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A Response to the Shaping the National Cancer Plan Consultation

29/04/2025

Executive Summary:

In response to this call for evidence on Shaping the National Cancer Plan by Department of Health & Social Care, we provide evidence and policy recommendations in relation to the following questions (from the terms of reference): 5, 6,7,8,9, 10.

About Authors:

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About Centre for Psychosocial Research in Cancer: CentRIC+

We work closely with people affected by cancer as well as healthcare professionals, commissioners, policymakers and charities. Their insights help us identify the evidence to deliver patient-centred care. Our research involves people at increased risk of cancer, those living with and beyond a cancer diagnosis, care-givers and health workers. We consider all aspects of health and well-being, including the physical, psychological, social, spiritual, cultural, and financial consequences of cancer.

Response:

EARLY DIAGNOSIS:

Q.5. What actions should the government and the NHS take to help diagnose cancer at an earlier stage? (Select the 3 actions that would have the most impact)

- Support timely and effective referrals from primary care (for example, GPs)

- Develop and expand interventions targeted at people most at risk of developing certain cancers

- Increase support for research and innovation

Please explain your answer. (Do not include any personal information in your response. Maximum 500 words.)

Interventions targeted at those at increased genetic risk: Genetic testing to identify those at increased risk for cancer is increasingly common. Clinicians tell us that they do not have adequate time to support patients to make informed choices regarding choosing whether or not to have such tests or navigate subsequent risk management. Our research group have demonstrated that this can be achieved by digital decision support tools such as Breast Cancer Choices and Lynch Choices. These are theory and evidence based and co-created with patients and health professionals and endorsed by the UK Cancer Genetics Group. Our research shows that these tools can be feasibly introduced into cancer care pathways as a complement to clinical conversations. They are well accepted by HCPs and have a positive impact on patient confidence in decision making and reduced decisional regret.

https://www.breastchoices.org.uk/

Grimmett et al (2019). Development of breast cancer choices: a decision support tool for young women with breast cancer deciding whether to have genetic testing for BRCA1/2 mutations. https://doi.org/10.1007/s00520-018-4307-x

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Kohut et al. (2024) Codesign of Lynch ChoicesTM: using implementation science to create a clinically deliverable patient decision support website to transform cancer genetics care pathways. https://doi.org/10.1002/pon.6330

A research priority: Research shows that symptom awareness alone has limited efficacy for early diagnosis; given that most potential cancer symptoms are much more likely to have a non-cancer cause. Interventions which target those most at risk of developing certain cancers, or with a high risk of late diagnosis, are needed to tackle barriers to timely help-seeking, and barriers to early GP referral.

Disparities in appropriate and timely diagnosis which occur independently of patient help seeking behaviours suggest that a focus on effective referrals from primary care, and use of direct access tests in primary care is warranted. Research investment is needed to first characterise and quantify differences in patterns of help-seeking, and disparities in the primary care interval relating to patient and GP practice characteristics. We must then learn more about patient - GP communication in relation to identified at-risk groups. This can then inform the development of targeted interventions required for those most at need.

TREATMENT

Q.6. What actions should the government and the NHS take to improve access to cancer services and the quality of cancer treatment that patients receive? (Select the 3 actions that would have the most impact)

- Improve communication with patients, ensuring they have all the information they need

- Increase the availability of physical and mental health interventions before and during cancer treatment

- Increase the use of genomic (genetic) testing and other ways of supporting personalised treatment

Please explain your answer. (Do not include any personal information in your response. Maximum 500 words.)

We recommend providing specific communication skills training to ensure treatment decisions for prostate cancer are well informed.

Early diagnosis can save lives, increasing the potential for treatment with curative intent. However, in prostate cancer there are real risks of over treatment. There are many men with prostate cancer that will never become clinically significant; they will die with the disease, not from it, so are at risk of receiving unnecessary treatments that can permanently affect their continence and sexual function, with profound implications for quality of life. It is vital that risk of cancer progression and treatment risks are communicated effectively at diagnosis to support informed preference-sensitive decision making about prostate cancer treatments.

HCP risk communication training informed by our research (The Understanding Consequences Study) reduced patient over-estimation of cancer risk and cancer worries, increased preparedness for decision-making, and led to men remaining on Active Surveillance for longer, thereby avoiding side effects of treatments.

Providing such a training programme would prevent thousands of men from experiencing life changing side effects of treatments that could have been avoided.

Brindle LA, Young A, Rowsell A et al. TrueNTH Understanding Consequences Study. Report to PCUK. 2019)

Stewart SJ, Roberts L, Brindle LA. Shared decision-making during prostate cancer consultations: Implications of clinician misalignment with patient and partner preferences. Social Science & Medicine. 2023 May 23:115969

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LIVING WITH AND BEYOND CANCER

Q.7. What can the government and the NHS do to improve the support that people diagnosed with cancer, treated for cancer, and living with and beyond cancer receive? (Select the 3 actions that would have the most impact)

- Provide more comprehensive, integrated and personalised support after an individual receives a cancer diagnosis and (if applicable) after treatment

- Improve the emotional, mental health and practical support for patients, as well as their partners, family members, children and carers

- Offer targeted support for specific groups, such as ethnic minority cancer patients, children and bereaved relatives

Please explain your answer. (Do not include any personal information in your response. Maximum 500 words.)

