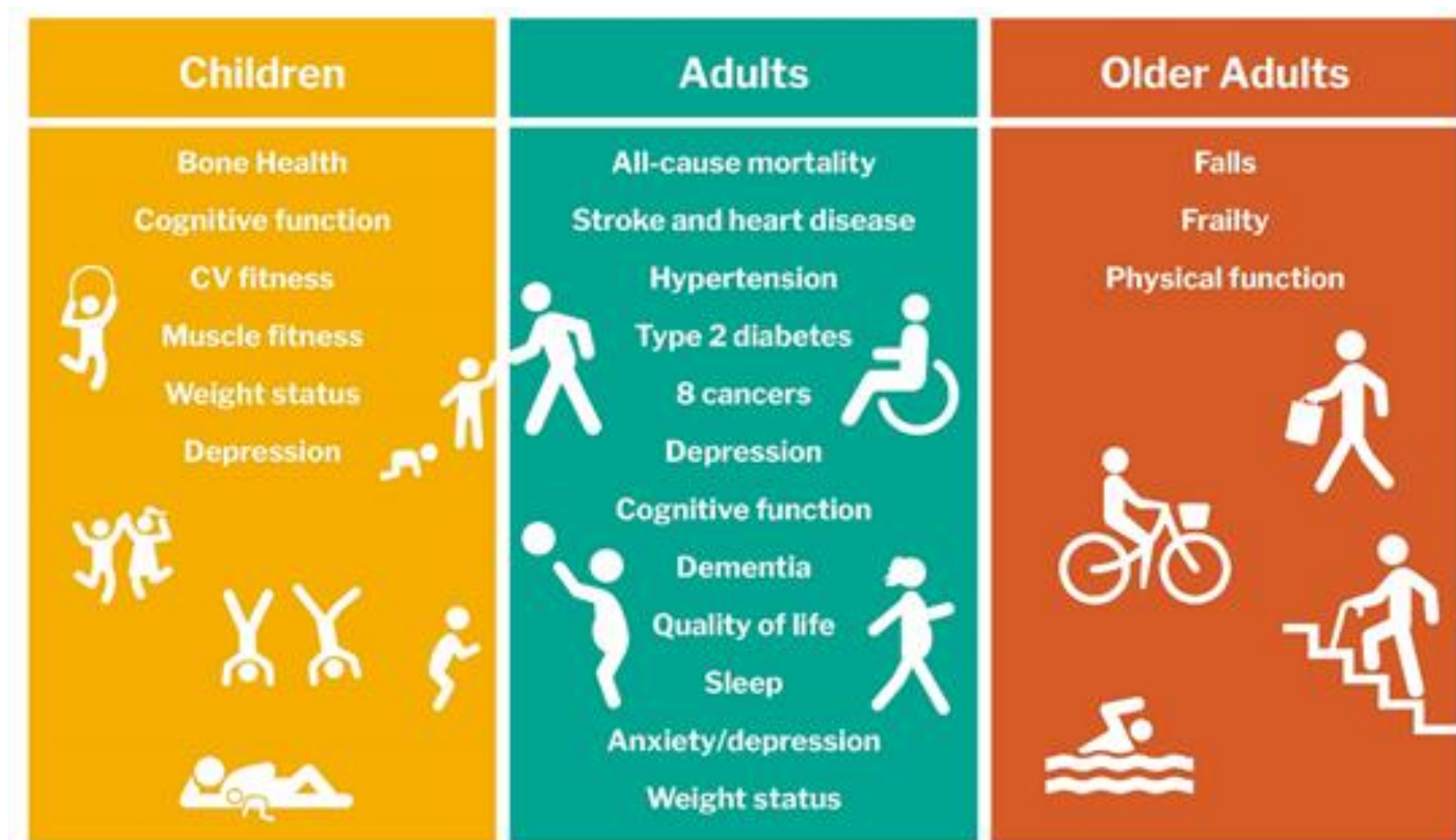
Public Health
England

Protecting and improving the nation's health

Physical Activity & Cancer Healthcare Professionals Resources

December 2019

Health benefits of physical activity



https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/832868/uk-chief-medical-officers-physical-activity-guidelines.pdf

e-Learning for Health – Physical Activity & Cancer

Free short module available on Health Education England e-learning portal Learning for Health.

