

Embedding high quality information throughout cancer pathways

Briefing pack to support workshops
on 31 March and 5 April

The purpose of this briefing pack is to provide you with background information so that the majority of the workshop time can be spent on discussion and developing ideas to help put in place high quality information into cancer pathways

#	Section	Purpose of reading	Reading time	Slide no.
1	Introductions	To introduce you to the North Central London Cancer Alliance and the work that we do in North Central London (NCL)	3 min	
2	Context	<p>Explains how are we improving patient experience before and after diagnosis of cancer</p> <p>Provides information about why are we focusing on making sure information and support is available</p> <p>Explains the stages of the cancer pathway and issues relating to information do some of our patients experience?</p>	6 mins	
3	Aims and outline of the workshop	Provides you with information about the aims of the workshop and what the session will include	2 mins	

1) Introduction to the North Central London Cancer Alliance

We are:



We aim to:

Encourage presentation for early diagnosis

Optimise and reduce variation in diagnosis and treatment

Provide high quality personalised support and care for all patients diagnosed with cancer

Restore services after the covid pandemic, and ensure resilience to future waves

- 1** Royal National Orthopaedic Hospital
- 2** Barnet Hospital
- 3** Chase Farm Hospital
- 6** Royal Free Hospital
- 4** North Middlesex University Hospital NHS Trust
- 5** Whittington Health NHS Trust
- 7** University College London Hospitals NHS Foundation Trust
- 8** Great Ormond Street Hospital for Children NHS Foundation Trust
- 9** Moorfields Eye Hospital NHS Foundation Trust

Royal Free London NHS Foundation Trust:

2) Context:

How are we improving patient experience before and after diagnosis of cancer?

Why are we prioritising this work?

Improving experience of care

Overarching aims:

- 1) All people living with and affected by cancer in North Central London to have the best possible experience and outcomes through high-quality personalised care and support.
- 2) People living with and affected by cancer are partners in their own support and care, and will make decisions on 'what matters to them' and what they really need.

How can we achieve these aims?

There are a number of ways we are addressing this. One important project to help us achieve these aims is to make sure that people who have been sent for tests for cancer or who are living with cancer have the **right information and support which works for them**, at the **right time** and in the **right format**.

Improving experience of care

Project: Cancer Information Checklist

To do this, we will co-design a **cancer information checklist for people affected by cancer**. The checklist will include information that is important at key points in the cancer pathway such as diagnosis, treatment and follow up care.

The checklist will include information that helps people to understand their care and treatment. It will also enable people to know what to expect in their care at all times, feel confident and actively involved in their care, and enable shared decision making with the healthcare team.

What are issues relating to information do some of our patients experience?

- **Confusing appointment details and lack of support information**
- **Long waits for cancer investigation results**
- **Slow communication of test results and/or diagnosis (cancer and non-cancer)**
- **Disjointed onward referrals for investigations of non-cancer diseases**
- **Information provided cancer diagnosis and treatments available may not be easy to understand**
- **Variation in information about local services to provide support**
- **Patients may have difficulty contacting healthcare teams when needed – which department? How?**

