The National Cancer Research Institute

Supportive & Palliative Care, Primary Care and Living with and Beyond Cancer

PRIME Conference, November 2019

Dr Ian Lewis
Head of Strategy and Initiatives

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National Cancer
Research Institute

NCRI Strategy 2017-22

BBSRC
bioscience for the future

BREAST CANCER NOW
The research & care charity

Children with Cancer UK
Keeping families together

HSC Public Health Agency

MRC Medical Research Council

tenovus cancer care
gofal canser

Bloodwise
The blood cancer research charity

CANCER RESEARCH UK

Department of Health

MACMILLAN CANCER SUPPORT

pancreatic cancer research fund

wellcome

Brain Tumour Research

CHIEF SCIENTIST OFFICE

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Marie Curie
Care and support through terminal illness

PROSTATE CANCER UK

Our purpose:

To improve health and quality of life by accelerating progress in cancer-related research, through collaboration.


Accelerating cancer research
A strategy for collaboration between cancer research funders in the UK (2017-22)
NCRI

Together we will:

Ensure a coordinated portfolio of research related to cancer

Improve the quality and relevance of research related to cancer

Seize opportunities and address challenges in research relevant to cancer

Accelerate translation of cancer-related research into practice

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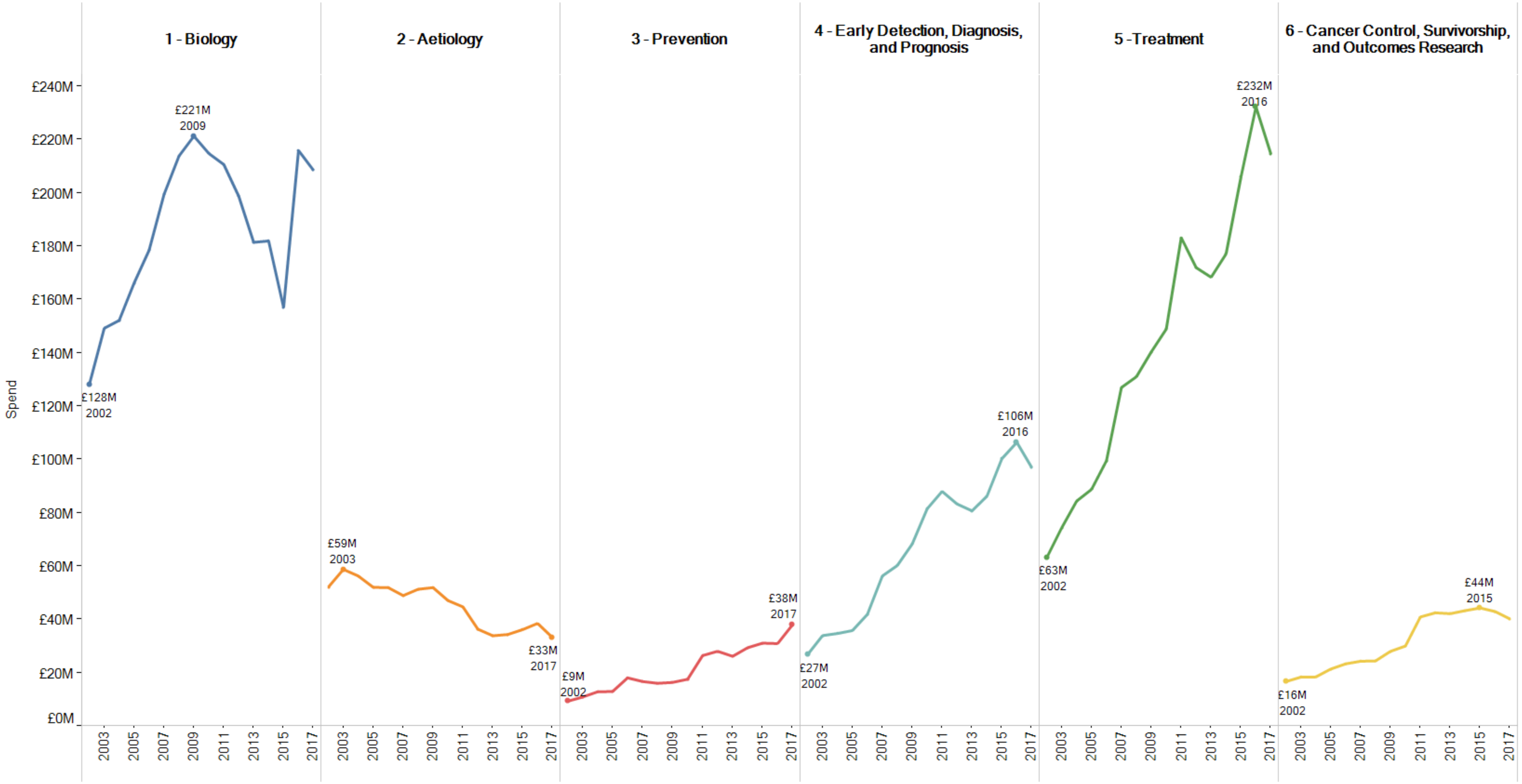
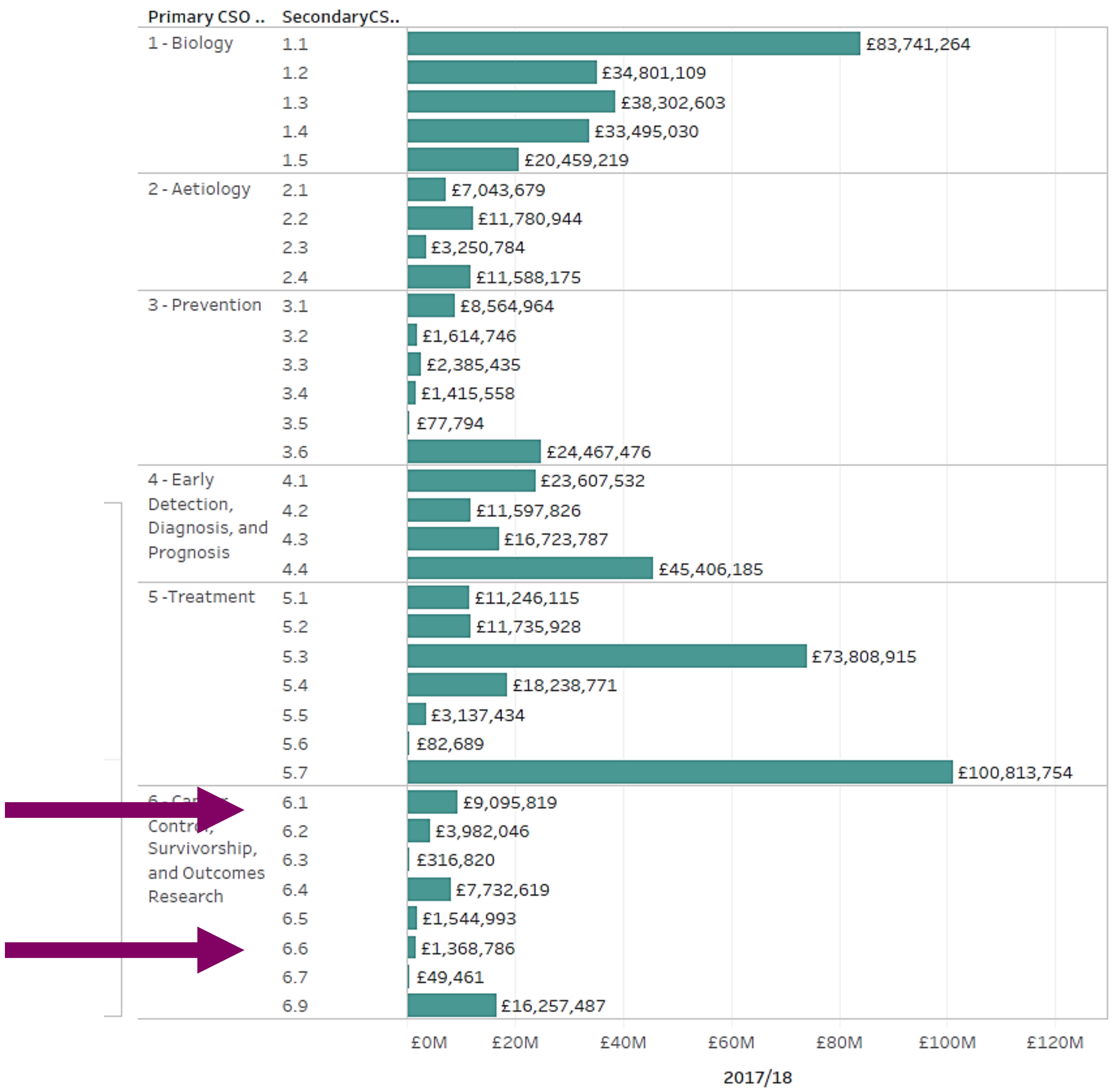
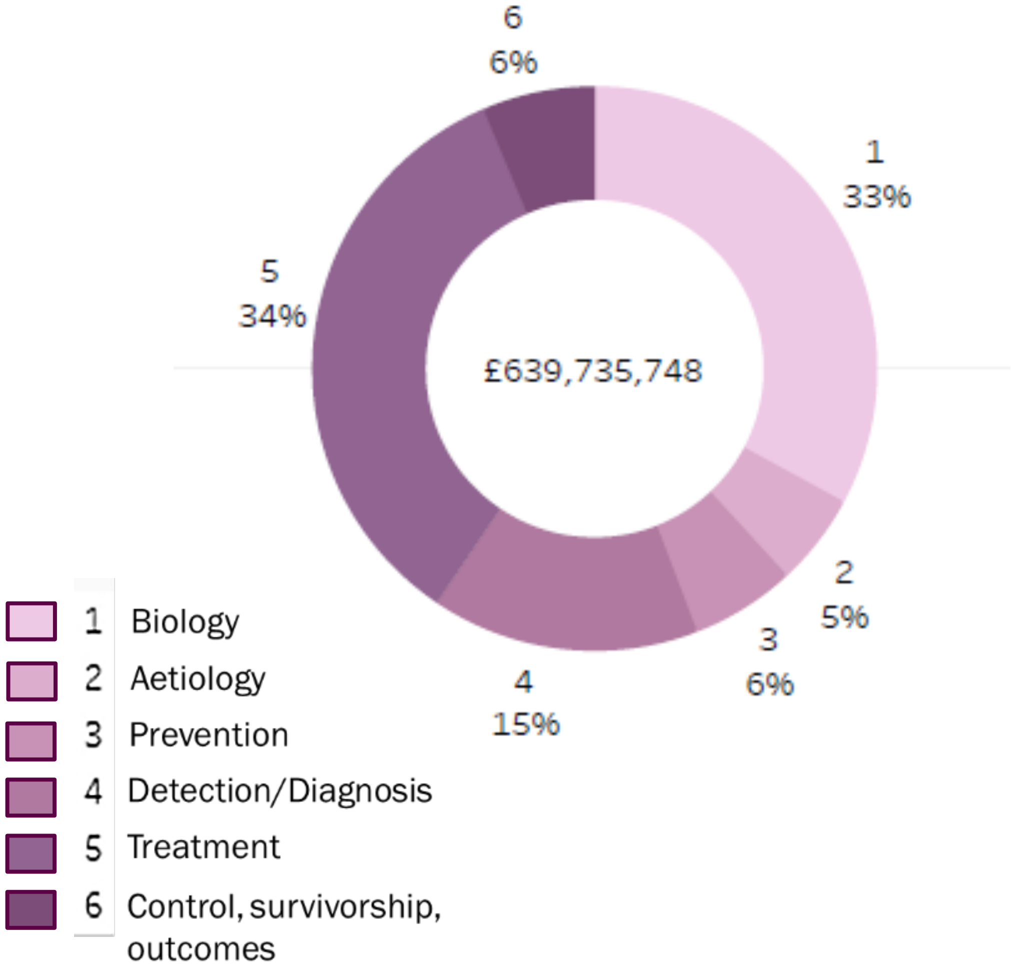
NCRI Cancer Research Database Partner Research Spend (2002-2018)