Physical Activity & Cancer e-learning

- 5 minute quick look or 20 minute full module discusses the positive impact of physical activity on people living with cancer.



Macmillan Move More resources

A range of free tools and digital online support to help patients start and keep active throughout their cancer journey.

Tools include:

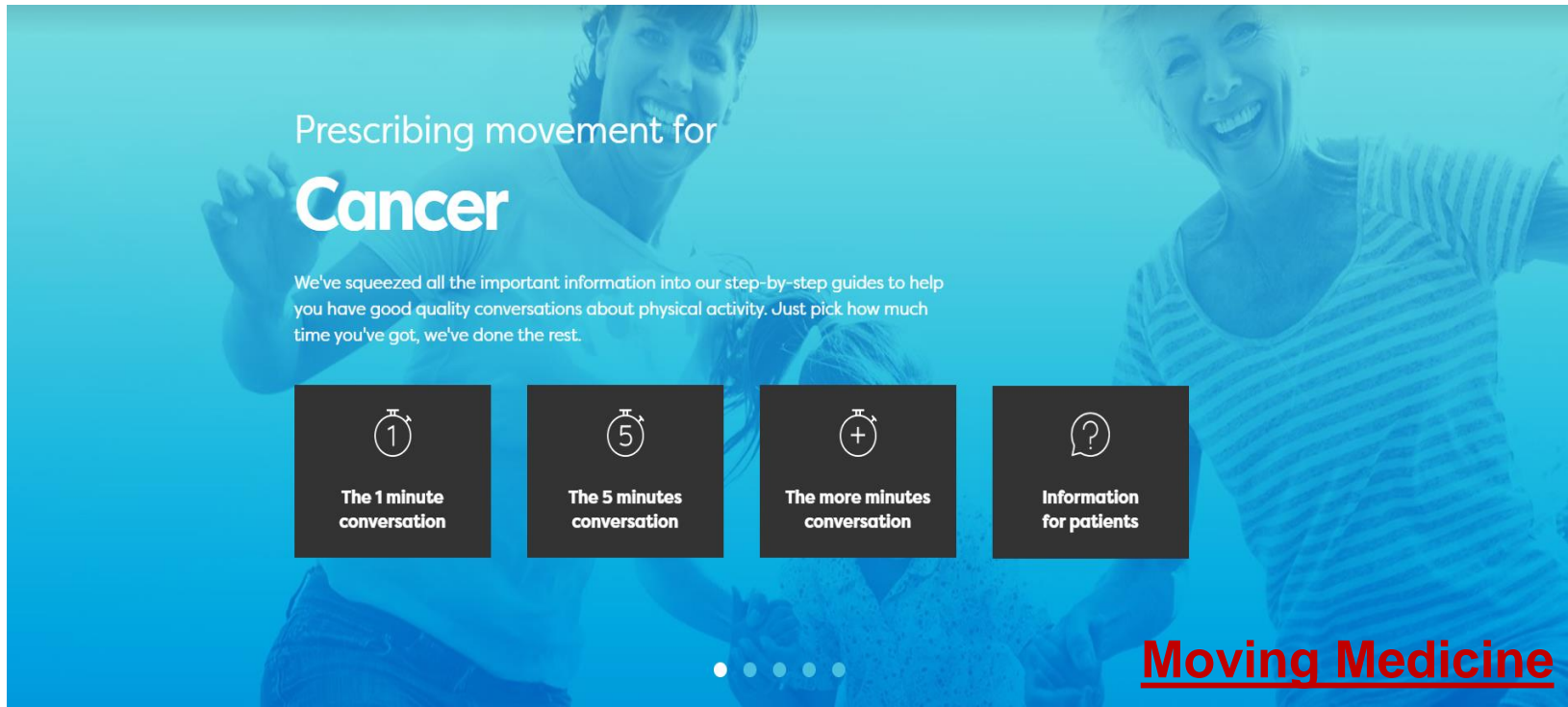
Move more guide provides information on physical activity & cancer and a range of ways to be active, includes an activity chart to see achievements and a DVD of activities to do at home.

