# Making your research matter to people living with and beyond cancer

**Monday 29 April 2019, 10:00 – 16:30**

International Suite, Mercure Manchester Piccadilly Hotel, Portland Street, Manchester M1 4PH

## Agenda

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<th>Time</th>
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<tr>
<td>09:30</td>
<td>Arrival and registration</td>
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<tr>
<td>10:00</td>
<td>Welcome and introduction</td>
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<td></td>
<td>Dr Iain Frame</td>
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<td><strong>Session 1: Living With and Beyond Cancer (LWBC) research priorities</strong></td>
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<tr>
<td>10:05</td>
<td>How we got here: the LWBC James Lind Alliance Priority Setting Partnership</td>
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<td></td>
<td>Prof Diana Greenfield</td>
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<td>10:15</td>
<td>The LWBC research priorities</td>
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<td>Richard Stephens</td>
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<td>10:30</td>
<td>Q&amp;A</td>
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<td><strong>Session 2: The role of the National Cancer Research Institute (NCRI) and Clinical Studies Groups (CSGs) in developing LWBC research studies</strong></td>
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<td>10:40</td>
<td>Introduction: The NCRI CSGs and other groups</td>
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<td></td>
<td>Nicola Keat</td>
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<td>10:50</td>
<td>From generating research ideas to improving outcomes: what the NCRI CSGs can deliver</td>
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<td>Prof Sam Ahmedzai</td>
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<td>11:00</td>
<td>Q&amp;A</td>
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<td>11:05-11:25</td>
<td>Coffee</td>
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<td><strong>Session 3: Successful study design</strong></td>
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<td>11:25</td>
<td>Optimising patient-reported outcome (PRO) capture in research</td>
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<td>Dr Derek Kyte</td>
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<td>11:40</td>
<td>Macmillan HORIZONS Programme: establishing a UK-wide prospective cohort to understand the impact of cancer and its treatment on everyday lives</td>
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<td>Prof Claire Foster</td>
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<td>11:55</td>
<td>HOPON, DAHANCA 21 – lessons in methodology and avoiding pitfalls</td>
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<td>Prof Richard Shaw</td>
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<td>12:10</td>
<td>Q&amp;A</td>
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<td><strong>Session 4: Funding for LWBC research</strong></td>
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<td>12:25</td>
<td>Macmillan Cancer Support</td>
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<td>Meera Craston</td>
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<td>National Institute for Health Research (NIHR)</td>
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<td>Dr Ruth Nebauer</td>
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<td>Marie Curie</td>
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<td>Dr Sabine Best</td>
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<td>Medical Research Council (MRC)</td>
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<td>Dr Mariana Delfino-Machin</td>
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<td>13:05</td>
<td>Q&amp;A</td>
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<td>13:15-14:05</td>
<td>Lunch</td>
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<td><strong>14.05</strong></td>
<td>Parallel workshop sessions – please see over for information</td>
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<td>15:30-15:55</td>
<td>Coffee</td>
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<td>15:55</td>
<td>Feedback from breakout session</td>
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<td>Dr Iain Lewis</td>
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<td>16:25</td>
<td>Summary and close</td>
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**Sponsored by:**

[Macmillan Cancer Support](https://www.macmillan.org.uk)

[Wi-Fi connection: Conference Access code: Mercure24](#)
Living With and Beyond Cancer

14:05 – 15:30 Workshops

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<th>A – Models of care</th>
<th>Breakout Room: Park Avenue (4th floor)</th>
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<td>Facilitator: Dr Agnieszka Lemanska</td>
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<th>B – Consequences of treatment</th>
<th>Main Room: International Suite (3rd floor)</th>
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<td>Facilitators: Prof Claire Foster, Dr Eloise Radcliffe</td>
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<th>C – The challenge of PROs in LWBC research</th>
<th>Breakout Room: Portland (1st floor)</th>
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<td>Facilitators: Dr Lynn Calman, Dr Joshua Turner</td>
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Suggested reading on PROs and PROMs:
- Collecting PROs – [www.birmingham.ac.uk/PROlearn](http://www.birmingham.ac.uk/PROlearn)

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<th>D – Keeping research close to the patients</th>
<th>Breakout room: Senate (2nd floor)</th>
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<td>Facilitator: Prof Diana Greenfield</td>
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Suggested reading:

Our event sponsor: Macmillan Cancer Support

We put the current and future needs of people living with cancer at the centre of our research, to ensure we understand the numbers, needs and experiences of people living with cancer. We directly provide, work in partnership with or influence others to help everyone with cancer live life as fully as they can. Our partnership with the NCRI supports this and enables us to work together with the other cancer research bodies in the UK to achieve this mission.

We’re here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we’re right there with you.

Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland.

[www.macmillan.org.uk](http://www.macmillan.org.uk)

**WI-FI**

Wi-Fi connection: Conference

Access code: Mercure24

**Join the conversation**

This event uses [slido.com](https://slido.com) for audience questions and polls. Joining in is easy.

1. Open a browser on your laptop, tablet or smartphone
2. Go to slido.com
3. Enter the event code #LWBC2019
4. Ask your question or vote for your favourite, and join the polls
The UK living with and beyond cancer research priorities

“The priority questions address what we go through as people with the disease and its treatments, and what happens afterwards too. There is a lot of research on curing; these questions are about coping.”