Transforming Personalised Care in Cancer
Our internationally recognised research demonstrates that cancer patients with poor mental health, low self-efficacy, limited social support, and comorbidities experience poorer long-term outcomes[1,2,3,4].

Personalised Care in Cancer

(PACC) study and the Right by You Wessex Evaluation conducted by our group found that current personalised care processes, intended to identify and support these patients, often fall short. Despite good intentions, personalised care is too often reduced to a metric-driven, tick-box exercise. Patients deserve care grounded in high-quality, supportive conversations.

To improve early and ongoing assessment, we recommend:

- Enhancing the Holistic Needs Assessment to include:
    - Assessment of self-efficacy to manage cancer/treatment concerns
    - Assessment of mental health to identify personalised needs
    - Tailored support and stratified psychological interventions as part of prehabilitation
- Shifting focus to quality supportive care conversations and co-created care plans, with training for cancer professionals
- Reconfiguring services to meet patient needs in the community, particularly for underserved groups
- Strengthening links between primary and secondary care to optimise patient care and experience

We have demonstrated that impactful service reconfiguration can be cost-neutral.
Our Cancer Nursing Across Boundaries (CNAB) model supported these improvements, with Cancer Nurse Specialists (CNSs) in boundary-spanning roles across primary care, enhancing cancer management knowledge and holistic patient support.
Right by You Wessex further showed the value of CNSs and Cancer Support Workers working across primary and community care. There were notable benefits for underserved populations such as people in prison or experiencing homelessness where delivery of personalised care is particularly challenging.

Our health economic evaluation showed monthly service costs of approximately £25,772, offset by NHS savings of around £31,854, mainly through reduced GP and ED attendance.

The PACC study also demonstrated that service improvements can be achieved without additional costs by:

- Deploying existing staff
- Using an evidence-based proforma informed by national cohort data
- Initiating supportive care conversations early after diagnosis
- Clearly documenting and signposting needs across the care pathway

Patient experience significantly improved, alongside operational efficiencies.

Additionally, we recommend digital self-management tools to help mitigate the physical and psychological impacts of cancer and its treatment. Our team has developed such evidence-based resources supporting the management of cancer-related fatigue and psychological challenges Can-Empower - Home, enhancing care.

[1] Foster C et al Pre-Surgery Depression and Confidence to Manage Problems Predict Recovery Trajectories of Health and Wellbeing in the First Two Years following Colorectal Cancer: Results from the CREW Cohort Study. PLoS One. 2016 doi: 10.1371/journal.pone.0155434.

[2] Grimmett C et al Colorectal cancer patient's self-efficacy for managing illness-related problems in the first 2 years after diagnosis, results from the ColoREctal Well-being (CREW) study. J Cancer Surviv. 2017 Oct;11(5):634-642. doi: 10.1007/s11764-017-0636-x.

[3] Calman L et al Prevalence and determinants of depression up to 5 years after colorectal cancer surgery: results from the ColoREctal Wellbeing (CREW) study. Colorectal Dis. 2021 Dec;23(12):3234-3250. doi: 10.1111/codi.15949.

[4] Foster C et al HORIZONS protocol: a UK prospective cohort study to explore recovery of health and well-being in adults diagnosed with cancer. BMJ Open. 2019 Jul 26;9(7):e029662. doi: 10.1136/bmjopen-2019-029662

RESEARCH AND INNOVATION

Q.8. How can the government and the NHS maximise the impact of data, research and innovation regarding cancer and cancer services? (Select the 3 actions that would have the most impact)

- Improve the data available to conduct research

- Increase research into early diagnosis

- Speed up the adoption of innovative diagnostics and treatments into the NHS

Please explain your answer. (Do not include any personal information in your response. Maximum 500 words.)

Having developed robust interventions to support self-management and decision making, translation into clinical practice is challenging. Research is needed to determine how best to support timely transfer of robust, evidence and theory based interventions that have evidence of benefit into routine cancer care. These need to be developed and implemented with wide ranging expert partner and PPIE work to support codesign and implementation strategies. Expensive and time-consuming RCTs are not necessarily the best way forward. Greater recognition of alternative research designs is needed to ensure data capture to demonstrate benefit (or not) and agile designs to support real time evaluation and implementation.

INEQUALITIES

Q.9. In which of these areas could the government have the most impact in reducing inequalities in incidence (cases of cancer diagnosed in a specific population) and outcomes of cancer across England? (Select the 3 actions that would have the most impact)

- Improving and achieving a more consistent experience across cancer referral, diagnosis, treatment and beyond

- Improving the aftercare support for cancer patients

Please explain your answer. (Do not include any personal information in your response. Maximum 500 words.)

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PRIORITIES FOR THE NATIONAL CANCER PLAN

Q.10. What are the most important priorities that the national cancer plan should address? (Select the 3 most important priorities)

- Improving patient experience across cancer referral, diagnosis, treatment and beyond

- Improving the aftercare support for cancer patients