Move More resources







Moving Medicine

Moving Medicine is an free online resource for healthcare professionals on the evidence across many common diseases including cancer. It gives practical advice on having brief discussions with patients about physical activity in 1 minute, 5 minute and more minute conversations.

A banner for the 'Moving Medicine' resource, specifically for 'Cancer'. The background is a blue-tinted image of two smiling women, one younger and one older, both in motion. The text 'Prescribing movement for Cancer' is prominently displayed. Below this, a short paragraph explains the resource's purpose. At the bottom, there are four dark grey buttons with white icons and text: 'The 1 minute conversation' (with a clock icon showing 1), 'The 5 minutes conversation' (with a clock icon showing 5), 'The more minutes conversation' (with a clock icon showing a plus sign), and 'Information for patients' (with a question mark icon). A series of five dots is visible at the bottom center, with the fourth dot highlighted. The 'Moving Medicine' logo is in the bottom right corner.

Prescribing movement for
Cancer

We've squeezed all the important information into our step-by-step guides to help you have good quality conversations about physical activity. Just pick how much time you've got, we've done the rest.

- 
The 1 minute conversation
- 
The 5 minutes conversation
- 
The more minutes conversation
- 
Information for patients

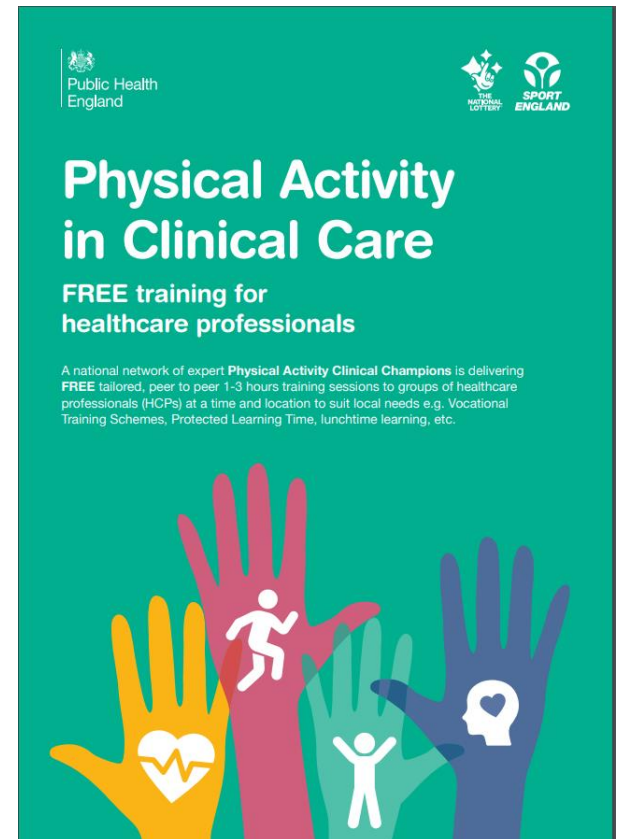
Moving Medicine

Clinical Champions- free group training

Free peer to peer training for healthcare professions from Physical Activity Clinical Champion. The sessions are tailored to be delivered within 1-3 hours at your setting.

- Supports healthcare professionals improve knowledge and confidence discussing physical activity with patients

**To access the training,
email physicalactivity@phe.gov.uk to be
put in touch with your local champion**



Free resources for HCPs

*** Cancer specific**

Peer-to-peer group training

PHE Physical Activity Clinical Champions

Guidance

UK CMOs guidelines and infographics

NICE guidance

National public campaigns

We are UndefeatABLE 15 UK Health Charities

One You / Change4Life Public Health England

Evidence-based resources

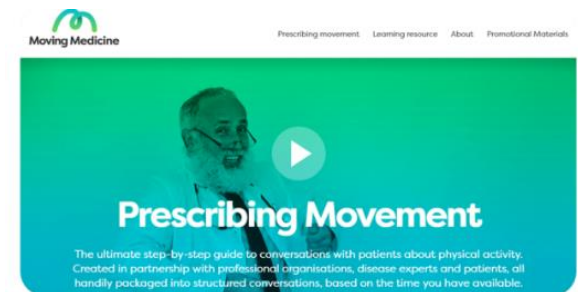
HEE E-learning for Health*

Moving Medicine*

All Our Health

Macmillan Cancer Support resources

Move More resources*



COSD v9 LWBC data items




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Personalised Care and Support Planning (PCSP)

based on

Holistic Needs Assessment (HNA)

