

# Influencing the next Cancer Strategy

**Cancer52 All Members' Meeting**  
**11th July 2018**

# Purpose of this project



- Identify priorities for the new strategy
- Influence the key decision makers and influencers.

# Project Overview

## Stage 1 Now

**Consult on Cancer52 priorities for next Cancer Strategy:**

- \* Members' survey
- \* Stakeholder interviews
- \* Review evidence and data
- \* Policy and Public Affairs Steering group

## Stage 2 Summer

**Explore potential solutions:**

- \* Consultation session at All Members' Meeting
- \* Patient survey and follow up interviews

## Stage 3 Late summer

**Draft priorities and report.**

## Stage 4 Autumn

**Consult on draft priorities:**

- \* Interviews with three key stakeholders
- \* Revision of priorities based on feedback

## Stage 5 By end 2018

**Finalise priorities and report:**

- \* Report
- \* Key messages and tweets
- \* Blog and comment piece
- \* Presentation of key findings
- \* Targeted emails

# What have we done so far

- Members' survey completed
- Facilitated a session at Cancer52 Policy and Public Affairs Steering Group
- Stakeholder interviews nearly complete (10-15 interviewees from key NHS and charity organisations eg PHE, NICE, ABPI, NHS England, Independent National Cancer Advisory Group)
- Patient survey drafted

# Member survey results

- Ran from 14 June to 6 July
- 33 respondents
- Questions about the progress of Cancer Strategy and priorities across the cancer pathway



Clear priorities

# Member survey results

## Prevention and awareness - Most important

- Ensuring people are aware of symptoms - 82%
- Ensuring people are aware of action they can take to to reduce risk - 36%

## Prevention and awareness - Less important

- Increased physical activity - 12%
- Increasing screening - 12%
- Reducing obesity - 6%

# Member survey results

## Diagnosis - Most important

- Repeatedly visiting GP - 78%
- Lack of awareness of symptoms GPs - 76 %

## Diagnosis - Less important

- Patients diagnosed in A&E - 39%
- Delays in accessing diagnostic tests - 24%
- Patients visiting several clinics - 15%

# Member survey results

## Secondary care - Important

- Access to new medicines - 61%
- Take part in clinical trials - 61%
- Lack of suitable new medicines - 33%

## Secondary care - Less important

- Postcode lottery - 27%
- Access to/quality of surgery - 18%
- Access to radiotherapy - 9%
- Access to/quality of chemotherapy - 9%



# Member survey results

## Support - Important

- Access to a CNS - 48%
- Access to care and support services - 36%
- Access to support groups - 30%
- Coordination of care - 30%

## Support - Less important

- Information about long term effects - 21%
- Help with managing side effects - 27%
- Support for carers; information about getting back to work - both 12%

# Member survey results

## Long term support - Important

- Support with long term effects - 70%
- Access to counsellors/help with getting back to work - 67%

## Long term support - Less important

- Information about recurrence - 33%
- GPs understanding post treatment needs - 33%
- Support groups - 33%
- Carers support - 18%

# Member survey results

## Recurrence - Important

- Help with getting back to secondary care - 40%
- Lack of suitable treatments - 36%
- Lack of information - 33%

## Recurrence - Less important

- Lack of CNS support - 18%

# Member survey results

## End of life care - Important

- High quality end of life care - 79%
- Dying in place of choice - 42%
- Accessing end of life care in a timely manner - 42%

## End of life- Less important

- Pain control - 33%
- Support for carers - 39%

# Member survey results

## Cancer Strategy progress

- Better than expected - 6%
- On track - 0%
- Progress being made in some areas but not all - 55%
- Disappointing progress - 24%
- Don't know - 15%

# Member survey results

## Key current issues impacting on cancer care

- Funding
- Investment in research
- System slow to approve new treatments
- Data sharing

## What one key thing would improve outcomes for patients?

- More research; ultimately a cure
- Better awareness leading to earlier diagnosis
- Specialist care for all
- Support post treatment

# Themes from interviews: 1

8 interviews conducted so far. Key points:

Overall:

- Improving survival rates and having outcomes as good as best countries will not happen without a focus on rare and less common cancers
- Cancer increasingly becoming a range of rare and less common cancers, as science leads to understand more about the common cancers - what can Cancer52 teach more common cancers?

Messaging:

- Cancer 52 should align its messages with the Cancer Strategy but tell the story of rare and less common cancers - it is less well understood
- Cancer strategy is making progress but it is early days

# Themes from interviews: 2

## Across the pathway:

- Diagnosis is more difficult. National pathway for concerning symptoms is underway, but risk stratification/better understanding of genetics/development of liquid biopsies holds more promise
- Hub and spoke model - now called chains - is favoured as the way services should be designed in the future
- Workforce remains a concern and there is always an ongoing risk of losing expertise for rare and less common cancers
- Living with and beyond offer needs to be appropriately tailored
- The new Cancer Drugs Fund is an improvement.



# Emerging priority issues: 1

- National and local targets do not necessarily incentivise improvements across ALL cancers
- New initiatives are mainly trialled in the common cancers so people with rare and less common cancers have to wait longer for new innovative treatment or care
- People with rare or less common cancers often ping ponged around the system before they receive a diagnosis
- People with rare or less common cancers may not be receiving optimal treatment and care from the right specialists

# Emerging priority issues: 2

- People with rare and less common cancers may still wait longer or can not access medicines for their disease
- People with rare and less common cancers can receive a poorer experience of care
- Although less than half of the cancers diagnosed are rare or less common, more people die from these cancers each year

# Some answers

## Supporting existing plans

- Development of awareness campaigns centred around 'know your body'
- Development of Multidisciplinary diagnostic centres
- Secondary care offered via chain delivery

## Asking for

- National targets for different cluster groups of cancers
- Improvements to trials and NICE system

# Next steps

- Patient survey to go live
- Complete interviews
- Seek case studies from members
- Draft report and priorities

# For discussion today

- What should be the ambition for rare and less common cancers for the next cancer strategy?
- How can we ensure people with rare and less common cancers receive support from a CNS?
- How do we speed up diagnosis for people with rare or less common cancers?
- How do we improve access to the best treatments and medicines for people with rare or less common cancers?

# Task- 40 minutes

In four groups, spend 10 minutes considering each question and write your ideas on the flip chart. Rotate every ten minutes. Final question - prepare your feedback for the other groups.

	Group 1	Group 2	Group 3	Group 4
0-10 minutes	Q1	Q2	Q3	Q4
10-20 minutes	Q2	Q3	Q4	Q1
20-30 minutes	Q3	Q4	Q1	Q2
30-40 minutes and feedback	Q4	Q1	Q2	Q3