Richard Stephens, patient (living with one cancer and beyond another), 2018 NCRI Cancer Conference

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)?

11. What are the most effective ways to stop cancer coming back (combining treatments and lifestyle changes)?

12. What are the social, financial and economic impacts of living with and beyond cancer – how does it affect families, relationships, finances, work and use of NHS services?

13. What are the best ways to cope with the fear and anxiety about cancer returning (combining self-management approaches, treatments and psychological support)?

14. How can we predict who is at risk of developing mental health conditions in people living with and beyond cancer (e.g. depression) and what are the best ways of supporting those with mental health conditions?

15. What are the best ways to support people living with and beyond cancer to make lifestyle changes to improve their health?
Living With and Beyond Cancer

16. If people with cancer are involved in their own healthcare decisions (including participating in multi-disciplinary team meetings with health professionals), does this lead to better outcomes?

17. What are the psychological and social impacts on children who have a parent (or parents) with cancer, and what are the best ways to support those children?

18. What is the best form of rehabilitation and other support to help people living with and beyond cancer return to or maintain their usual activities (e.g. work)?

19. What are the best ways to manage the consequences of nerve damage caused by cancer treatments?

20. How do the support needs of people with rare and less common cancers differ from people with more common cancers, and how are those needs best met?

21. What can be done to reduce and manage the impact of cancer treatments on people’s sex lives?

22. What are the best ways to support people living with and beyond cancer who live alone?

23. How is cancer perceived across multiple black and minority ethnic groups – what are the similarities and differences?

24. Can lymphoedema be prevented? If not, how is it best treated/managed?

25. What is the optimal follow-up approach to detect whether a cancer has come back?

26. What are the spiritual care needs of people living with and beyond cancer?
Partners in cancer research

Making your research matter to people living with and beyond cancer – what it means

The Living With and Beyond Cancer (LWBC) initiative grew out of the realisation that undefined research priorities have been a barrier to research – and thus better evidence-based care – in this broad arena.

- **Generate specific research proposals** – This is the first time that LWBC research has been clearly defined by the people that matter. We are now calling on the research community to take on the challenge of generating specific, high quality, research proposals to address each priority. This is what patients, carers, frontline clinicians and research funders have asked for.

- **Accelerate translation of research into practice** - When designing proposals, it is vital to involve NHS and implementation experts early on so if good evidence is generated then it is scalable, and implementation is optimised, applicable and cost effective for NHS and other care providers.

- **Address the gap in impact of research for patient benefit** – Our analysis of the 3,500 questions received in the LWBC PSP survey revealed a worrying gap – of questions already answered but still being asked because the answers aren't reaching the people who need them.


2 Five years’ refers to 2010-2015.


From: https://www.ncri.org.uk/ncri-cancer-research-database-old/spend-by-research-category-and-disease-site/
Living With and Beyond Cancer

Exhibitions
SafeSpace: a calming, healing virtual reality environment

SafeSpace is a virtual reality intervention study by the Royal Marsden NHS Foundation Trust and the University of Southampton. It is being funded by Macmillan Cancer Support as part their 2017 call which included grants for research proposals on ‘the use of digital technology to improve the experience and outcomes of people living with cancer’.

Visit the stand during the event for an opportunity to test the technology and to hear how the research team is co-developing – designing, creating and testing – SafeSpace with patients to enable people with cancer to experience a rapid reduction in stress and improved wellbeing. Find out as well about the anticipated long-term impact of SafeSpace for people living with cancer.

For more information about SafeSpace read the team’s blog, visit the Macmillan Cancer Support funded research site and find the study on the NCRI Portfolio Maps (‘Psychosocial Oncology and Survivorship’ area, Map A).

Their cancer journeys: artistic expressions of living with cancer

The event also features a small art display of mono-prints produced by cancer patients and carers provided by the Cancer Survival Group at the London School of Hygiene & Tropical Medicine. The LSHTM research group and the NCRI Consumer Forum have a longstanding relationship and the Forum was the first cancer patient group in the world to sign up to the group’s Concord 2 study, the global study of survival data, in 2012.

The artworks are the outcome of a one-day art workshop in Newcastle in November 2018, which gathered together cancer researchers, patients and a carer to produce prints representing their cancer journeys. The display was first exhibited at the Newcastle City Library.

Suggested reading
LWBC Priority Setting Partnership (PSP)

Visit www.ncri.org.uk/lwbc/resources for key documents, including:

- Living With and Beyond Cancer PSP first survey outcomes (all questions)
- Living With and Beyond Cancer PSP top 26 questions evidence check
- Living With and Beyond Cancer PSP engagement summary
- Other James Lind Alliance PSPs (updated to November 2018)

Patient Reported Outcome (PRO) tools

- Collecting PROs – www.birmingham.ac.uk/PROlearn

On patient led Patient Reported Outcome Measures (PROMs)


On improved outcomes for patients as a consequence of the conduct of clinical research

**Living With and Beyond Cancer**

**Speaker Profiles**

**Dr Iain Frame, National Cancer Research Institute**

Iain joined the NCRI as Chief Executive Officer in August 2018. Previously he was Director of Research at Prostate Cancer UK, leading the charity in key areas of business including, strategic planning, budget management, staff development and ensuring the successful delivery of the charity’s bold and ambitious strategy. Iain has also been involved with NCRI as a previous member of the NCRI Board of Trustees. Prior to his role at Prostate Cancer UK, Iain held the post of Research Director at Diabetes UK for five years, during which time he took forward its funding of high quality, internationally acclaimed studies and worked with the fundraising teams to help almost double the organisation’s research spend. Iain started in the world of charitable research funding with the Wellcome Trust, following many years actively involved in research as a parasitologist.