Timeline for this project

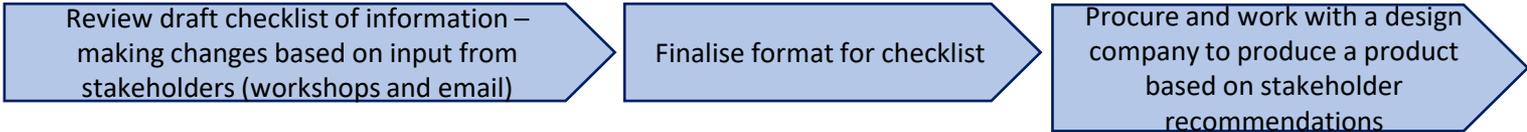
Today



Key Meetings

Delivery Group
12th April
Provide update

Key actions



Co-design Workshops

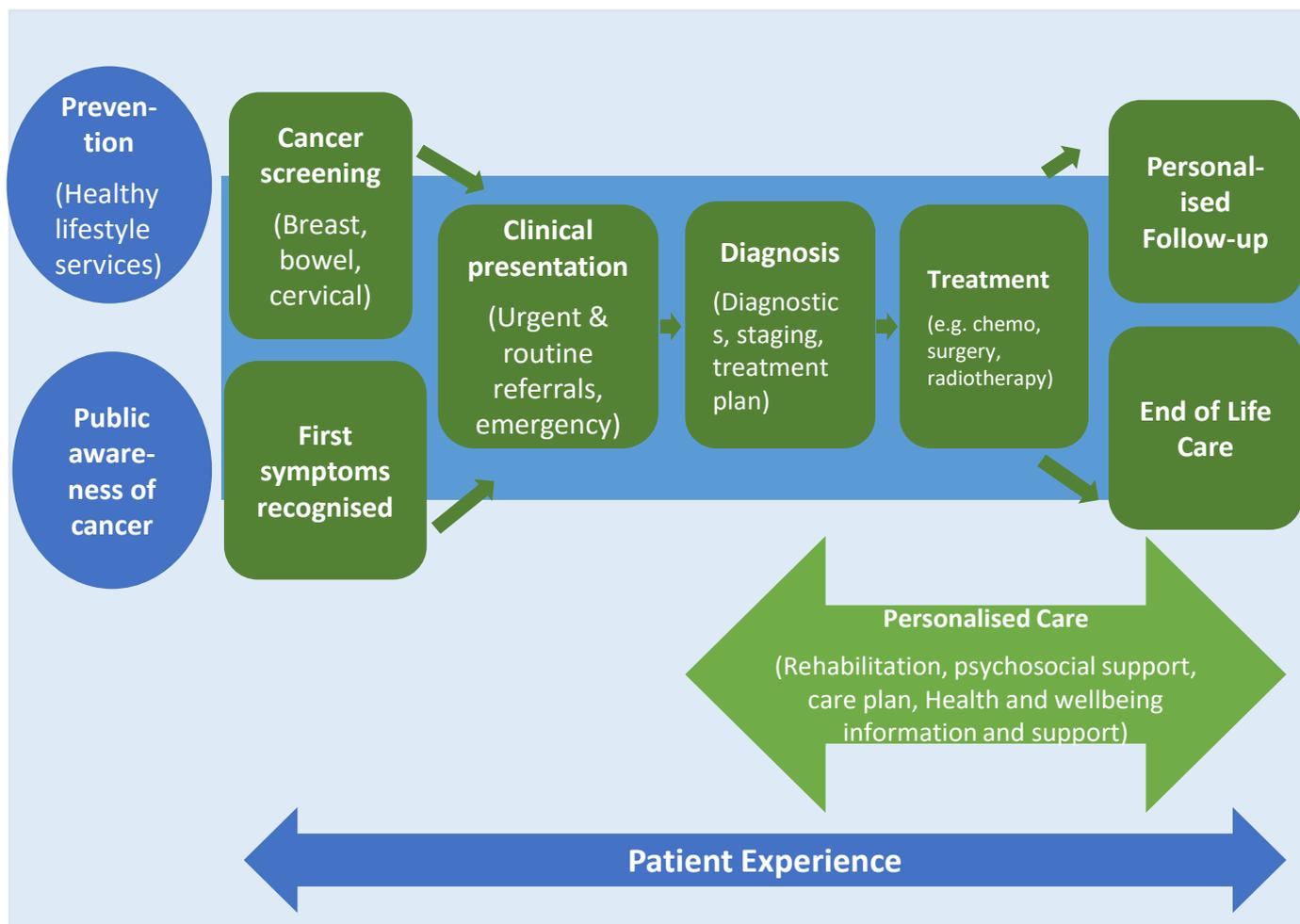


Key Stakeholders

Who are we engaging with to help us with this project:

- people with lived experience (living with cancer)
- people who have been through a cancer pathway (no cancer)
- people who currently use healthcare services and pathways and can contribute to improving the experience
- carers/relatives who support patients in the above categories
- Our local partners – Healthwatches, Macmillan Cancer Support

Overview of the cancer pathway



The cancer pathway is complex. Patients present for investigation, receive treatment and support through different routes and settings which in NCL involves 200 GP practices, 4 hospitals, a range of social care organisations and community settings/organisations.

Making sure that people have the information they need along different parts of the pathway can therefore be equally complex requiring close partnership working.

Why do we need a cancer information checklist?

- No **accepted standard for cancer information** that should be provided to patients and/or carers that aims to improve experience of care
- All **cancer pathways vary** – depending on type of cancer and where a person is receiving care
- **Patient experience of cancer care in NCL needs improving** for all, particularly in:
 - communication (with, and about, the person with cancer)
 - information exchange (with the person)
 - Ensuring that people understand the information that is provided/communicated
 - Care planning and signposting to local services
 - enabling people to actively participate in making decisions about their care

What national and local resources are in place to help us address issues with patient experience?

Healthwatch and the NHS have created patient facing empowerment tools to support patients in various healthcare settings. For example,

- Macmillan have produced online questions for patients to ask their healthcare team re their treatment.
- Macmillan have created a **raise your voice** toolkit - designed to understand care rights
- NICE have set put quality standards for improving patient experience

Locally, we have drafted the touchpoints in a generic cancer pathway and information that we recommend is provided

3) Aims and outline of the workshop

Aims of our stakeholder workshops

- 1) To work in partnership with you to design a checklist of information that should be available to support:
 - people who have been referred for tests to diagnose cancer
 - all individuals treated for cancer in NCL
 - all individuals who are being followed up after cancer treatment

- 2) The checklist will outline the information that workshop participants think is essential or really useful at key points in the pathway: Specifically,
 - noticing symptoms and having tests for these
 - diagnosis
 - treatment
 - follow-up care

Outline of the workshop – what to expect on the day

#	Item	Duration
1	Introduction <ul style="list-style-type: none">NCL Cancer Alliance – who we areAims for the workshop	10 mins
2	Context <ul style="list-style-type: none">Why are we focusing on making sure information and support is available	15 mins
3	Workshop Part 1: Information to include on a patient information checklist	30 mins
	Break	10 mins
4	Workshop part 2: Checklist format	30 mins
6	Closing remarks	5 mins