Living with and beyond cancer: Consequences of treatment workshop session

Prof Claire Foster
Dr Eloise Radcliffe

Macmillan Survivorship Research Group, University of Southampton
Objectives of the workshop

• Provide an opportunity for discussion of the UK top research priorities on consequences of treatment for those LWBC
• Flag ongoing research that addresses these priorities
• Identify priorities and opportunities for future research
• Identify the main challenges to building research evidence and potential solutions
Many of the themes identified in the UK Top 26 Living With and Beyond Cancer research priorities relate to consequences of treatment

**Themes:**

- Symptoms and side-effects
- Psychological impact of cancer and its treatment
- Social and economic consequences of cancer
Symptoms and side effects

5. How can the short-term, long-term and **late effects** of cancer treatments be (a) prevented, and/or (b) best treated/ managed?

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)?

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)?
Symptoms and side effects

4. What causes **fatigue** in people living with and beyond cancer and what are the best ways to manage it?

8. What are the best ways to manage persistent **pain** caused by cancer or cancer treatments?

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

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

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?

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?

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?
Psychological impact of cancer and its treatment

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

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

26. What are the **spiritual care needs** of people living with and beyond cancer?
Social and Economic consequences of cancer

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?
Policy context - Top research priorities fit with the direction of the NHS

- NHS Long Term Plan (Jan 2019)- personalised care will become ‘business as usual’ by 2024.

- Personalised care ‘will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support’.

- Milestone for cancer: By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.

- NHS England are working to ‘improve the provision of services to manage the consequences of treatment, which cause poor quality of life and are often under-recognised. These include psychological difficulties, fatigue, pain, or bowel, bladder and sexual problems’ (NHS England 2019).
Questions for group discussion

• What research are people involved in that addresses the UK top research priorities on consequences of treatment?

• What are the main gaps in research?

• What are the opportunities for future research and collaboration?
Questions for group discussion

• What are the main challenges to building research evidence on consequences of treatment for those LWBC?

• What are the potential solutions?
Some potential challenges

• Funding
• Involvement of policymakers to maximise impact of research
• Effective implementation and sustainability of clinical services
• Development of next generation of research leaders

https://doi.org/10.1016/j.jcpo.2018.02.004