Iain is a strong advocate of getting results by developing partnerships and using innovative approaches to support the research community. Follow Iain @lainFrame.

**Professor Diana Greenfield, Sheffield Teaching Hospitals**

Diana is a Consultant Nurse at Sheffield Teaching Hospitals where she leads a late effects service for adults who had cancer as a child or young adult and those treated with bone marrow transplant. Diana is also Honorary Professor in the Department of Oncology and Metabolism, University of Sheffield, focusing on cancer survivorship and late effects research. Diana was also a member of the Steering Group that guided the NCRI and James Lind Alliance Living With and Beyond Cancer Priority Setting Partnership.

Diana has recently been selected to participate in the prestigious National Institute for Health Research 70@70 Senior Nurse and Midwife Research Leader Programme aiming to strengthen the research voice in nursing and drive improvements in future care. Follow Diana @greenfield_d.

**Richard Stephens, National Cancer Research Institute Consumer Forum**

Richard was until very recently the Chair of the NCRI Consumer Forum network of patient and carer advocates and sits on strategic groups for NIHR, NHS England, PHE-NCRAS, CQC, MRC CTU, Genomics England, Cancer Research UK, ABPI, BBMRI-ERIC and more.

Richard was the patient representative on the Independent Cancer Taskforce that produced the English National Cancer Strategy, and is a founder member of the AllTrials and useMYdata movements. During his Consumer leadership, Richard has helped to define the importance of Consumer involvement both in the work of NCRI and the wider cancer research landscape – in the UK and internationally.

Richard was diagnosed with two cancers, treated successfully (thus far) for both, but had several treatment-related co-morbidities, and identifies strongly with fellow patients who have a fear of recurrence. Richard was also a member of the Steering Group that guided the NCRI and James Lind Alliance Living With and Beyond Cancer Priority Setting Partnership. Richard remains a champion of ensuring that the Consumer voice is always heard.
Living With and Beyond Cancer

Dr Ian Lewis, National Cancer Research Institute

Ian is the NCRI Head of Strategy and Initiatives and was previously acting Head of Clinical Research Groups (maternity cover). As Head of Strategy and Initiatives, Ian is responsible for implementing NCRI’s strategy and overseeing the strategic initiatives that enable NCRI to accelerate cancer research. This includes the Living With and Beyond Cancer research initiative, of which he was the NCRI co-lead with Dr Feng Li of the LWBC Priority Setting Partnership. His team work to engage with NCRI Partners, and other stakeholders, providing strategic support, data and intelligence.

Prior to joining the NCRI Ian worked at Tenovus Cancer Care as the Director of Research and Policy. He completed his PhD in 2005 at Cardiff University studying the mechanisms that some breast cancers use to become resistant to common drug treatments. Follow Ian @DrIanto.

Nicola Keat, National Cancer Research Institute

Nicola is the NCRI Head of Clinical Research Groups. Nicola provides leadership and strategic input into the activities of the NCRI’s Clinical Research Groups (CRGs), ensuring a collaborative approach to clinical research endeavours.

Her team is responsible for the delivery of all of the activities of the NCRI CRGs, currently including Clinical Studies Groups (CSGs), Clinical and Translational Radiotherapy Research (CTRad) Working Group and the Cancer Clinical Trials Unit (CTU) Group. Nicola is also responsible for oversight of all patient involvement in NCRI activities via the NCRI Consumer Forum.

After completing a degree in Biological Sciences (with a placement year working at Novartis), Nicola moved into the research funding arena, working in the Clinical Trials Team at Cancer Research UK. Follow Nicola @NicolaTilley3.

Professor Sam Ahmedzai, National Institute for Health Research Clinical Research Network

Sam is the National Institute for Health Research (NIHR) Clinical Research Network (CRN) National Specialty lead for Community-based, Supportive and Palliative Care Research, Chair of the NCRI Supportive and Palliative Care Clinical Studies Group, Emeritus Professor of Supportive Care at the University of Sheffield, and Chair of NIHR Cancer and Nutrition Collaboration Steering Committee. He is an honorary consultant physician in palliative medicine, working in a hospital supportive care team and is lead clinician for supportive and palliative care in the North Trent Cancer Network.

Sam studied medicine at the Universities of St Andrews and Manchester. He obtained his clinical training in oncology and respiratory medicine in Glasgow and in 1985 became Medical Director of the Leicestershire Hospice, where he established the first UK palliative care research programme. In 1994 he became Professor of Palliative Medicine at the University of Sheffield, where he combined an academic career while heading one of the UK’s busiest hospital supportive care teams in the Weston Park and Royal Hallamshire Hospitals. He led the Adult Cancer Survivorship programme in Sheffield and has pioneered Consumer involvement in cancer research. Sam led the EORTC Quality Of Life Group, which produced the EORTC QLQ-C30, the world’s leading tool for measuring quality of life in cancer. Follow Sam @Samhja.