Recovery Package is now 'Personalised Care interventions'

From...	To...	Reason for change of language
Recovery Package interventions 	Personalised Care interventions	<ul style="list-style-type: none"> ▪ 'Recovery' implies person has completed treatment, whereas the interventions should be from diagnosis, regardless of prognosis. ▪ 'Package' implies a one-off delivery, whereas the interventions should be at several time points and on request. ▪ 'Personalised Care' is a key objective of the LTP.
Holistic Needs Assessment (HNA)  Care and Support Plan 	Personalised Care and Support Plan based on Holistic Needs Assessment	<ul style="list-style-type: none"> ▪ HNA is not a separate activity, it is part of care planning. ▪ Personalised Care and Support Planning is an essential component of the NHS England Comprehensive Model of Personalised Care.

What is a Personalised Care and Support Plan (PCSP)? (1)

<https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/>

1. **People are central** in developing and agreeing their PCSP including deciding who is involved in the process.
2. People have **proactive, personalised conversations which focus on what matters to them**, paying attention to their needs and wider health and wellbeing.
3. People agree the **health and wellbeing outcomes they want to achieve**, in partnership with the relevant professionals.
4. Each person has a **sharable PCSP** which records what matters to them, their outcomes and how they will be achieved.
5. People are able to formally and informally **review their PCSP**.

What is a Personalised Care and Support Plan (PCSP)? (2)

<https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/>

1. **PCSPs are for all conditions – not just for cancer**
2. **Based on Holistic Needs Assessment and the ‘What Matters To You’ ethos**
3. **No template and no mandatory questions**
4. **A gradual process to improve care planning, e.g.**
 - **Macmillan eHNA tool is being adapted to support PCSP**
 - **Training roll out during 2020 (tbc)**

- **PCSPs are a Long Term Plan headline indicator**
- **New SNOMED codes for PCSP from April 2020**

PCSP and HNA in COSD v9

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01	Offered and Undecided
02	Offered and Declined
03	Offered and Accepted
04	Not Offered
05	Offered but Patient Unable to Complete
06	Not required (no concerns from HNA)

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3

End of Treatment Summary



CR8420	Treatment	End Of Treatment Summary Date	New	Optional
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- An End of Treatment Summary (EOTS) is recommended but not required at the end of every acute phase of treatment
- There should be at least one EOTS relating to primary treatment
- The EOTS is 'complete' when it has been shared with the person and/or their GP
- The EOTS is different from a discharge summary letter due to the incorporation of specific information and advice for the patient and GP - often a template is used and standard information is provided, such as on signs and symptoms of recurrence, who to contact, and how to manage treatment side effects

How the main systems will support data capture

InfoFlex[®]
FROM CIMS

Better Data, Better Health

“CIMS will have incorporated the fields for data capture and submission into the core InfoFlex Cancer system and produced associated documentation by the end of December 2019. These changes and the documentation will then be available for our customers to be implemented in their local systems from the beginning of January 2020”

“The planned changes fit into our CNS screens on the Contact Tab and are all in one place for the CNS’s to access. These changes will be available within our spring release of 2020”



How the data can be used (examples)

- **Physical Activity**
 - Relationship to cancer survival
- **PCSP, HNA, EOTS roll out**
 - Measuring local and national roll out
 - PCSP is headline LTP indicator
- **Insights into people & processes around LWBC**
 - Take-up of offer of PCSP/HNA
 - Link to outcomes
 - What staff are involved?
 - Cancer type differences?



Where will data be reported?



