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)?

Top 11-26 priorities

11. What are the most effective ways to stop cancer coming back (combining treatments and life-style 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?
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?