NCRI Cancer Research Database Partner Research Spend (2017-2018)





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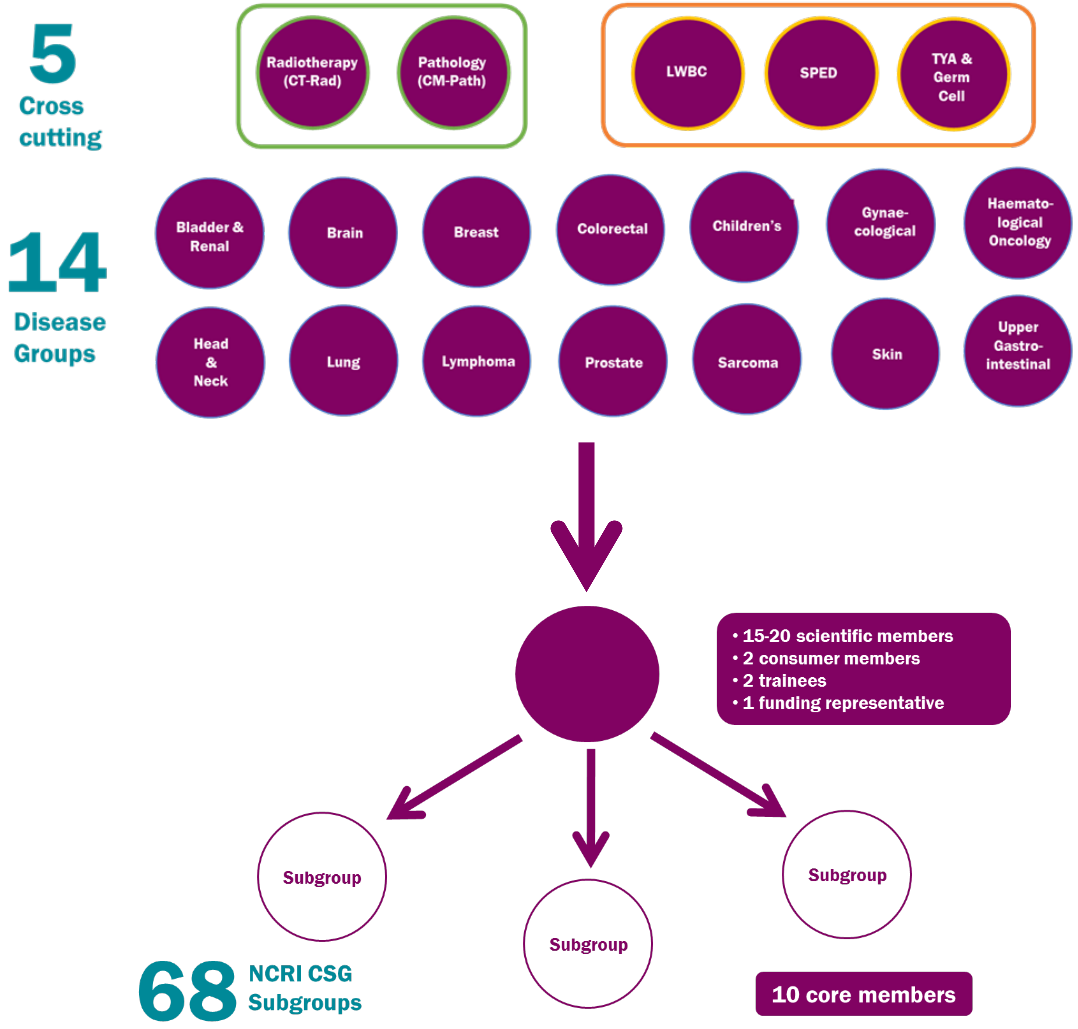
NCRI Cancer Research Groups