- **CancerStats2**
 - HNA from COSD v8 is already there
- **Local LWBC reporting** e.g. trusts, STPs, Cancer Alliances
- **National Cancer Programme reports**



Not in COSD v9



- **Health and Wellbeing Information and Support**
 - Patients can choose where/when/how they access HWBIS
 - Impossible to define and capture for COSD purposes
 - Measure at health system level?
- **Personalised Stratified follow up**
 - % of people on supported self managed follow up
 - Difficult to define and capture for COSD purposes
 - Does not fit with remit of COSD
- **Cancer Care Review**
 - Currently captured within QoF
- **QoL metric**
 - But will be linkable to COSD data items

What else is happening in LWBC

- **LWBC Outcomes Framework**
- **Quality of Life Metric**

What else is happening in LWBC

LWBC Outcomes Framework to be developed

- Cancer Alliance Quarterly Assurance reporting (mostly trust-level data)
- LWBC metrics (to be confirmed) – using COSD data
- QoF data – Cancer Care Review
- Measure(s) of Health and Wellbeing Information and Support
- QoL Metric
- Other data sources
 - CPES
 - eHNA
 - Local data – audits, surveys, evaluations etc



- NHS England is leading the way in cancer care by recognising that QoL outcomes are as important to patients as survival.
- Monitoring QoL outcomes will help us understand the impact of cancer and its treatment.
- NHS England is working in joint partnership with Public Health England to produce the new metric. This aims to measure quality of life after a diagnosis of cancer at a scale and depth that is not being matched anywhere else in the world.

Importance of quality of life outcomes

Guide the national cancer programme – priority setting, managing the impact of cancer

Prompt improvement discussions at a Cancer Alliance, commissioner and provider level

Empower patients

QoL Metric Questionnaires



EQ-5D 5L (QoL measures)

Summary scores include
Utility/Profile, QALY, 1-100
VAS

EORTC QLQ-C30 (30 items)

Summary scores include
summary domains and the
overall score

Both electronic and paper questionnaires
are in use

Your own health state today

By placing a tick in one box in each group below, please indicate which statement best describes your own health state today.
Do not tick more than one box in each group.

Mobility
I have no problems in walking about
I have some problems in walking about
I am confined to bed

Self-care
I have no problems with self-care
I have some problems washing and dressing myself
I am unable to wash and dress myself

Usual activities (eg. work, study, housework, family or leisure activities)
I have no problems with performing my usual activities
I have some problems with performing my usual activities
I am unable to perform my usual activities

Pain/discomfort
I have no pain or discomfort
I have moderate pain or discomfort
I have extreme pain or discomfort

Anxiety/depression
I am not anxious or depressed
I am moderately anxious or depressed
I am extremely anxious or depressed

Your own health state today

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is.

Best imaginable health state

100
90
80
70
60
50
40
30
20
0

Your own health state today

EORTC QLQ-C30 (version 3)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your details:

Your birthdate (Day, Month, Year):

Today's date (Day, Month, Year): 31

	Not at all	A little	Quite a bit	Very much
1. Do you have any trouble doing strenuous activities, like carrying heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stop in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, drinking, washing yourself or using the toilet?	1	2	3	4

During the past week:

	Not at all	A little	Quite a bit	Very much
6. Were you limited in doing other your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you been upset?	1	2	3	4
14. Have you felt nervous?	1	2	3	4
15. Have you worried?	1	2	3	4

QoL Metric – patient summary

Questionnaire results

This report shows your results to the Quality of Life questionnaire you recently completed.

- The scores on the questionnaire are out of 100. The higher the scores the better quality of life at the moment. Lower scores may indicate that you have some health issues.

- Green** means that **three**  **out of four people**

75%

typically have results like this. This is a good result and suggests that you do not have any problems in this area.

- Orange** means that **one**  **out of four people**

25%

typically have results similar to yours. This may indicate that you have some concerns in this area.