Emma Kinloch, National Cancer Research Institute Consumer Forum

Emma was recently appointed in April 2019 as NCRI Consumer Lead, taking over as Chair from Richard Stephens. Emma has a wealth of experience in galvanising patient involvement in research. Emma founded a London based Head and Neck cancer support group and recently expanded her activities to set up a charity focused on furthering research into rare salivary gland cancers, launching in May 2019. She is a member of the Head and Neck EURACAN domain, has been a member of the NCRI Head and Neck Clinical Studies Group for 4 years and is a joining the PHR Funding Committee.
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Dr Derek Kyte, University of Birmingham

Derek is a Lecturer in Health Research Methods at the University of Birmingham, NIHR Fellow and Chair of the NCRI Psychosocial Oncology and Survivorship CSG subgroup: Understanding and measuring the consequences of cancer and its treatment. He has extensive experience in trials methodology, systematic reviews, meta-analysis, and epidemiology. His primary research interests surround health outcomes, including the best-practice use of patient reported outcome (PRO) assessment in clinical trials and routine practice.

Derek completed his undergraduate degree in Physiotherapy at the University of Bradford in 1996. He worked as a Specialist Musculoskeletal Physiotherapist in the NHS for 11 years, before taking up a part-time post as a Clinical Tutor at the University of Birmingham in 2007. He gained an MSc at the University in 2009 and went on to successfully complete his PhD in 2015. Derek then took up his current post as a HEFCE-funded Lecturer in Health Research Methods in 2015. Follow Derek @derekgkyte.

Professor Claire Foster, University of Southampton

Claire is Professor of Psychosocial Oncology, Director of the Macmillan Survivorship Research Group and leads the Cancer Survivorship and End of Life Care Research Theme in Health Sciences at the University of Southampton.

Claire's research programme focuses on understanding the impact of cancer and its treatment on everyday lives and how equipped people feel to manage this; understanding the impact of a family history of cancer on people's lives; and developing and testing supportive resources to support people affected by cancer to manage some of the consequences of treatment and make complex decisions about treatment or genetic testing. This is achieved through large prospective cohort studies, qualitative studies, development and testing of complex interventions working closely with clinical, patient, academic and policy stakeholders to support the design, conduct and dissemination of the research.

Claire is a member of the British Psychosocial Oncology Society (Executive), NCRI Psychosocial Oncology and Survivorship CSG and Bowel Cancer UK Scientific Advisory Board. Follow Claire @ClaireFosterW.

Professor Richard Shaw, National Institute for Health Research Clinical Research Network

Richard is the National Institute for Health Research (NIHR) Clinical Research Network (CRN) National Specialty Lead for Surgical Oncology and Professor of Head and Neck Surgery and Honorary Consultant in Oral and Maxillofacial Surgery (OMFS) in Aintree and Royal Liverpool NHS Trusts.

Richard graduated in Bristol and Glasgow from primary degrees in dentistry and medicine. After surgical training in Glasgow, Richard moved to Liverpool in 2001 to undertake higher training in OMFS and subsequently a head and neck oncology fellowship. Integrated within this clinical training, Richard completed his thesis as an RCSEng Research Fellow, as well as DoH Genetics in Healthcare Fellowship at MD Anderson Cancer Centre, USA. Richard was appointed to Liverpool University and Aintree in 2007, gaining his personal chair in 2012. Richard co-chairs the Mersey Head and Neck Oncology Research Group (MHNORG), an expanding and vibrant multidisciplinary collaboration of clinicians and scientists committed to improving understanding and treatment of malignancies of the mouth, throat and larynx.

Following several senior roles in the NCRI Clinical Studies Groups, Richard was appointed as an associate director of CRN (Cancer) with specific remit for advancing surgical oncology trials and the role of surgeons in the national cancer portfolio. He also represents OMFS on the Royal College Cancer Services Committee and is an elected Board Member and Trustee of the British Association for Surgical Oncology. He is an Officer of Council and Treasurer for the International Academy of Oral Oncology.
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Meera Craston, Macmillan Cancer Support

Meera is the Head of Evidence at Macmillan Cancer Support. Her team is responsible for the development, use and dissemination of high quality evidence and insight, to achieve policy and system change for the benefit of people living with cancer across the UK.

Meera is an Economist by training, completing her undergraduate degree at UCL and gaining an MPhil from the University of Cambridge. Her areas of expertise include research and evaluation relating to families and young people with additional needs, and personalisation and service integration across the public sector. Meera is a passionate advocate of personalised care (and integration) and for the past ten years has sought to build an evidence base to support and influence its evolution. She is also a Trustee of Miscarriage Association and is an Observer on the NCRI Psychosocial Oncology and Survivorship CSG. Follow Meera @meeracraston.

