

Patient Perspectives on Cancer Treatments

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Perspectives on Priorities – Patients and Public (UK)

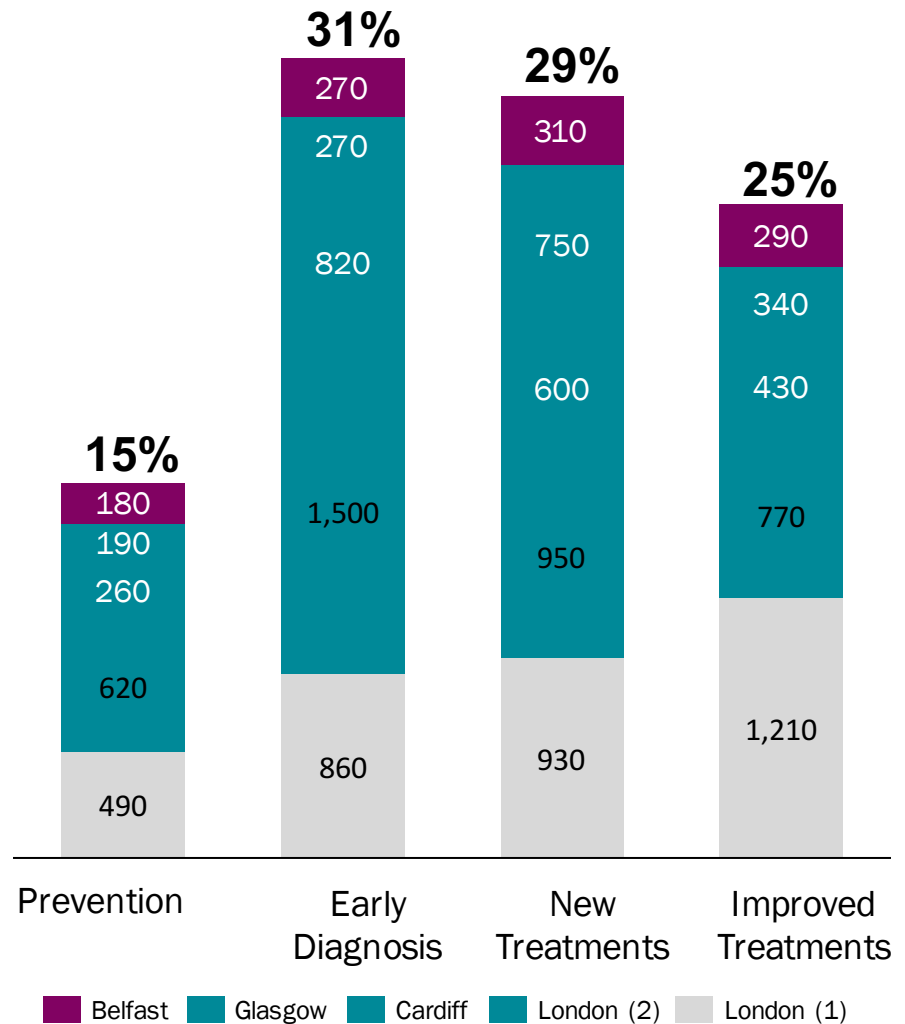
- Public – 2 in 5 get it – so prevent it
- Patients – 50% survive, so cure more people
- Carers – cure but with less suffering
- Survivors – cure but with fewer late effects
- Variations by age, by cancer, by prognosis, by past and current experience

Summary: Areas identified for CRUK research priority

| | |
|--|---|
| Common themes across multiple objectives | <ul style="list-style-type: none">• Cancers with poor outcomes, those that are hard to treat, or rare cancers• Partnership approaches• Looking to international approaches that could inform UK research |
| Prevention | <ul style="list-style-type: none">• Translating more awareness into actual behaviour change (need for strong interventions)• Genetic testing in risk identification (particularly familial risk)• Mixed opinion of which of the main lifestyle factors (tobacco, alcohol, diet) should be of focus• Continued investment in long term, large scale population studies looking at lifestyle factors |
| Early Diagnosis | <ul style="list-style-type: none">• GP education / recognition of symptoms / earlier referrals• Research into new screening tests or technologies• Behavioural research in to what makes people attend screening/ act on symptoms• Improving symptom awareness and influencing people's behaviour (i.e. presentation) |
| New Treatments | <ul style="list-style-type: none">• Focus where there is no/lack of pharma interest• Biomarkers (to support development of new/personalised /targeted treatments)• Combinations• Continued focus on improvements in radiotherapy and surgery• Immunotherapy• Childhood |
| Improved Treatments | <ul style="list-style-type: none">• Long-term impacts of treatments / quality of life improvements• Personalised treatments based on genetic profiles• Increasing participation in clinical trials |
| Also mentioned often | <ul style="list-style-type: none">• Post-treatment impact on the patient – e.g. psychological, economic |

Spend allocation across strategic objectives (£M)

- Following the discussion on research priorities within each objective, patients were asked how they would allocate CRUK's research budget
- Patients were each given £350M to allocate across the 4 objectives
- There were no restrictions on how they could allocate their money



Perspectives on Treatments – Patients (UK)

Add years to my life and life to my years

- Key factors – prognosis and understanding options
- Supportive of research within treatment eg trials, also providing data, samples etc
- Good sources of information & awareness of novel options - immunotherapy, cyber knife, proton beam et al... But not yet Bacteria...

