











National Institute for Health and Care Research University College London Hospitals



# **Improving cancer care in prisons** Summary



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A recently published research study showed that people in English prisons with cancer have substantially poorer outcomes than comparable groups in the general population.<sup>1,2,3</sup> This includes both clinical outcomes – such as survival rates – and their experiences of cancer care. Underpinning these outcomes are challenges throughout the care pathway, including a lack of awareness of symptoms and support available, difficulties in accessing clinical expertise for both diagnosis and care, a lower level of treatment (for a variety of reasons), and limited access to and availability of other support and after-care.

In March 2022 we convened a Policy Lab<sup>5</sup> which brought together researchers, professionals from health and prison services, charities, policymakers, and those with personal experience of the relevant issues to reflect on these challenges and develop practical ideas to improve cancer outcomes for patients in prison.

# There are significant barriers to providing effective care in prisons

Improving cancer care in prisons means working across healthcare and prison systems that are structurally, operationally and culturally very different, and in doing so, overcoming an array of obstacles:

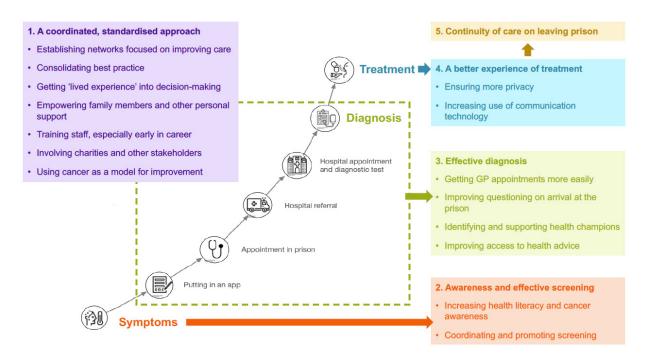
- A prison culture of control and disempowerment can clash with the health system's culture of care.
- Difficulties seeing a general practitioner. This requires patients to make a written or online 'application' which is then triaged by staff, which may hinder a prompt diagnosis and referral.
- Prisons can be 'mysterious' places for external teams to understand and interact with.
- As in other areas of healthcare, budgets are limited.
- Security and other prison policies can restrict access to support and create logistical challenges, including the availability of prison officer escorts to appointments and patients having limited opportunities to communicate with their oncology clinicians (eg regarding appointment times).
- Patients may not be afforded privacy, for example in receiving bad news or giving samples, since prison officers must be present in all consultations.

 Mental health and addiction issues can sometimes be an issue, both when assessing symptoms (eg a suspicion that the person may be trying to access drugs) and in the focus of prison healthcare systems and processes.

#### Improvements can be made throughout the care pathway

The Policy Lab generated a wide range of ideas focusing on different points of the care pathway and considered the roles of different stakeholders in supporting improved care. These ideas are set out in figure 1 under five themes relating to the need for: a coordinated, standardised approach; awareness and effective screening; effective diagnosis; a better experience of treatment; and continuity of care. Further detail on each area is provided in the full report, available here: www.kcl.ac.uk/policy-institute

#### Figure 1. Proposed improvements at each stage of the care pathway



Credits for images: Treatment – Nithinan Tatah from Noun Project (CC-BY); Diagnosis – Amethyst Studoi from Noun Project (CC-BY): Hospital Appointment - Phoniaphat Thongsriphong from Noun Project (CC-BY); Hospital referral - Nawiconm from Noun Project (CC-BY); Appointment in prison – DinosoftLab from Noun Project (CC-BY); Putting in an app – Arslan Shahid from Noun Project (CC-BY): Symptoms – Noun Project (CC-BY) We also asked participants to prioritise a set of concrete proposals based on both the potential impact they could have over the next three years and how possible they would be to implement. This resulted in four proposed "top improvements":