Dr Sabine Best, Marie Curie

Sabine is Head of Research at Marie Curie, overseeing the charity’s portfolio of research activities, from the identification of research priorities to disseminating results. She is part of the charity’s leadership team and has a particular interest in service user involvement in research as well as ensuring that results from charity-funded research activities are widely distributed and accessible to patients, carers and clinicians. Sabine was instrumental in initiating the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance, which brought together more than 30 organisations with an interest in palliative and end of life care. Through this pioneering collaboration, the initiative helped identify the top 10 palliative and end of life care research priorities from the perspectives of patients, carers and clinicians.

Sabine was previously a biomedical researcher and has held research management roles at the Biotechnology and Biological Sciences Research Council, the Royal Society and Breakthrough Breast Cancer. Sabine is also an Observer on the NCRI Supportive and Palliative Care CSG. Follow Sabine @sabinebest.

Dr Ruth Nebauer, National Institute for Health Research

Ruth runs the NIHR Invention for Innovation (i4i) programme and is responsible for the delivery and strategic development of this medtech funding scheme, with a particular focus on engaging with SMEs. She has more than eight years’ experience in funding, developing and partnering preclinical and clinical technologies in the healthcare sector. Previously, Ruth worked as a Business Development Manager for the commercialisation arm of Cancer Research UK. Ruth has a PhD in Biochemistry and Cell Biology.

Dr Mariana Delfino-Machin, Medical Research Council

Mariana is Programme Manager for Cancer at the Medical Research Council (MRC), Molecular and Cellular Medicine. Cancer research areas within her remit include: cancer biology (including but not limited to dysregulation of molecular mechanisms and carcinogenesis, tumour metabolism, tumour heterogeneity, microenvironment interactions, metastasis); radiobiology biology and oncology; genome damage stability (in relation to the pre-disposition and development of cancer); exploratory clinical cancer research (including patient stratification, early diagnosis, investigation of novel therapeutic targets, pre-clinical development, and first-in-human studies) and cancer epidemiology.

Mariana came from Costa Rica to do her Ph.D. in the laboratory of Prof. Kate Storey at the University of Dundee, in Scotland. There, she studied the cells in the “stem zone” of the neural tube, which provide neural progenitors for the spinal cord. As a postdoc in Bath (England) and in Seville (Spain), she studied the development of the neural crest, a multipotent cell population that contributes to a wide range of tissues in the embryo. Follow Mariana @TangaraUK.
Living With and Beyond Cancer

Mariano Kälfors, National Cancer Research Institute

Mariano joined the NCRI in November 2018 (maternity cover) as Programme Manager for its Living With and Beyond Cancer (LWBC) research initiative. Mariano is responsible for facilitating more focussed research to help improve health and quality of life for people living with the consequences of cancer and its treatment.

Prior to NCRI, Mariano was with the World Cancer Research Fund (WCRF) as Project Manager for its research programme on diet, nutrition, physical activity and cancer prevention and survivorship, the Continuous Update Project (CUP). As CUP Project Manager, Mariano helped oversee and deliver the successful launch of WCRF’s 2018 Diet and Cancer report (dietandcancerreport.org). Mariano also has many years of experience in charity communications and project management. Follow Mariano @Mariano_LWBC.

Dr Agnieszka Lemiska, University of Surrey

Agnieszka (or Agz) is a Lecturer in Integrated Care at the School of Health Sciences, University of Surrey, a Pharmacist and a Statistician. Her main research interests are in the area of Big Data analytics and Data Linkage and its applications to healthy ageing, long-term health, multimorbidity and cancer survivorship. She combines her clinical and statistical expertise to deliver research projects with a vision to improve the long-term health of the population.

Agz first trained as a pharmacist and completed her training graduating with an MSc in Pharmacy in 2005. She then studied for her PhD in Chemometrics at the University of Bristol. She was a recipient of a fully funded PhD studentship from GlaxoSmithKline. In 2012 she completed her PhD with a thesis titled “Chemometrics and pattern recognition applications to high-shear wet granulation process monitoring and metabolomic data”.

Agz was one of the Investigators on the TruNTH Diet and Exercise project, led by Prof Sara Faithfull, which developed and tested in nine community pharmacies an innovative community pharmacy lifestyle intervention to support men after prostate cancer. The project was funded by Movember Foundation and Prostate Cancer UK as part of the global TrueNTH initiative. Follow Agz @AgzLemiska.

Dr Lynn Calman, University of Southampton

Lynn is Senior Research Fellow in Macmillan Survivorship Research Group [MSRG] in Health Sciences at the University of Southampton. She works as part of the Macmillan funded MSRG research programme, and associated projects, designed to inform the development of more efficient and effective services to support survivors and enhance their recovery. Lynn has a particular interest in lung cancer survivorship. The team work closely with people affected by cancer as Research Partners in the development and conduct of research projects. Lynn has a background in adult and mental health nursing.

Lynn joined MSRG in 2012 after completing an MRC post-doctoral fellowship in health services research and health of the public at the University of Manchester; to develop an intervention for the follow-up of lung cancer patients after primary treatment. She has a particular interest in survivorship in lung cancer and is part of a team awarded funding from the Roy Castle Lung Cancer Foundation to establish the feasibility of a cohort to understand the natural history of recovery and wellbeing after curative treatment.

Lynn is working as part of a Cochrane Group undertaking systematic review: Strategies to increase participant recruitment to research studies by healthcare professionals. She also is part of a team of researchers funded by Dimbleby Cancer Care - Maintaining psychological well-being in advanced illness: What can we learn from patients' and carers' own coping strategies?