5 Cross cutting

Radiotherapy (CT-Rad)
Pathology (CM-Path)

LWBC
SPED
TYA & Germ Cell

14 Disease Groups

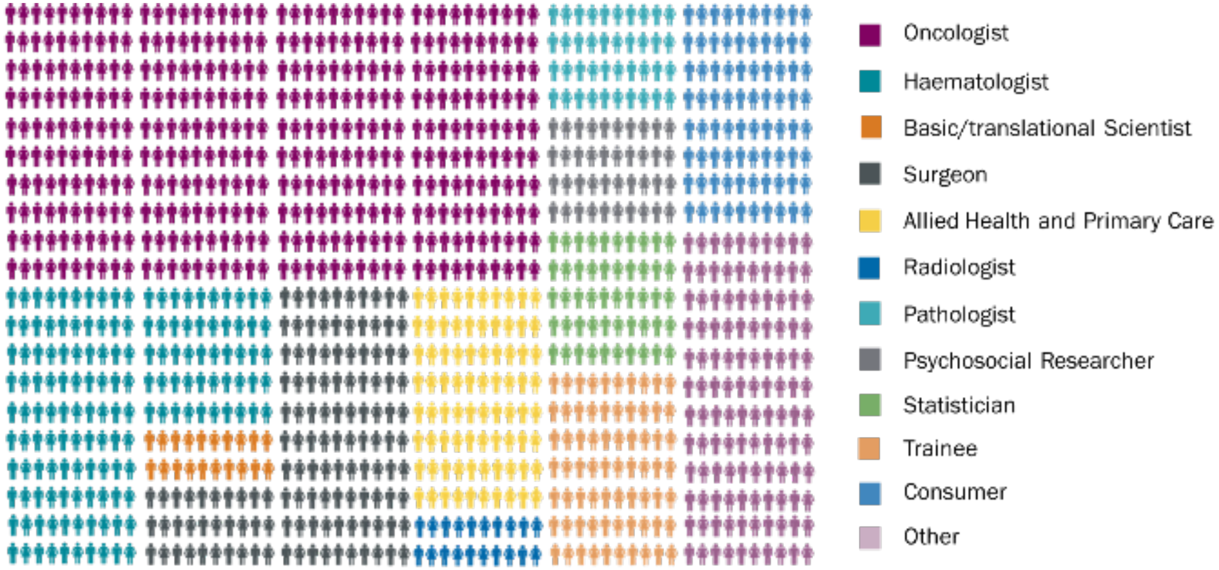
Bladder & Renal
Brain
Breast
Colorectal
Children's
Gynae-cological
Haemato-logical Oncology
Head & Neck
Lung
Lymphoma
Prostate
Sarcoma
Skin
Upper Gastro-intestinal

- 15-20 scientific members
- 2 consumer members
- 2 trainees
- 1 funding representative

Subgroup
Subgroup
Subgroup

68 NCRI CSG Subgroups

10 core members



- ○ Develop a **national portfolio of clinical trials** and **high quality research**
- ○ Liaise with **funding bodies**
- ○ Interact with the **UK clinical research networks** to optimise delivery of cancer clinical trials
- ○ Add an **expert voice** to the development of national initiatives, strategic partnerships and national consultations relevant to cancer clinical trials