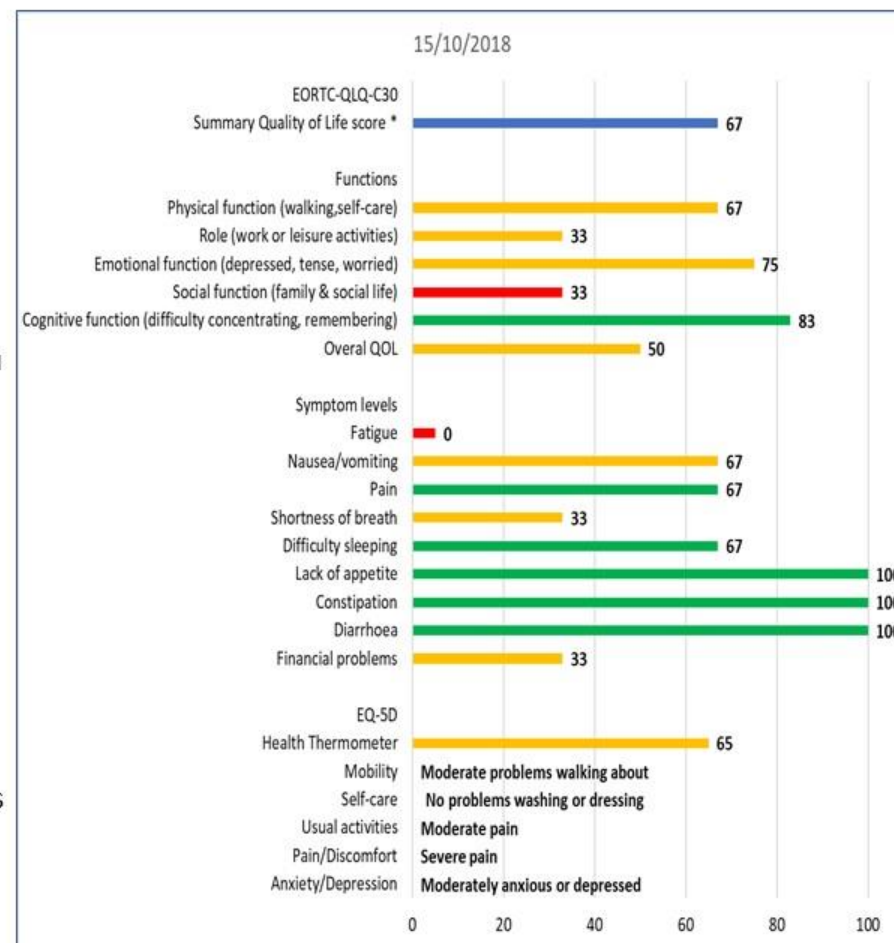
- Red** means that **one**  **out of ten people**

10%

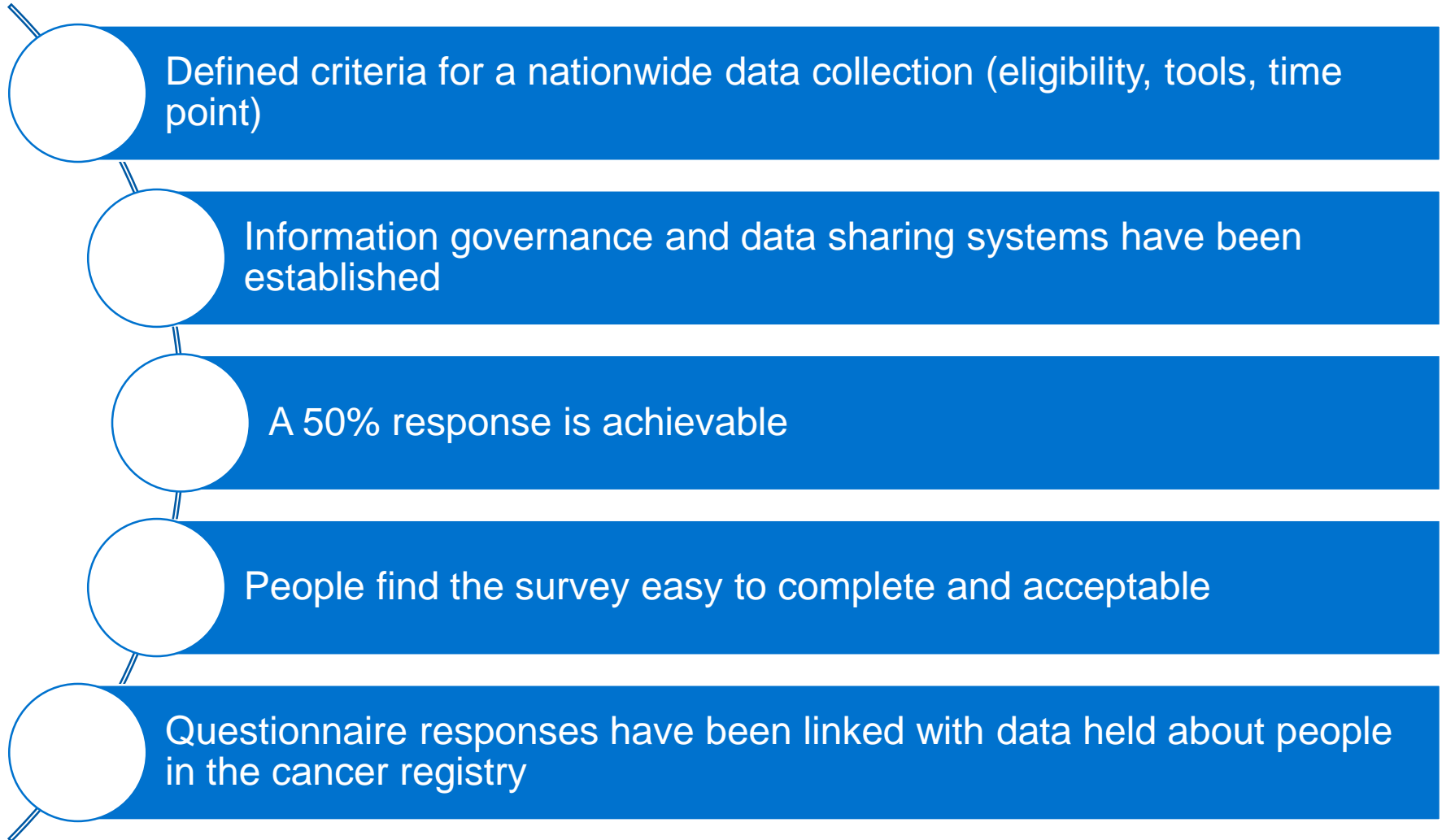
typically have results similar to yours. This may indicate an issue which is bothering you.