Lynn was previously a member of the National Cancer Research Institute (NCRI) Psychosocial Clinical Studies Group (CSG) and Chair of the Patient Reported Outcome Measurement (PROMS) Subgroup, and is a current member of the NCRI Lung CSG. She is also a member of the International Association for the Study of Lung Cancer (IASLC) and is a member of the Education and Nurses and Allied Health Professionals Committees. Follow Lynn @LynnCalman.
Living With and Beyond Cancer

Delegates (including workshops)

- Mr Adam Spiller, Macmillan Cancer Support, Learning and Development Manager, B - Consequences of treatment
- Dr Agnieszka Lemanska, University of Surrey, Lecturer in Integrated Care, A - Models of care
- Mr Alan Bateman, Macmillan Cancer Support, Trainer, C - Patient reported outcomes (PRO)
- Mr Alastair Richards, North West Cancer Research, CEO, D - Keeping research close to the patients
- Dr Alexander Renziehausen, National Cancer Research Institute, Programme Manager, B - Consequences of treatment
- Dr Alice Simon, NHS England, Senior Project Manager, C - Patient reported outcomes (PRO)
- Miss Aman Hassan, National Cancer Research Institute
- Ms Ann Muir, Patient, D - Keeping research close to the patients
- Dr Anna Williams, Macmillan Cancer Support, Senior Academic Research Officer, C - Patient reported outcomes (PRO)
- Miss Bethany Maddison, Service Solutions Specialist, C - Patient reported outcomes (PRO)
- Mrs Bijal, Purohit, NHS, Programme support Manager
- Dr Caroline Danciger, St Bartholomew's Hospital, Lead Clinical Psychologist, B - Consequences of treatment
- Dr Catherine Cowell, Cancer Research UK, Research Funding Manager, B - Consequences of treatment
- Mrs Catherine Neck, North Bristol NHS Trust, Macmillan Cancer Rehabilitation/LWBC Lead, B - Consequences of treatment
- Ms Chiara De Biase, Anthony Nolan, Assistant Director of Patient Services, C - Patient reported outcomes (PRO)
- Mrs Christine Allmark, National Cancer Research Institute, NCRI Consumer Forum Member, C - Patient reported outcomes (PRO)
- Mr Christopher Bedding, University of Leeds, PhD Student, C - Patient reported outcomes (PRO)
- Dr Claire Higham, The Christie NHS Foundation Trust, Consultant Endocrinologist, B - Consequences of treatment
- Professor Claire Foster, University of Southampton, Director of Macmillan Survivorship Research Group
- Mrs Clare Wheatley, National Institute for Health Research (NIHR) Clinical Research Network (CRN), Cancer Patient Research Ambassador, B - Consequences of treatment
- Ms Colette Hamilton, Genesys, Principal Economist, B - Consequences of treatment
- Mr Colin Bamford, National Institute for Health Research, Public Representative on Cancer and Nutrition Collaboration, D - Keeping research close to the patients
- Dr Cynthia Forbes, Hull York Medical School, Research Fellow, C - Patient reported outcomes (PRO)
- Ms Dany Bell, Macmillan Cancer Support, Specialist Advisor Treatment and Recovery, C - Patient reported outcomes (PRO)
- Prof David Baguley, University of Nottingham, Professor in Hearing Sciences, Research Lead for Hearing loss and tinnitus caused by medical treatments, C - Patient reported outcomes (PRO)
- Mrs Debbie Owen, University of Warwick, Nurse, C - Patient reported outcomes (PRO)
- Dr Debbie Cavers, University of Edinburgh, Research Fellow, D - Keeping research close to the patients
- Dr Derek Kyte, University of Birmingham, Lecturer in Health Research Methods, C - Patient reported outcomes (PRO)
- Prof Diana Greenfield, Sheffield Teaching Hospitals NHS Foundation Trust, Consultant Nurse, D - Keeping research close to the patients
- Dr Dinesh Gopal, Queen Mary University of London, Academic Clinical Fellow, General Practice, A - Models of care
- Dr Eloise Radcliffe, University of Southampton, Research Fellow, B - Consequences of treatment
- Ms Emma Kinloch, National Cancer Research Institute, NCRI Consumer Forum Member, B - Consequences of treatment
- Ms Emma Nicklin, University of Leeds, PhD Student
- Ms Gemma Clifford, NHS, Senior Manager, Personalised Care (Strategy), NHS England, C - Patient reported outcomes (PRO)
- Miss Georgina Wiley, Macmillan Cancer Support, Treatment and Recovery Advisor, A - Models of care
- Ms Geraldine O'Gara, The Royal Marsden Hospital, Nurse Researcher, D - Keeping research close to the patients
- Dr Gil Shalom, Bloodwise, Head of Research Funding, D - Keeping research close to the patients
- Dr Gillian Prue, Queen's University Belfast, Senior Lecturer in Chronic Illness, D - Keeping research close to the patients
- Ms Gilly Howard-Jones, Southampton General Hospital, Recovery Package Lead, A - Models of care
- Ms Hannah Fox, NHS England, Senior Strategy Manager - NHS Cancer Programme, A - Models of care;
Living With and Beyond Cancer