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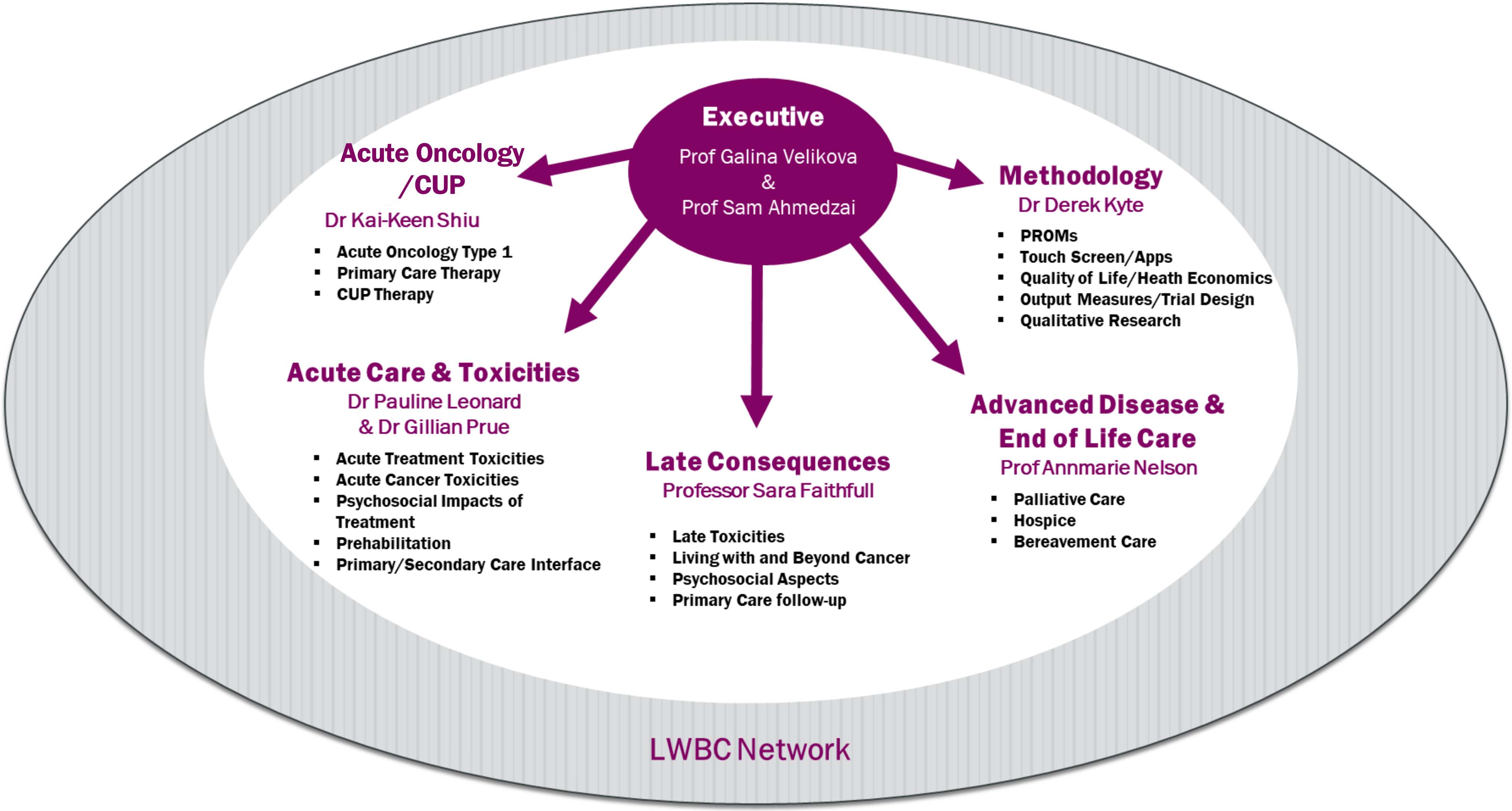
NCRI Cancer Research Groups- LWBC



Executive

Prof Galina Velikova
&
Prof Sam Ahmedzai

Acute Oncology /CUP

Dr Kai-Keen Shiu

- Acute Oncology Type 1
- Primary Care Therapy
- CUP Therapy

Methodology

Dr Derek Kyte

- PROMs
- Touch Screen/Apps
- Quality of Life/Heath Economics
- Output Measures/Trial Design
- Qualitative Research

Acute Care & Toxicities

Dr Pauline Leonard
& Dr Gillian Prue

- Acute Treatment Toxicities
- Acute Cancer Toxicities
- Psychosocial Impacts of Treatment
- Prehabilitation
- Primary/Secondary Care Interface

