



Extended Research Article

Cancer in English prisons: a mixed-methods study of diagnosis, treatment, care costs and patient and staff experiences

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Published February 2025

DOI: 10.3310/HYRT9622

Scientific summary

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Health and Social Care Delivery Research 2025; Vol. 13: No. 3

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Scientific summary

Background

The growing and ageing English prison population makes it increasingly important that prison and health professionals, policy-makers and advocacy groups have much more accurate and detailed data on cancer incidence, treatment, outcomes, care costs, and patients' experiences of diagnosis and treatment for this population group. Cancer is common in the general population, but currently there is very little research either in the UK or internationally that has considered how cancers are diagnosed in prison, how patients in prison are treated or cared for, how the experiences of people diagnosed in prison differ from those of people in the general population or how care costs may differ. This mixed-methods study is, to our knowledge, the first to investigate these factors using national cancer data and in-depth interviews to identify barriers to and enablers of accessing cancer services. The overall aim is to develop recommendations that can inform improved cancer practice, policies and research between NHS services and English prisons.

Methods

We used previously unanalysed National Disease Registration Service (NDRS) data to identify invasive cancers and cervical cancers in situ diagnosed in prison and the general population based on residential postcode at diagnosis from 1998 to 2017. Population data from the Ministry of Justice and the Office for National Statistics were used to calculate age-standardised incidence rates and incidence rate ratios in each population cohort. We then used a comparative cohort approach, matching patients diagnosed with a first primary cancer in prison during 2012–7 to the general population using a 1 : 5 ratio based on 5-year age group, gender, diagnosis year, cancer site and disease stage. These cancer registration records were then linked to Hospital Episode Statistics (HES) and radiotherapy treatment and systemic anti-cancer therapy data sets to obtain information on hospital admissions, length of stay, and curative treatment. We used logistic regression and Cox proportional hazards modelling to compare access to curative treatment and survival for these patients, and adjusted for matching variables, ethnicity and comorbidity. To analyse and compare the costs of treatment, we used a cohort of patients from 2012 to 2017, 6 months from diagnosis. Outpatient and inpatient HES data were costed using NHS Reference Costs and inflated to 2017–8 costs. We also conducted 55 semistructured, qualitative, audio-recorded interviews with people with cancer in prison ($n = 24$), custodial staff ($n = 6$), prison healthcare staff ($n = 16$) and oncology specialists ($n = 9$). Patients were identified and approached by prison healthcare services. Experts by Experience – people with previous experience of having cancer in prison or of caring for another patient in prison – were involved in designing, conducting and analysing the interviews. Professional participants were recruited via mailing lists, newsletters and social media. Interviews were conducted either face to face or over the telephone. Data were transcribed and analysed using reflexive thematic analysis. We also compared recent National Cancer Patient Experience Survey (NCPES) data available from patients diagnosed in prison with those from patients in the general population for the years 2012–8. Key findings were presented to a senior group of prison and health professionals, cancer policy stakeholders and Experts by Experience at a facilitated half-day Policy Lab event. The aim of the event was to determine what this group collectively considered the main feasible and immediate priorities for improving cancer care policies for patients in prison.

Results

We identified 2015 incident cancers among 1556 men and 459 women in prison between 1998 and 2017. The age-standardised incidence rate for men in prison was initially lower than that for the general population but increased to similar levels by 2017. Women in prison were far more likely to be diagnosed with cervical cancer in situ than those in the general population [incidence rate ratio 2.13, 95% confidence interval (CI) 1.91 to 2.36]. Between 2012 and 2017 a lower percentage of patients in prison had hospital admissions than general population controls (40% vs. 46%). Patients from prisons had slightly longer hospital emergency admissions than controls (median 6 vs. 5 days; $p = 0.003$). Patients

diagnosed in prison were far less likely to undergo curative treatment [odds ratio (OR) 0.63, 95% CI 0.53 to 0.75] than the general population. The difference was most pronounced for surgical resections (OR 0.64, 95% CI 0.53 to 0.78). Being diagnosed with cancer in prison carries a small but significantly increased risk of death [hazard ratio (HR) 1.16, 95% CI 1.03 to 1.30]. Differences in treatment with curative intent explain half of this increased risk (HR 1.08, 95% CI 0.96 to 1.22): 879 prison and 4326 general population cancer diagnoses were identified in HES. The adjusted 6-month cost of cancer care was significantly lower for people in prison (−£1216, 95% CI −£1638 to −£795), driven by fewer outpatient attendances and planned inpatient stays and hence a significantly lower cost for planned care. People diagnosed in prison had higher emergency care costs than their matched general population controls (£497, 95% CI £375 to £619) and higher total costs when security escort costs were added. From the qualitative interview data, we identified three core themes: communication, care and custody, and control and choice. By mapping our findings to the cancer care pathway, we identified that people in prison follow a similar diagnostic pathway to people in the general population. However, there are several additional barriers to being diagnosed with cancer in prison, including health literacy, the complex process for booking a general practitioner appointment, and communication both between prison staff and with oncology clinicians. Not all barriers were specific to prison, with some (i.e. late diagnosis) experienced by people residing in the general population, but many are exacerbated by the prison environment. These findings were largely confirmed in a separate analysis of previously collected NCPES data, which showed patients in prison reporting worse experiences of cancer care than those in the general population. The Policy Lab event identified many potential ways of improving cancer care, with priority being given to providing clinical teams in the NHS with a better understanding of the prison system, promoting cancer screening programmes in prisons to increase uptake, developing the role of 'health champions' in prison and raising health literacy and awareness of cancer symptoms in prison.

Conclusions

Cancer incidence in English prisons rose between 1998 and 2017, with patients diagnosed in prison having fewer but longer emergency hospital admissions, fewer curative treatments, and a lower survival rate. Following a cancer diagnosis, people in prison have significantly lower planned care costs but higher emergency care costs, and an overall higher care cost due to the additional provision of security escorts. This is alongside evidence of poorer self-reported experiences of care in both qualitative interviews and NCPES data. Cancer care in prison is complex, not least because people in prison move between a health and a prison environment. However, tensions between control and choice in prison healthcare impacted on patients' experience of cancer care in terms of symptom management, accessing information about their illnesses, and the involvement of family in their care. Initial policy priorities are to improve understanding between prison and cancer clinical teams to improve care, and to develop the role of 'health champions' in prison to raise health literacy and awareness of national cancer screening and potential cancer symptoms among people in prison.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: 16/52/53) and is published in full in *Health and Social Care Delivery Research*; Vol. 13, No. 3. See the NIHR Funding and Awards website for further award information.

Health and Social Care Delivery Research

ISSN 2755-0079 (Online)

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Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA), NCBI Bookshelf, Scopus and MEDLINE.

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Editorial contact: journals.library@nhr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nhr.ac.uk/hedr.

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This article

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The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as award number 16/52/53. The contractual start date was in May 2018. The draft manuscript began editorial review in August 2022 and was accepted for publication in July 2024. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

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