- Mrs Hayley Leonard, Anthony Nolan, Lead Nurse, A - Models of care
- Miss Helen Pitman, National Cancer Research Institute, Programme Manager, A – Models of care
- Dr Iain Frame, National Cancer Research Institute, CEO, D - Keeping research close to the patients
- Dr Ian Lewis, National Cancer Research Institute, Head of Strategy and Initiatives, C - Patient reported outcomes (PRO)
- Mrs Jane Ireson, Sheffield Teaching Hospitals NHS Foundation Trust, Clinical Nurse Specialist/ PhD student (NIHR fellowship), C - Patient reported outcomes (PRO)
- Prof Janet Dunn, Warwick Clinical Trials Unit, Professor of Clinical Trials, C - Patient reported outcomes (PRO)
- Dr Joshua Turner, University of Southampton, Research Fellow, C - Patient reported outcomes (PRO)
- Mrs Julie Armoogum, Other, Senior Lecturer - Adult Nursing, D - Keeping research close to the patients
- Mrs, June, Davis, Macmillan Cancer Support, Allied Health Professional Advisor, B - Consequences of treatment
- Dr Karen Robb, Healthy London Partnership, Macmillan Rehabilitation Clinical Lead, B - Consequences of treatment
- Ms Kathleen Kane, University of Leeds, PhD Student, C - Patient reported outcomes (PRO)
- Dr Kathryn Cunningham, University of St Andrews, Chartered Psychologist and Researcher, C - Patient reported outcomes (PRO)
- Mrs Kathy Rogers, Other, Senior Lecturer - Adult Nursing, B - Consequences of treatment
- Ms Katie Sheen, Brain Tumour Research, Interim Research Manager, D - Keeping research close to the patients
- Professor Krishnan Bhaskaran, London School of Hygiene and Tropical Medicine, Professor of Statistical Epidemiology, B - Consequences of treatment
- Mrs Laura Miller, Nottingham University Hospitals NHS Trust, Macmillan project lead dietitian, NiiCproject, C - Patient reported outcomes (PRO)
- Miss Laura Williams, Liverpool Heart and Chest Hospital, Thoracic Cancer Support Worker,
- Dr Lesley Howells, Maggie's Centres, Lead Consultant Clinical Psychologist and Research Lead, B - Consequences of treatment
- Dr Lesley Smith, NHS England, Senior Programme Manager Living With & Beyond Cancer, A - Models of care
- Ms Lindsey Wilby, The Christie NHS Foundation Trust, Macmillan Project Manager - Living with and Beyond Cancer, A - Models of care
- Ms Lisa Ottiwell, Other, COLORECTAL SPECIALIST NURSE, A - Models of care
- Dr Lisa Durrant, Macmillan Consultant Radiographer for radiation late effects, B - Consequences of treatment
- Dr Lisa Murray, The Royal Marsden Hospital, Nurse Researcher, D - Keeping research close to the patients
- Mrs Lisa Formby, Bangor University, research project support officer, D - Keeping research close to the patients
- Ms Liz Price, Healthy London Partnership, Associate Director, C - Patient reported outcomes (PRO)
- Dr Lizzy Banwell, University Hospitals Bristol NHS Foundation Trust, Highly Specialist Clinical Psychologist, B - Consequences of treatment
- Dr Lorna Fern, National Cancer Research Institute, TYA Researcher and Patient/Public Involvement Lead, D - Keeping research close to the patients
- Dr Louise Worswick, Cancer Alliance, Macmillan LWBC Evaluation and Commissioning Manager, A - Models of care
- Dr Lynn Calman, University of Southampton, Principal Research Fellow, C - Patient reported outcomes (PRO)
- Dr Mariana Delfino-Machín, Medical Research Council, Programme Manager, B - Consequences of treatment
- Mr Mariano Kaifors, National Cancer Research Institute, Programme Manager, D - Keeping research close to the patients
- Dr May Teoh, Royal Surrey County Hospital, Consultant Clinical Oncologist, B - Consequences of treatment
- Mrs Meera Craston, Macmillan Cancer Support, Head of Evidence, A - Models of care
- Mrs Michelle Collinson, University of Leeds, Principal Statistician, B - Consequences of treatment
- Dr Natasha Crawford, NHS England, CADEAS Lead Analyst, A - Models of care
- Mr Niall Smith, NHS England, Communications Manager,
- Ms Nicola Keat, National Cancer Research Institute, Head of Clinical Research Groups (CRGs), B - Consequences of treatment
- Mrs Noor Jhan-Butt Sherwani, NHS, Senior Project Management,
- Mrs Patricia Fairbrother, Independent Cancer Patients Voice, Patient Advocate, D - Keeping research close to the patients
- Mrs Perline Skovlund, Aarhus University Hospital, Denmark, Nurse, PhD student, C - Patient reported outcomes (PRO)
- Miss Rabab Al Sunni, University of Nottingham, PhD student, B - Consequences of treatment
Living With and Beyond Cancer