Perspectives on Treatments – Patients (UK)

The screenshot shows the 'About Yakult' page on the website. The browser address bar displays 'www.yakult.co.uk/about-yakult'. The navigation menu includes 'HOME', 'ABOUT YAKULT', 'THE DIGESTIVE SYSTEM', 'HEALTHY LIVING', and 'YOUR QUESTIONS'. A search bar is located in the top right corner.

Yakult

ALL ABOUT YAKULT

WHAT IS YAKULT?
Yakult is the original probiotic. Each little bottle contains over 6.5 billion of our probiotic bacteria, which can help top up the existing beneficial bacteria in your digestive system.

HISTORY AND VISION
Using the unique strain of bacteria he had discovered, Dr Shirota made a simple fermented milk drink and in 1935 produced the first bottle of Yakult.

COMPANY INFORMATION
Yakult was launched in the UK in 1996, and is available in 32 countries worldwide. Yakult employs some 80,000 people across the globe, including many scientists in our research centres.

Friendly bacteria for your gut

Developed by Dr Shirota in 1935.

NUTRITIONAL INFO

| YAKULT | YAKULT LIGHT |
|--|--------------|
| Ingredients | |
| Water, skimmed milk (reconstituted), glucose-fructose syrup, sugar, maltodextrin, flavouring, contains <i>Lactobacillus casei</i> Shirota. | |
| Nutritional Values | |

75 YEARS OF BEING THE EXPERTS

MON TUE WED THU FRI SAT SUN

LISTEN TO YOUR GUT

469 people like this

National Cancer Patient Experience Survey (NCPES) (2014 results below) - It's OK To Ask!

- 😊 32% of cancer patients have discussions about research
- 😊 67% of those asked go on to take part in research
- 😊 95% of those asked are ok to be asked
- 😐 53% of those not asked are ok to be asked
- 😊 **Taking part in research is associated with better experience of care;** 88% of all cancer patients are satisfied/v satisfied with care; increases to 93% for research participants
- 😊 4 posters produced by NCRI Consumer Forum 2013-15 on these results; shown at NCRI and NCIN Conferences;
<http://www.ncri.org.uk/resources/ncri-consumer-forum/>

The NCRI Consumer Forum – Who We Are

😊 82 **experienced and trained** cancer research Consumers

- on NCRI committees and groups
- on NIHR groups, **funding panels**, TMGs, TSCs, RECs, CCGs, HRA, national & local bodies in/across 4 UK nations
- Induction programme, training opportunities and Toolkit

- 15 have international links/experience
- 22 have been published
- 9 have scientific/research degrees/backgrounds (3 PhDs)
- 8 sit at Trustee/Board level on Charities
- 2 work in NHS, 1 is a journal editor, 1 sits as CCG NED etc

The NCRI Consumer Forum – What We Do; The Theory

Terms of Reference:

To create a professional, focussed and committed constituency of consumer research partners for NCRI, who can help NCRI achieve its aims.

Consumer Forum members' own agreed Guiding Principle:

Working together to build a community, with the common purpose of providing patient and public perspectives throughout the research process, to deliver research with better outcomes and experiences for all.

The NCRI Consumer Forum – What We Do: The Practice

- ✓ NCPES – using patient experience of research opportunities to drive service improvements and to promote research awareness
- ✓ Dragons' Den – researchers bring ideas or problems to patients
- ✓ NIHR Industry Alliance - Independent Patient Panel with AstraZeneca (including Hackathon with the Christie)
- ✓ National Cancer Strategy, NICE Guidelines, RECs & HRA training
- ✓ NIHR LCRN Patient Research Ambassadors, Independent Cancer Patients' Voice (ICPV), Northern Ireland Consumer Research Forum
- ✓ Support for/endorsement of programmes – eg Concord 2; NIHR Cancer and Nutrition Infrastructure Collaboration

Dragons' Den 2015



Dragons' Den (with very friendly Dragons)

**NCRI Conference, Liverpool
6-9 November 2016**



Your chance to meet consumers, try out your ideas, get some feedback ready for the CTRad workshop – or just tell us your problems, let us help you put your world to rights, and we'll all enjoy Cancer Research UK's free lunch

Especially suitable for junior researchers and/or involvement at early stage of study design