- Blue** means that we do not have enough information about how other people feel to make a comparison with your results.

If you are concerned about any health issues please contact your GP or clinical team



QoL Metric Progress



QoL Metric opportunities and challenges

- Asking patients to do too much
- Existing tools may not capture all of patient concerns
- Administrative issues
- Exact use of data and who would have responsibility to address poor scores



- Patient and clinical teams feedback
- QoL metric for all cancers
- Different to but complements HNA
- Informs and influences clinical care and outcomes
- Opportunity to share best practice

QoL Metric project update

Phase three: Pilot data collection



April 2017 – June 2019

- 7 Trusts in 5 Cancer Alliances collect data
- EQ-5D and EORTC
- Over 1000 breast, prostate and colorectal cancer patients
- Outline options for further phase four
- Consult on implementation plan.

Phase four: Test new criteria



April 2019 – March 2020

- Establish method for 'scale up'
- Test additional tumour types
- Determine central vs local systems
- Improve automation
- Feedback outcomes to pilot sites; review service improvement options

Phase five: Launch QoL metric

April 2020 – March 2021

- Launch June 2020
- Breast, prostate, colorectal initially
- Metric report March 2021
- Promote equality of access
- Test in 'rarer' cancers
- Translate all materials
- Test patient-level feedback.

QoL Metric - Next steps



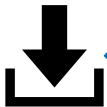
Complete Phase 4 and start Phase 5



Share updates and results with our key stakeholders and partners



Set processes in place to deliver national roll-out in breast, colorectal, prostate in 2020



Seek further input from other cancer groups to allow rapid inclusion of these following initial rollout



Inclusion of all cancers in the QoL metric by 2022

1. LWBC / Personalised Care is a Long Term Plan priority
2. LWBC in COSD v9 – data collection from April 2020
 - Physical Activity Status
 - Personalised Care and Support Plans
 - Holistic Needs Assessments
 - End of Treatment Summaries

Key take-home messages:

- **Ensure systems are in place to capture new items**
- **Maximise data quality**
- **Get ready to use data**
- **Use resources & support (e.g. training, webinars etc)**

3. LWBC Outcomes Framework including QoL Metric



Thank You!
Questions?

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