Late Consequences

Professor Sara Faithfull

- Late Toxicities
- Living with and Beyond Cancer
- Psychosocial Aspects
- Primary Care follow-up

Advanced Disease & End of Life Care

Prof Annmarie Nelson

- Palliative Care
- Hospice
- Bereavement Care

LWBC Network

James Lind Alliance
Priority Setting Partnerships

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Partners in cancer research

Living With and Beyond Cancer

First Survey (September 2017)

1492 respondents proposed 3500 unanswered questions

55% patients, 20% carers and 25% professionals

Data analysis

Questions checked against systematic reviews and guidelines

Compiled to form 54 research questions.

Second survey

1918 patients, carers and professionals ranked the 54 questions.

Data analysis

Created shortlist of 26 questions

Workshop

32 participants ranked the 26 questions

TOP 10 PRIORITIES LAUNCHED
(November 2018)

UK Top 10 living with and beyond cancer research priorities*

1. What are the best **models for delivering long-term cancer care** including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc)?
2. How can patients and carers be **appropriately informed** of cancer diagnosis, treatment, prognosis, long-term side-effects and late effects of treatments, and how does this affect their treatment choices?
3. How can care be better co-ordinated for people living with and beyond cancer who have **complex needs** (with more than one health problem or receiving care from more than one specialty)?
4. What causes **fatigue** in people living with and beyond cancer and what are the best ways to manage it?
5. What are the short-term and long-term **psychological impacts** of cancer and its treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families?
6. How can the **short-term, long-term and late effects** of cancer treatments be (a) prevented, and/or (b) best treated/ managed?
7. What are the **biological bases of side-effects** of cancer treatment and how can a better understanding lead to improved ways to manage side-effects?
8. What are the best ways to manage **persistent pain** caused by cancer or cancer treatments?
9. What specific **lifestyle changes** (e.g. diet, exercise and stress reduction) help with recovery from treatment, restore health and improve quality of life?
10. How can we **predict** which people living with and beyond cancer will experience **long-term side-effects** (side-effects which last for years after treatment) and which people will experience **late effects** (side-effects which do not appear until years after treatment)?

*Priorities relate to adults living with and beyond cancer

Top 10 research priorities for palliative and end of life care

Palliative and end of life care Priority Setting Partnership (PeolcPSP)

For more information visit
www.palliativecarepsp.org.uk

@PeolcPSP

James Lind Alliance
Priority Setting Partnerships

Marie Curie
Chief Scientist Office
NHS National Institute for Health Research
mnda motor neurone disease association
Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales
AIIHPC
We are Macmillan. Cancer Support
MRC Medical Research Council
Cancer Research UK
E·S·R·C Economic & Social Research Council

Top 10 research priorities for palliative and end of life care

1 What are the best ways of providing palliative care **outside of working hours** to avoid crises and help patients to stay in their place of choice?
This includes symptom management, counselling and advice, GP visits and 24-hour support, for patients, carers and families.

2 How can access to palliative care services be improved for **everyone regardless of where they are in the UK?**

3 What are the benefits of **advance care planning** and other approaches to **listening to and incorporating patients' preferences?** Who should implement this and when?

4 What **information and training** do carers and families need to provide the best care for their loved one who is dying, including training for giving medicines at home?

5 How can it be ensured that staff, including healthcare assistants, are **adequately trained** to deliver palliative care, no matter where the care is being delivered? Does increasing the number of staff increase the quality of care provided in all settings? To what extent does funding affect these issues?

6 What are the best ways to determine a person's palliative care needs, then initiate and deliver this care for patients with **non-cancer diseases** (such as chronic obstructive pulmonary disease (COPD), heart failure, motor neurone disease (MND), Aids, multiple sclerosis, Crohn's disease, Parkinson's disease, dementia and stroke)?

7 What are the **core palliative care services** that should be provided no matter what the patients' diagnoses are?

8 What are the benefits, and best ways, of **providing care in the patient's home** and how can home care be maintained as long as possible? Does good coordination of services affect this?