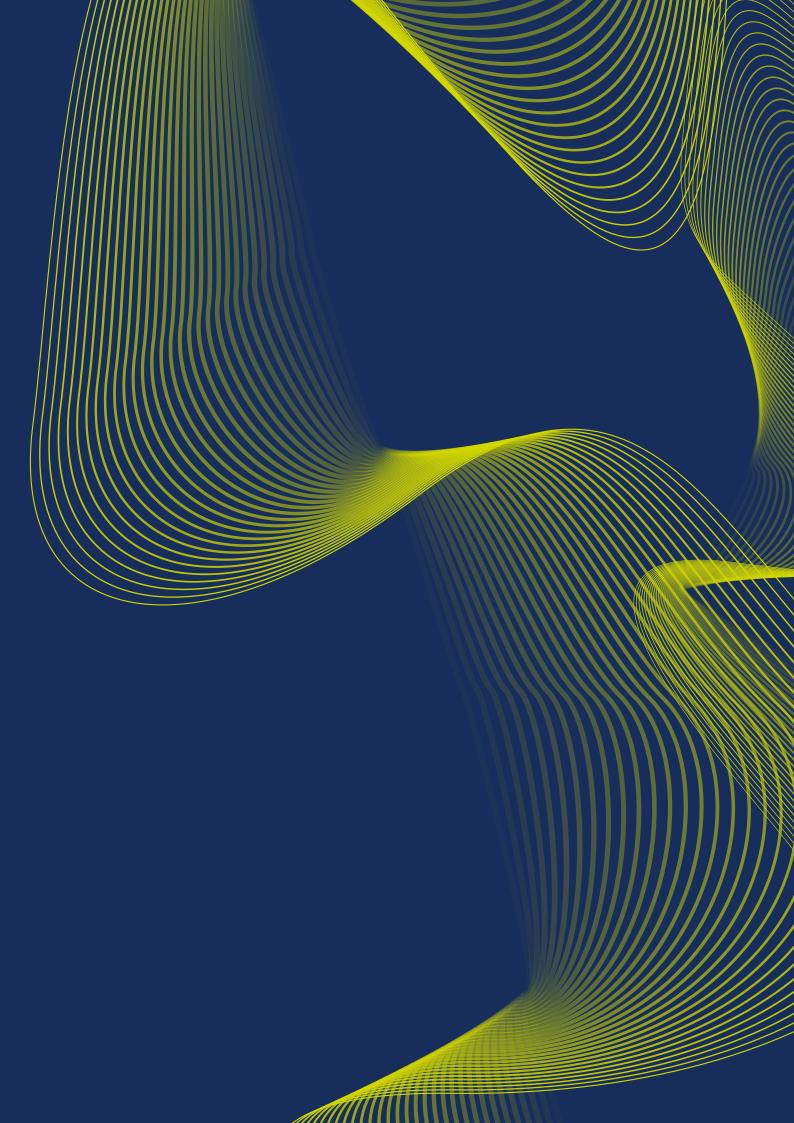
- Communicating to clinical teams how the prison system works, as part of efforts to join different parts of 'the system' and achieve a more integrated approach. This might be supported by the establishment of informal local networks that include prison guards, local hospitals' administration teams, clinical staff, voluntary support groups and family/personal support networks, as well as through specific training on the particular challenges presented by the prison context (eg a short course for medical students).
- Coordinating and promoting an effective approach to screening that significantly increases take-up and facilitates early intervention. In addition to providing more information on screening via a variety of channels, regular screening sessions should be scheduled to fit around other events and routines of prison life.
- Establishing "health champions" amongst prisoners to advise and support others. People tend to be more willing to speak to their peers about issues that they may perceive as embarrassing or likely to draw stigma. Health champions can share practical information on symptoms and the processes of diagnosis and treatment, while also helping navigate the first steps in accessing the healthcare pathway.
- Raising health literacy and awareness of symptoms using different media, especially radio, TV and video. Using a range of channels to promote health literacy among the prison population could both encourage preventative behaviours and raise awareness of potential cancer symptoms. Materials developed for prison TV and radio may be particularly effective in doing this and could also be used to share information on routine screening and practicalities of navigating healthcare processes.



## References

- 1. Lüchtenborg M, Huynh J, Armes J, Plugge E, Hunter R, Visser R, Taylor RM, Davies EA. How do cancer incidence, treatment and survival in the prison population compare with the general population? Results from a population-based study. Lancet Oncology, 2024.
- 2. Armes J, Visser R, Lüchtenborg L, Huynh J, Wheatcroft S, X A, Barber A, Plugge E, Taylor RM, Hunter RM, Davies EA. Cancer in prison: barriers and enablers to diagnosis and treatment. eClinicalMedicine, 2024
- Hunter RM, Huynh J, Lüchtenborg M, Armes J, Plugge E, Taylor RM, Visser R, Davies EA. Does the cost of cancer care for people in prison differ from those in the general population? Analysis of matched English cancer registry and hospital records. eClinicalMedicine, 2024
- 4. https://www.youtube.com/watch?v=B1VK26EiVws
- 5. Hinrichs-Krapels S, Bailey J, Boulding H, Duffy B, Hesketh R, Kinloch E, Pollitt A, Rawlings S, van Rij A, Wilkinson B, Pow R. Using Policy Labs as a process to bring evidence closer to public policymaking: a guide to one approach. Palgrave Communications. 2020 Jun 1;6(1):1-9.





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The views expressed in this report are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Images from the film *Cancer Cells* (King's College London in association with Synergy Theatre Project). Credit: Chris Beston

















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