- Dr Rachel Broadbent, The Christie NHS Foundation Trust, Research Fellow, C - Patient reported outcomes (PRO)
- Professor Richard Shaw, NIHR Clinical Research Network Coordinating Centre, Professor of Head and Neck Surgery, NIHR CRN National Specialty Lead for Cancer Surgery
- Mr Richard Stephens, National Cancer Research Institute, Chair, Consumer Forum, A - Models of care
- Dr Ruth Nebauer, National Institute for Health Research, Assistant Director, Innovation Programmes, B - Consequences of treatment
- Dr Sabine Best, Marie Curie Cancer Care, Head of Research, B - Consequences of treatment
- Ms Sadie Myhill, Cancer Research UK, Patient Involvement Support Officer, D - Keeping research close to the patients
- Ms Salina Tsui, The Christie NHS Foundation Trust, PhD student, D - Keeping research close to the patients
- Professor Sam Ahmedzai, National Institute for Health Research (NIHR) Clinical Research Network (CRN), National Speciality Lead for Cancer Research - Supportive Care, A - Models of care
- Ms Sarah McDonald, Sarcoma UK, Director of research, information & support, C - Patient reported outcomes (PRO)
- Ms Sarah Randall, Brighton & Sussex University Hospitals, Macmillan CNS team lead, C - Patient reported outcomes (PRO)
- Mrs Sarah Guest, Hull and East Yorkshire Hospitals NHS Trust, CNS, C - Patient reported outcomes (PRO)
- Ms Sarah Allen, Macmillan Cancer Support, Senior Evidence Adviser, C - Patient reported outcomes (PRO)
- Dr Silvia Panico, Breast Cancer Now, Research Information Officer, B - Consequences of treatment
- Mrs Sophie Gasson, University of Warwick, Research Fellow, C - Patient reported outcomes (PRO)
- Miss Stephanie Pearson, University of Nottingham, PhD Student, B - Consequences of treatment
- Dr Steve Wootton, University of Southampton, Associate Professor in Human Nutrition, B - Consequences of treatment
- Mr Steven Rowntree, Prostate Cancer UK, Service Improvement Lead,
- Ms Su-Lin Lee, Ovarian Cancer Action, Grants and Impact Manager, D - Keeping research close to the patients
- Mrs Susie Aldiss, University of Surrey, Research Fellow, B - Consequences of treatment
- Ms Suzanne Hartley, University of Leeds, Head of Trial Management, C - Patient reported outcomes (PRO)
- Dr Tania Seale, North West Cancer Research, Research Manager, D - Keeping research close to the patients
- Dr Tim Ward, National Cancer Research Institute, NCRI Consumer Forum Member, B - Consequences of treatment
- Mrs Vanessa Brown, The Royal Marsden Hospital, Senior Project Manager Personalised Cancer Care, A - Models of care
- Miss Wendy Brown, The Swallows, Charity Executive,
- Mr Yubo Wang, University of Manchester, PhD student, B - Consequences of treatment
- Ms Yuki Alencar, Cancer Survival Group Coordinator, London School of Hygiene and Tropical Medicine
- Ms Zoe Grant, University of Suffolk, Lecturer and Course Leader in Therapeutic Radiography, B - Consequences of treatment
- Miss Zoe Lingard, Division of Molecular and Clinical Cancer Sciences, University of Manchester, Research Project Manager, D - Keeping research close to the patients
Who are we?

Macmillan put the current and future needs of people living with cancer at the centre of our research, to ensure we understand the numbers, needs and experiences of people living with cancer. We directly provide services, and work in partnership with or influence others, to help everyone with cancer live life as fully as they can.

Our partnership with the NCRI supports this and enables us to work together with other cancer research bodies in the UK to achieve this mission.

Why are we here?

There are currently 2.5 million people living with and beyond cancer in the UK, with the number expected to rise by 3% each year. Macmillan proudly partnered with the NCRI and others in the James Lind Alliance (JLA) Priority Setting Partnership, to develop the UK Living with and Beyond Cancer (LWBC) research priorities. These priorities provide a focus and direction for meaningful research in this area which will help people with cancer live life as fully as they can.

What are we doing?

- Macmillan champions the LWBC research priorities and much of the research we fund has and is furthering our understanding within these priority areas.
- We support a wide range of research related activities, developing and delivering these both internally and in partnership with others to enable us to support people living with cancer to live life as fully as they can. This includes service evaluations, analytical partnerships with the cancer registries in each nation, influencing and advisory activities and academic research, the latter of which we have invested in for many years, formerly through individual grant awards and more recently via the Macmillan Research Grants Scheme.
- To find out more about our work, please visit our stand. The following key projects from our portfolio also feature in today’s programme…

Claire Foster & Lynn Calman
Macmillan Survivorship Research Group, Uni. of Southampton
Presenting findings from the ColoRECTal Wellbeing (CREW) study and HORIZONS

Derek Kyte
University of Birmingham
Presenting a large body of work on patient reported outcomes, including findings from the Macmillan funded EPIC Study.

Lisa Murray, Geraldine O’Gara
Royal Marsden NHS Foundation Trust
Demonstrating a virtual reality headset being co-designed through the Macmillan funded SafeSpace study.

Where next? At Macmillan we are proud of the role we play in funding and championing research which spans the majority of the JLA top 10 priorities. We will continue to contribute not only through our own research activity, but also by influencing others to prioritise research funding in this area, to help everyone with cancer live life as fully as they can.