9 What are the best ways to make sure there is **continuity for patients at the end of life**, in terms of the staff that they have contact with, and does this improve quality of palliative care? Would having a designated case coordinator improve this process?

10 What are the best ways to **assess and treat pain and discomfort** in people at the end of life with communication and/or cognitive difficulties, perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example?

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NCRI Strategy Advisory Group

Tim Maughan (Chair)	University of Oxford
Paul Workman (Dep Chair)	The Institute of Cancer Research (ICR)
Manuel Salto-Tellez	Queen’s University Belfast
Richard Gilbertson	Cancer Research UK Cambridge Centre
Sarah Blagden	University of Oxford
Ruth Plummer	Newcastle University
Andrew Tutt	The Institute of Cancer Research (ICR)
Anthony Byrne	Cardiff University
Erik Sahai	Francis Crick Institute
Emma Kinloch	NCRI Consumer Lead
Rob Jones	Wales Cancer Research Centre, H&CRW
Matt Seymour	NIHR Clinical Research Network / NCRI Clinical Research Director
David Cameron	Chief Scientist’s Office, Scotland
Stuart McIntosh	Breast Surgeon/Northern Ireland Cancer Trials Network
Helen Campbell	Department of Health
Ian Walker	Cancer Research UK
Jonathan Pearce	MRC
Sabine Best	Marie Curie
Alasdair Rankin	Bloodwise
Michael Baumann	Chairman and Scientific Director of the German Cancer Institute (DKFZ)
TBC	ABPI Cancer Working Group representative

- Scientific Opportunities:
  - Health data and AI
  - Prevention and early detection & diagnosis
  - Immunology and immunotherapy
  - Living With and Beyond Cancer (LWBC)
  - Imaging
- Workforce and Organisation:
  - Clinical research delivery
  - Training and retention
- Function of Existing NCRI Components:
  - Consumer Forum
  - NCRI Research Groups (formerly CSG’s)
  - NCRI identity

NCRI Conference and Meetings

2020 NCRI Cancer Conference

ICRP
International Cancer
Research Partnership

Annual Meeting
London, UK
12-13 May 2020

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Hosted by the National Cancer Research Institute

Diolch yn fawr
Thank you

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@drianto

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The NCRI Consumer Forum - background

NCRI's Terms of Reference for the Consumer Forum (April 2015):

- To create a professional, focussed and committed constituency of consumer research partners for NCRI, who can help NCRI achieve its aims.
- To provide a pool of well-trained consumers to have input into NCRI and Partner research activities, committees and groups, as equal and valued partners

The Consumer Forum's own Guiding Principle (drafted and agreed by members, summer 2015):

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.

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Top 10 Living With and Beyond Cancer Research Priorities

1. What are the best models for delivering long-term cancer care including screening, diagnosing and managing long-term side effects and late-effects of cancer and its treatment (e.g. primary and secondary care, voluntary organisations, self-management, carer involvement, use of digital technology, etc)?
2. How can patients and carers be appropriately informed of cancer diagnosis, treatment, prognosis, long-term side-effects and late effects of treatments, and how does this affect their treatment choices?
3. How can care be better co-ordinated for people living with and beyond cancer who have complex needs (with more than one health problem or receiving care from more than one specialty)?
4. What causes fatigue in people living with and beyond cancer and what are the best ways to manage it?
5. What are the short-term and long-term psychological impacts of cancer and its treatment and what are the most effective ways of supporting the psychological wellbeing of all people living with and beyond cancer, their carers and families?
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The NCRI Consumer Forum – What Do We Do?

The themes on which we work as a group to promote and/or deliver:

- ✓ Prioritise research aiming at patient benefit (funders)
- ✓ Improve the quality of the research itself (researchers)
- ✓ Improve awareness of research (public)
- ✓ Improve access to opportunities to take part in research (patients)
- ✓ Ensure patients have conversations about taking part in research as a routine part of treatment choices
- ✓ Advocates for policy & practice